Western Norway
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The social health and help needs of those bereaved by a drug-related death. Mixed methods research

Øyvind Reehorst Kalsås

Thesis for the degree of Philosophiae Doctor (PhD)
at the Western Norway University of Applied Sciences

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Scientific environment

The overarching research project “The Drug Death Related Bereavement and Recovery Study” (The END project), was conducted at the Western Norway University of Applied Sciences, Department of Welfare and Participation. This research initiative served as the primary academic environment for my doctoral work. Throughout my PhD journey, my main supervisors were professor, sociologist and grief researcher Kari Dyregrov in 2020-2021 and social educator and grief researcher Kristine Berg Titlestad from 2021-2023. In addition, my co-supervisors were professor and MD Lars Thore Fadnes and social worker and family- and addiction researcher Sari Kaarina Lindeman (2023).

The collaborative efforts of the END project group and the END advisory board played a pivotal role in shaping the research direction and facilitating discussions on our findings. The PhD programme in Health, Function and Participation at the Western Norway University of Applied Sciences, where the doctoral project took place, has influenced the framework of this thesis, integrating the results and discussion within the context of health and social health.

Moreover, my involvement in the Muni-Health-Care research school has been a valuable framework for understanding and applying the findings and implications within the Norwegian welfare and public health context. Additionally, my research stay at Aarhus University’s Unit for Bereavement Research was essential in gaining a profound understanding of bereavement research and immersing myself in a scientific environment rooted in a quantitative approach to exploring this phenomenon.

Finally, the research group on Mental Health and Substance Abuse at Western Norway University of Applied Sciences, the National Research Network for Couple and Family Therapy, and “Lillestige, ” an academic forum established for four PhD students associated with the END project, have all contributed to shaping the research process and direction of the doctoral project.

Takksigelser (Acknowledgements)

Et av de tydeligste minnene mine fra barneskolen kommer fra sløydsalen, hvor en av våre tidligste utfordringer var å lage en smørkniv. Vi tegnet formen, mens læreren vår, Atle, kuttet emnet med hjelp fra båndsagen. Vår jobb var så å ferdigstille arbeidet med sandpapir i ulike grovheter. Etter å ha holdt på i det som føltes som mange måneder, og gått trinnene fra P40 til P140, gikk jeg til Atle:

- Nå tror jeg den er ferdig.

- Nei, sa Atle.

Jeg gikk tilbake til høvelbenken, brukte noen uker til med P160, før jeg gikk til Atle igjen.

- Jeg tror den er ferdig nå.

- Hmm ... nei, sa Atle.

Tilbake igjen til høvelbenken. En måned med stålull.

- Jeg tror den er ferdig nå.

- Tja ... nei, sa Atle.

Han la kniven i varmt vann, og overflaten ble igjen ujevn. Nok en runde med stålull.

- Atle, jeg tror den er ferdig nå.

- Ja, nå er den ferdig.

Smørkniven ble veldig glatt. Det kjenner jeg fremdeles de gangene jeg spiser frokost hos min far og bonusmor.

Disse tre årene har vært min voksne versjon av barndommens smørkniv. Men mens Atle var min eneste sparringspartner på smørkniven, er et doktorgradsprosjekt så til de grader et lagarbeid, og jeg har mange å takke.

Først og fremst, består emnet mitt i denne avhandlingen av alle de 255 erfaringene fra mennesker som har mistet noen de var glade i. Det at dere har delt erfaringene deres, har gitt meg en mulighet til å få en innsikt i de opplevelsene dere har, den situasjonen dere har stått i, og behovene dere har kjent på. Det har også vært grunnlaget for å kunne formidle kunnskap om dette videre til andre, både i Norge og i utlandet. Jeg er dypt takknemlig for at jeg fikk den muligheten av dere, og jeg har gjort, og skal fortsatt gjøre, mitt beste for å forvalte dette ansvaret på en anstendig måte.

Et doktorgradsarbeide trenger god jord og gode vekstvilkår. De vilkårene har jeg fått fra Høgskolen på Vestlandet og mine gode kolleger her. Særlig Etterlatte ved narkotikarelatert død - END-prosjektet, med tilhørende prosjektgruppe har vært avgjørende. Uten dette jordsmonnet ville avhandlingen blitt betydelig fattigere. Her har jeg fått alt som trengs av rammer, innspill, rom, spørsmål, motforestillinger og støtte slik at doktorgradsprosjektet fikk retning. Dere har betydd mye.

Noen mennesker på laget fortjener en særlig takk, blant dem tre kvinner foruten jeg aldri hadde vært her. Den første er Margit, min kjæreste i 25 år. Du har i dette som alt annet støttet meg, løftet meg opp, vist passe med oppmerksomhet og stolthet, men ikke så mye at jeg har blitt (for) høy på meg selv. Kristine, du har vært min hovedveileder for brorparten av prosjektet. Du kvistet en sti som gjorde det lettere for meg å finne veien, og i tillegg så har du utvidet den ved å fote deg tilbake for å gå den en gang til sammen med meg. Et utrolig godt samarbeid som har gjort denne avhandlingen til det som den har blitt, og som jeg er enormt takknemlig for. Sari, du har, etter et kort rollebytte i 2003, vært den som har hatt de klareste tankene om hva jeg bør gjøre i karrieren min, og i tillegg vært en jeg har kunnet snakke med om alt på denne veien.

Jeg vil også rette en stor takk til mine andre veiledere - Kari, min første hovedveileder, som ga meg tillit i et stort og nyskapende prosjekt som ingen andre enn du ville klart å skape her i landet. Lars Thore, som sporet meg på riktige veier i den kvantitative jungelen, og har hatt min gamle lærer sin grundighet i gjennomføring av analyser og presentasjon av resultater. Lillian, som var med å gi retning på prosjektet mitt og har vært en stor inspirasjon å samarbeide med som prosjektleder. I tillegg har LilleStige har vært en kjær og stabil oase sammen med mine kjære medstipendiater Gunhild (Bør eg søke stillingen? GJØR DET! Tenk kor gøy hvis vi kan gjøre dette sammen 😊), Hilde-Margit (fikk du en sammenheng mellom ontologien og epistemologien?), og Birthe (Hva ble figur for deg?).

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Så er det også slik, at uten resten av familien min ville jeg aldri vært her jeg er i dag. Aller mest, Trym, Alva og Bendik, som forankrer meg i livet, og min søster, mine brødre, mamma, pappa og Jenny. Sammen med de andre betydningsfulle menneskene i livet mitt, hjelper dere meg å huske på å feste blikket på det som er viktig, som er flere ting enn en doktorgrad. Selv om det er viktig det også.

Olsvik, oktober 2023.

Øyvind Reehorst Kalsås

Introduction

…therefore, death itself becomes a post in the debate about the value of human life. Some remain when we are gone. We live on in some. And so, in a way, death becomes the greatest testimony to man's immortality.

(Myskja, 2012, p. 15 my translation)

The passing of my grandfather on my father's side was my first experience of death and bereavement as a seven-year-old. At the formal gathering following the funeral, I kept thinking that people expressed too much joy. Death was a sad event and should not be confused with positive feelings.

Soon thereafter, my maternal grandfather, who lived with us in our home, also passed away. Our close bond made the experience of grief more profound and transparent.

Slightly over a decade later, my grandmothers passed away in relatively quick succession. Both had endured prolonged illnesses and lengthy stays in institutions. Having witnessed their suffering, which had reduced their quality of life for many years, their deaths were somewhat easier to accept, even though our bond had been close. My view of death was now more nuanced. Death was not all bad. The consequences might be both good and bad.

My initial experiences with death were what are often considered "timely" and "natural," following the expected order of events. This perception changed one evening 15 years later when my sister contacted me urgently to inform me that my brother had been found dead in his home. Around a week later, I was informed that his death was as a result of suicide. His death had a very different impact on me and our family, causing psychological and relational displacements still evident as I write these words.

The death of someone with whom one has a significant relationship causes wounds and irreversible changes for those still living. Some wounds are healed. Some wounds create lasting damage. Some leave deep scars. The available future paths change.

This thesis concerns those who experience drug-related deaths, losses that often are stigmatized and sudden, “untimely” and violent.

Abstract

Introduction: This doctoral project has focused on the help needs, experiences of help and the social health of those bereaved through a drug-related death. The doctoral project is part of the Drug Death Related Bereavement and Recovery study (The END project) at Western Norway University of Applied Sciences, aiming to generate new knowledge on the situation, coping and needs of those bereaved.

Background: Drug-related deaths represent a significant public health challenge, and those bereaved often experience severe psychological and social distress, persisting for a prolonged duration after the death. Previous research within the END project demonstrated that bereaved parents may require individually tailored, need-based professional assistance over an extended period. This thesis explores and expands the understanding of the support needs of those bereaved by contextualizing them within the framework of their social health, their family, and their social network.

Aim: The overall purpose of this doctoral project has been to map the needs for and experiences of professional help among DRD-bereaved people, examine dimensions of their social health, explore family processes following bereavement, and derive implications for help provisions based on the findings. The following overarching research question has been developed: *How are the social health and help needs of DRD-bereaved people, how can they be explained, and what implications can be drawn in relation to the provision of help?*

Method. This thesis consists of a synopsis and three articles. The first two articles utilize quantitative methods and survey data from a cross-sectional study that included 255 bereaved people with various relationships with the deceased. The third article is based on a qualitative analysis of interview data from 14 bereaved parents.

Article I. *Needs for help and received help for those bereaved by a drug-related* *death: a cross-sectional study*. This article maps the needs and experiences of professional help reported by the survey sample of DRD-bereaved people.

Article II. *The social health domain of people bereaved by a drug-related death and associations with professional help. A cross-sectional study*. This article maps how the survey sample of DRD-bereaved people report social health dimensions.

Article III. *Drug-death bereaved parents' perspectives on family interactions and help needs. A qualitative study*. This study explores how DRD-bereaved parents experience and describe their family interactions to gain an understanding of their need for support on a family level.

Synopsis. *The social health and help needs of those bereaved by a drug-related death*. In the synopsis, the most central findings from the articles are discussed in relation to previous research and the theoretical framework situated in micro-sociology.

Findings: Most participants expressed the need for professional assistance for themselves and their family's children right from the early stages following the death. The majority reported that children in the family had not received help, and the assistance provided to children was often considered unsatisfactory. The social health of the participants was, on average, poor compared to other groups of bereaved individuals. Several bereaved parents described family connection and cohesion as essential for adapting to life after the loss. However, many also described significant needs and communication challenges within the family.

Discussion and conclusion: Based on the findings, I discuss how a family- and network-focused public health model based on early support including the naturally occurring people in the lives of the bereaved may be feasible. The thesis underscores the importance of incorporating a community-based approach into professional bereavement care, building upon the existing relationships of those bereaved. In the Norwegian context, these ideas complement existing recommendations for supporting those bereaved by traumatic deaths.

Sammendrag

Introduksjon: Dette doktorgradsprosjektet har satt søkelys på hjelpebehov, opplevelser av hjelp fra fagfolk, og den sosiale helsen hos etterlatte ved et narkotikarelatert dødsfall. Doktorgradsprosjektet er en del av Etterlatte ved narkotikarelatert død, END-prosjektet, ved Høgskolen på Vestlandet. END-prosjektet har som mål å frembringe ny kunnskap om situasjonen, ressursene og behovene til dem som opplever narkotikarelaterte dødsfall i nære relasjoner.

Bakgrunn: Dødsfall knyttet til narkotikabruk utgjør en betydelig folkehelsemessig utfordring, og de etterlatte opplever ofte en stor psykisk og sosial belastning i lang tid etter dødsfallet. Tidligere forskning gjennomført i END-prosjektet har vist at etterlatte foreldre kan trenge individuelt tilpasset, behovsbasert faglig hjelp over en lengre periode. Denne avhandlingen utforsker og utvider forståelsen av hjelpebehovene til de etterlatte ved å kontekstualisere dem innenfor rammen av deres sosiale helse, deres familie og deres sosiale nettverk.

Mål: Hovedmålet med dette doktorgradsprosjektet har vært å kartlegge behovene og erfaringene med profesjonell hjelp for etterlatte ved narkotikarelaterte dødsfall, undersøke aspekter ved deres sosiale helse, utforske familiære prosesser etter tapet og utlede implikasjoner for hjelpetiltak basert på funnene. Følgende overordnede forskningsspørsmål ble laget: *Hvordan er den sosiale helsen og hjelpebehovene til etterlatte ved narkotikarelaterte dødsfall, hvordan kan funnene forklares, og hvilke implikasjoner kan det gi for organisering av hjelpetjenester for gruppen?*

Metode: Avhandlingen består av en kappe og tre artikler. De to første artiklene gjør bruk av kvantitativ metode og spørreskjemadata fra en tverrsnittsundersøkelse som inkluderte 255 etterlatte med ulike relasjoner til den avdøde. Den tredje artikkelen bygger på kvalitativ analyse av intervjudata fra 14 etterlatte foreldre.

Artikkel I. *Behov for hjelp og mottatt hjelp for etterlatte ved narkotikarelaterte dødsfall. En tverrsnittsstudie.* Denne artikkelen kartlegger behovene og erfaringene med hjelp fra fagfolk som de etterlatte fra spørreskjemautvalget rapporterte.

Artikkel II. *Den sosiale helsen til etterlatte ved narkotikarelaterte dødsfall og sammenhenger med profesjonell hjelp. En tverrsnittsstudie.* Denne studien kartlegger hvordan de etterlatte fra spørreskjemautvalget rapporterte ulike dimensjoner av sosial helse og undersøkte eventuelle sammenhenger med erfaringer med profesjonell hjelp.

Artikkel III. *Foreldres perspektiver på familiens samspill og hjelpebehov ved narkotikarelatert død. En kvalitativ studie.* Denne studien utforsker hvordan etterlatte foreldre opplevde og beskrev familiens samspill for å oppnå en forståelse av deres hjelpebehov på familienivå.

Kappe. *Den sosiale helsen og hjelpebehovene for etterlatte ved narkotikarelaterte dødsfall.* I kappen diskuteres de mest sentrale funnene fra artiklene innenfor tidligere forskning og den teoretiske rammen som er knyttet til mikro-sosiologi.

Funn: De fleste deltakerne ga uttrykk for behov for hjelp fra fagfolk fra et tidlig tidspunkt etter dødsfallet, både for seg selv og barna i familien. Flertallet rapporterte at barn i familien ikke hadde fått hjelp, og den hjelpen som ble gitt til barn ble ofte vurdert som utilfredsstillende. De undersøkte aspektene ved de etterlattes sosiale helse var gjennomsnittlig dårlige sammenlignet med andre grupper av etterlatte. Flere etterlatte foreldre beskrev kontakt og samhold i familien som essensielt for å tilpasse seg livet etter tapet, men mange beskrev også store behov i familien og utfordringer med kommunikasjon om tapet og sorgen.

Diskusjon og konklusjon: Basert på funnene drøfter jeg hvordan en familie- og nettverksorientert folkehelsemodell, som bygger på tidlig hjelp til de etterlatte, kan være gjennomførbar. Avhandlingen understreker viktigheten av å inkludere en sosial tilnærming i profesjonell hjelp som bygger videre på de eksisterende relasjonene til de etterlatte. I den norske sammenhengen supplerer disse ideene de eksisterende anbefalingene for hjelp til dem som er etterlatte ved traumatiske dødsfall.

List of publications

Kalsås, Ø. R., Titlestad, K. B., Dyregrov, K., & Fadnes, L. T. (2023). Needs for help and received help for those bereaved by a drug-related death: a cross-sectional study. Nordic Studies on Alcohol and Drugs. https://doi.org/10.1177/14550725221125378

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Kalsås, Ø. R., Dyregrov, K., Fadnes, L. T., Lindeman, S. K., & Titlestad, K. B. (2023). Drug Death-Bereaved Parents' Perspectives on Family Interactions and Help Needs: A Qualitative Study. Contemporary Family Therapy. https://doi.org/10.1007/s10591-023-09676-7

Contents

ARTICLES I-III

APPENDICES

Appendix 1: Information and consent form
Appendix 2: The END survey
Appendix 3: Flyer with information for recruitment
Appendix 4: Detailed steps in logistic regression analysis, Article I
Appendix 5: Interview guide
Appendix 6: Ethical approval for the END project
Appendix 7: Approval of extended storage and usage of research data
Appendix 8: Approval with names of PhD students
Appendix 9: Information letter to the END project`s participants

List of tables and figures

Notes on terminology

Bereavement:	The state of having lost someone significant to death (Boerner et al., 2017).
Bereavement care:	Care and follow-up by professional service providers offered to relatives and/or close non-kin close to their loved one's death, to support them in coping with the loss (see Boven et al., 2022).
Complicated grief reactions:	Severe and persistent bereavement-related distress that emerge after the loss of a loved one and is experienced as caused by or related to the loss (Komischke-Konnerup et al., 2021; Rando, 2012).
Drug-related death:	Deaths directly caused by the use of psychoactive chemical substances classed as narcotics, or related to the drug use, for example, through accidents, violence or disease (Norwegian Directorate of Health, 2014).
Drugs:	Substances used for intoxicating purposes, that induce consciousness changes and are often associated with habituation or addiction, excluding alcohol (Merriam-Webster. (n.d.). 2023).
Resilience:	The capacity to withstand and rebound from adversity (Walsh, 2021).
Grief:	All emotional, cognitive, social, behavioural and physical responses to the loss of an attachment figure (see Boerner et al., 2015; Gharmaz & Milligan, 2006).
Manner of death:	How the death occurred (Delaveris et al., 2014).
Overdose death:	Deaths directly caused by using psychoactive chemical substances, mostly used "non-therapeutically" or illegally (Norwegian Institute of Public Health, 2019).
Psychosocial help:	Professional help, for example from health- and welfare services, that aims to protect or promote psychosocial well-being and/or prevent or treat mental illness (see Inter-Agency Standing Committee (IASC), 2007).
Public health:	Health services and all components relevant to the operation of a health system for a population, for example the distribution of

	health services, environmental issues impacting health, development and organization of programs (Tulchinsky & Varavikova, 2000, p. xix).
Social health:	The quality of social relationships, the sense of belonging in a community, and the capacity to manage social life (cf. Baumeister & Leary, 1995; Cho et al., 2020).
Social health dimensions:	Encompass various aspects of the social health domain, such as perceived social support, interpersonal connections, closeness or distance in relationships, engagement in social activities, and family cohesion.
Social support:	Having access to others who are willing to listen, who provide support in emotional and practical ways when necessary, and who do not make the person feel worse in any way (Andrews & Brown, 1988; Elklit et al., 2001).
Substances:	Legal and illegal substances used for intoxicating purposes, that induce consciousness changes and are often associated with habituation or addiction, including alcohol/ethanol.
Traumatic deaths:	"Deaths that are sudden, violent, premature or stigmatized" (Bradach & Jordan, 1995, p. 316)

1 Background

Death and bereavement can impact human life profoundly on a small and a large scale, and over a short-term or long-term period. On a small scale and from a short-term perspective, a beloved family member, partner or friend's sudden and violent death can devastate those close to the deceased and their intimate relationships. A deterioration in the physical, mental and social health domains, the latter defined as the quality of social relationships, the sense of belonging in a community and the capacity to manage social life (see Baumeister & Leary, 1995; Cho et al., 2020); are common consequences (see Stroebe et al., 2007). However, on a large scale, bereavement can also set significant social and political changes in motion. For example, the organization "Moms Stop The Harm," made up of thousands of Canadians, was founded by two mothers following their drug-related bereavement (Moms Stop The Harm, 2022). In Norway, people bereaved by DRDs are presently leading the campaign to form a national support organization for those bereaved. Thus, the recovery from devastating bereavement can also result in mobilization, together with other people, in the meaningful pursuit of societal changes.

The negative health consequences of bereavement are well documented. Deaths in close relationships increase the risk of health deterioration and even the death of the surviving person, especially soon after the loss (Stroebe et al., 2007). The likelihood of such consequences differs depending on various variables, especially the manner and circumstances of the death. Deaths that are expected and happen in "natural circumstances" usually have a less severe impact than deaths that occur suddenly, unexpectedly, early in life/prematurely, violently and/or are shrouded by stigma (see Chapple et al., 2015; Djelantik et al., 2020; Stroebe et al., 2007). Deaths of the latter kind will be labelled "traumatic deaths" in this dissertation. These deaths significantly increase the likelihood of severe, adverse consequences among the bereaved, like complicated grief reactions, including mental disorders (Djelantik et al., 2020; Kristensen et al., 2012). A high proportion of DRDs are traumatic deaths (see Titlestad, 2021).

The World Health Organization (2023) estimates that around 500,000 annual deaths due to DRD occur worldwide, approximately one death every minute. The number of individuals severely impacted by each death varies across different contexts and cultures, and only estimates can be given. A calculation of the number of bereaved people in the United States for each Covid-19 death was estimated at approximately nine (Verdery et al., 2020). In the Western world, a similar estimate can be made for DRDs, considering that one DRD can result in one partner, one close friend, two children, two siblings, one parent and one step-parent being significantly affected. Taking the figure of nine as a vantage point would mean that around 4,500,000 people worldwide can be considered "close bereaved" by a DRD each year.

With the knowledge of the highly negative consequences traumatic deaths might have on those bereaved and the high number of DRDs worldwide, there is a need for more information on this population's psychosocial health, help needs, resilience factors and conditions for adjustment and recovery. Much research on bereavement has focused on the impact at an individual level after bereavement, in general, and traumatic deaths, in particular (see Djelantik et al., 2020; Stroebe et al., 2007). This research has documented the increased likelihood of negative, individual health consequences and the likely help and support required. Less research has focused on the interpersonal and social level of consequences and how families cope with bereavement (see Delalibera et al., 2015; Stroebe et al., 2013b). This thesis addresses the help needs and experiences, the social health and the family interactions of those bereaved by DRDs.

1.1 Clarification of concepts and terms

Some key concepts in this thesis, such as drugs, drug-related deaths (DRDs), and traumatic deaths, are difficult to precisely define and categorize. I have chosen to define "drugs" as substances used for intoxicating purposes, that induce consciousness changes and are often associated with habituation or addiction, *excluding* alcohol (Merriam-Webster. (n.d.). 2023). When using the term "substances", I include alcohol, the only legal intoxicating substance in many

Western countries. Studies on substances sometimes include alcohol, and sometimes not. However, although this thesis focuses on DRDs, studies involving alcohol are also highly relevant. Alcohol is often used together with other drugs, and the commonalities of the physiological, psychological and social effects of alcohol and other drugs are more striking than the differences (see Degenhardt & Hall, 2003; Gjersing & Amundsen, 2018).

The definition of DRDs in the thesis parallels the definition of drug-related mortality in EMCDDA (2009). This definition comprises deaths directly attributable to the drugs or administration thereof (overdose and drug-induced deaths) *and* deaths indirectly related to the use of drugs, like drug-related disease, violence and accidents (EMCDDA, 2009). Thus, a DRD might include different manners of death, like suicide with drugs, death by hepatitis C, homicide associated with the deceased's use of drugs or an unintentional overdose. Overdoses (i.e., drug-induced deaths) make a subcategory of DRDs but are, almost exclusively, only manner of death included in the official national death registries (Norwegian Institute of Public Health, 2023). Thus, when referring to drug-induced or overdose deaths, I will use the term "overdose deaths", knowing that these deaths only count for maybe half of the total DRDs (see United Nations, 2019).

A common label for the phenomenon of sudden deaths caused by external, often violent circumstances is an "unnatural death" or "unnatural loss" (cf. Boelen et al., 2016; Djelantik et al., 2020). This term was used in Article I, although a small minority of the deaths experienced by the survey participants were "natural" (e.g., caused by a disease related to drug use). We chose to adhere to this label in the original draft of Article II. However, one reviewer explicitly asked us to consider abandoning the term "defined in the negative and remaining ambiguous with a more positive and clearer term, like "traumatic deaths"" (Reviewer 1, feedback on Kalsås et al. 2022, 12. September 2022). Thus, I changed the wording to "traumatic deaths" in this article and in further studies.

The label, "traumatic deaths," also has some ambiguity. It might suggest that the death must have had traumatic consequences for those bereaved or that the death happened in a traumatic manner (e.g., physically violent). However, the definition I have chosen from Bradach and Jordan (1995, p. 316), denoting traumatic deaths as "deaths that are sudden, violent, premature *or* stigmatized," better covers the phenomenon of DRDs as a broad term.

1.2 Norway as a context and research ground

This doctoral project was conducted in Norway. Around 275 people die due to overdose deaths in Norway annually (Norwegian Institute of Public Health, 2023), an average rate of 5.6 per 100,000 people. This rate is high compared to the reported rates from other European countries, which in 2021 were 1.8 deaths per 100,000 people aged 15 to 64 (European Monitoring Centre for Drugs and Drug Addiction, 2023). For many years, reducing this number has been a central political aim (Norwegian Directorate of Health, 2019). However, although considerable resources have been used and the psychosocial follow-up of people with problematic drug use has been a prioritized task within health- and social services (Ministry of Health and Care, 2015), there is no current trend towards a decrease (Norwegian Institute of Public Health, 2021).

The Norwegian welfare state provides an essential backdrop in the effort to reduce overdose deaths, meet the needs of those bereaved and understand the population's expectations of public services. The welfare state model is built on three major dimensions (Pedersen & Kuhnle, 2017): 1) the strong role of the state and local government, including extensive public services (like health- and social services); 2) the principle of universal social rights that also covers the middle classes and 3) the value of equality between people in different areas, for example, income, gender and ethnicity. The municipalities' responsibility for providing healthcare services for their inhabitants is regulated under the Health and Care Act, and medical and psychosocial help in situations involving accidents or other emergencies is part of this responsibility (Health and Care Act, 2011).

The national guideline Psychosocial Measures in Crises, Accidents and Disasters provides norms for psychosocial help covering all crises, accidents and catastrophes that could potentially traumatically affect individuals, families and communities (Norwegian Directorate of Health, 2016). "Crises" are exemplified by the sudden death of an infant, suicide or individual accidents leading to death, whereas "disasters" refer to large-scale deaths (e.g., mass-killings, deaths caused by flooding or earthquakes) (Norwegian Directorate of Health, 2016, p. 14). Although DRDs are not specified in the text, a DRD should be considered a crisis where the guidelines' recommended measures are relevant (Reime & Dyregrov, 2022).

In 2015, a significant White Paper on the future of Norwegian primary healthcare was published. It addressed the challenges related to fragmentation within public health services caused by the silo organizational structure and a focus on disease, often resulting in service providers reacting only after serious problems had arisen (Norwegian Ministry of Health and Care, 2015). Furthermore, this White Paper highlighted the need for services to apply more proactive measures "to distribute resources in line with the needs" (Norwegian Ministry of Health and Care, 2015, p. 20). The guideline for Psychosocial Measures in Crises, Accidents, and Disasters confronts these challenges related to psychosocial help in crises through various approaches, advocating for prompt, proactive, and recurrent assistance to those who are grieving and emphasizing that professionals should proactively reach out to the bereaved individuals (Norwegian Directorate of Health, 2016).

Moreover, the guideline underlines the municipalities' overarching responsibility for coordinating the efforts provided and establishing thorough procedures to assist with all incidents (Norwegian Directorate of Health, 2016). The guideline does not clearly define who should be considered "close bereaved" in different circumstances (Norwegian Directorate of Health, 2016), meaning that kin and non-kin could be included in the service providers' focus, depending on the assessments the service providers make in the focal case. In addition to early and proactive help, the guideline highlights the role of psychosocial, cross-disciplinary crisis teams and maintains that help for the bereaved should be coherent and, if necessary, of a long duration (Norwegian Directorate of Health, 2016). Thus, it has been suggested that services, when the situation demands, should go beyond the confines of traditional organizational structures during the follow-up.

The Norwegian drug policy is also important when enquiring about the needs of DRD-bereaved people in this country. Norway has operated a restrictive drug policy from the late 1960s until recently, with high penalties for using and possessing drugs (NOU 2019: 26, 2019). After the millennium, a more nuanced discourse has emerged, with its ensuing changes in policy and practice, heralding a shift from a more dominant “punitive” regime towards a more “helpful” regime (cf. NOU 2019: 26, 2019). This change is based on several factors, for example, the recognition that a criminal prosecution could add to the stigma and could constitute a barrier to helping people (NOU 2019: 26, 2019), rather than understanding drug addiction as an illness (cf. Stoltenbergutvalget, 2010). However, although the stigma has been reduced, drug use and drug addiction are still considerably stigmatized, with potential consequences for the health and functioning of people who use or are affiliated with drug use (see Dyregrov & Selseng, 2021; Sheehan & Corrigan, 2020).

1.3 The END project – the context for the PhD study

This PhD thesis is part of the END project at Western Norway University of Applied Sciences. END is a Norwegian acronym for Drug Death Related Bereavement and Recovery. The project was started in 2017 as a response to the high number of overdose deaths and the lack of awareness and research into the situation of those bereaved (see Titlestad et al., 2021a). The project’s primary objectives included advancing our understanding of the grief and consequences of DRDs for those bereaved and exploring their coping strategies. Furthermore, the project has focused on the efforts of health- and welfare services in relation to close bereaved persons and facilitated a means of knowledge translation, aiming to improve the functioning of the former in practice. The project has also striven to propose actions to improve the health and quality of life of the bereaved, reduce stigma and contribute to the societal drug policy discourse.

Figure 1 shows the END project structure, with three work packages and the corresponding data material. This doctoral project is situated in Work Package 1, Study 1 and 2, and enquires about (1) the consequences and strains and (2) the bereaved persons’ need for and experiences of help and support. The data material for this study was gathered from a survey (n=255) and in-depth interviews with parents (n=14).

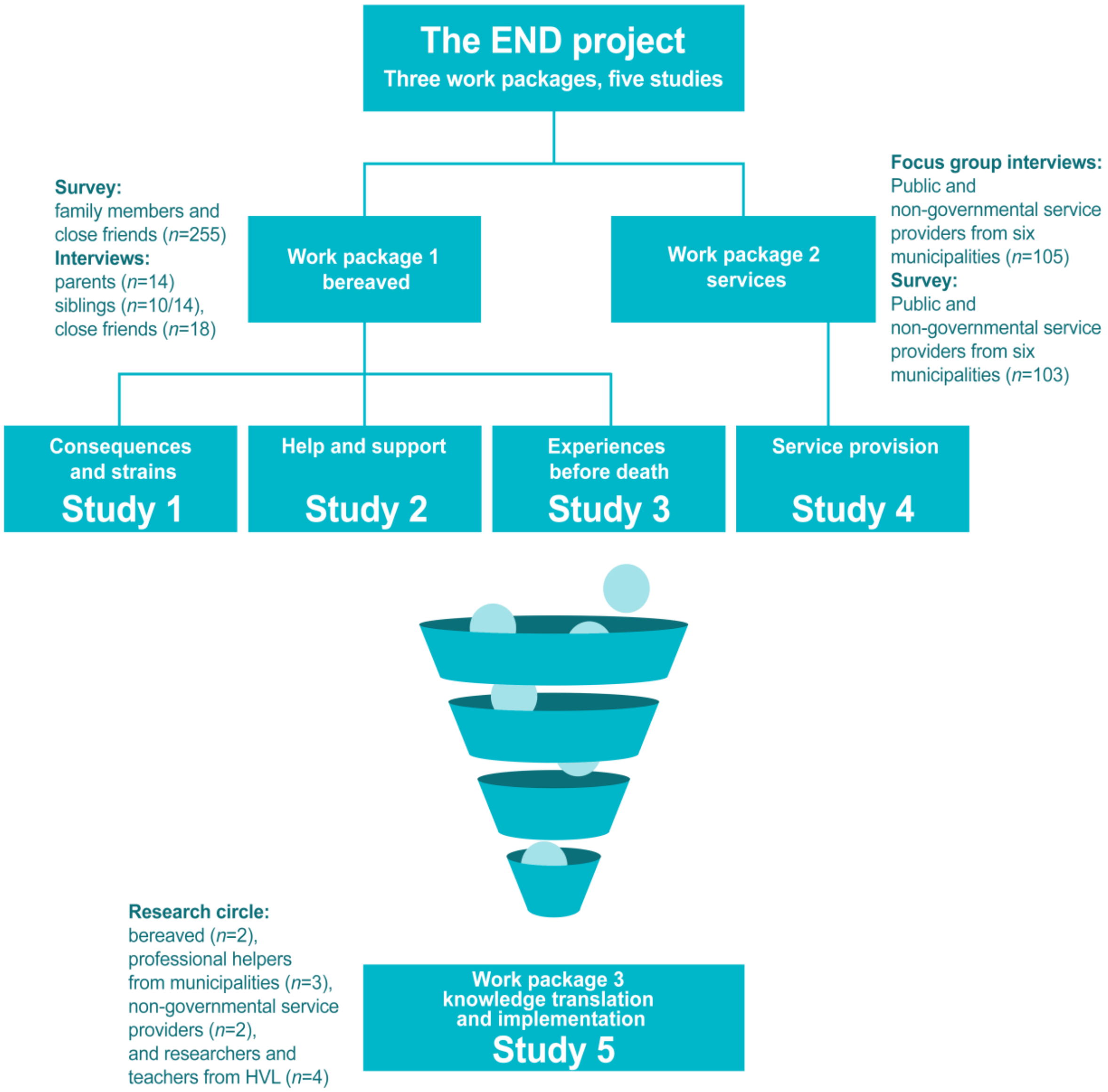


Figure 1. The structure, foci and data material of the END project

The END project has a project group and an advisory board. The project group comprises 11 researchers from the Western Norway University of Applied Sciences, with expertise in substance use, grief and bereavement, psychosocial crises and family therapy, and four user representatives, each with a relationship with a person who died from a DRD. The advisory board comprises 13 researchers and professionals from various countries including Norway, belonging to non-governmental organizations, municipalities, hospitals and universities. The expertise represented in the group covers bereavement, substance use, stigma, recovery and health services. User representatives and the advisory board have been actively engaged in the PhD through presentations and the discussion of research questions, research foci, methods and findings.

1.4 Adversity following DRDs

1.4.1 Similarities between DRDs and suicides

The rationale for studying the help needs, social health and family interactions of DRD-bereaved people is that their situation, in some ways, is “special” and thus deserves special attention. The following section will focus on studies that shed light on this assumption, particularly the relational and social context. Moreover, because of the many overlaps and similarities between suicidal deaths and DRDs, studies on both kinds of bereavement are included.

DRDs and suicidal deaths are often self-inflicted and sudden, and often happen to young people. Many DRDs *are* actually suicides (see Oquendo & Volkow, 2018) and both are stigmatized, although this varies depending on the culture and context (cf. Bottomley et al., 2023; Chapple et al., 2015; Dyregrov & Selseng, 2021). Persisting feelings of guilt and blame are frequently reported across different relationships after suicide bereavement (Shields et al., 2017), paralleling the experiences of DRD-bereaved parents (Titlestad et al., 2021b) and other relationships after DRD-bereavement (Lambert et al., 2021; O’Callaghan et al., 2022; Titlestad et al., 2021a). Furthermore, both groups of bereaved people often report complex social relations and challenging communications regarding their loss (see Sajan et al., 2021; Shields et al., 2017; Titlestad et al., 2021a; Titlestad et al., 2021b). Hence, knowledge of the situation and the needs of suicide-bereaved people is often transferable to DRD-bereaved people.

Both suicide and DRDs are stigmatized in many countries. Several studies indicate that self-inflicted and stigmatized deaths are more likely to be associated with adverse health consequences than other traumatic deaths. For example, a study from the United States found that suicide-bereaved people had the highest rates of lifetime depression, pre-loss suicide ideation, self-blaming thoughts and impaired work and social adjustment, compared with people bereaved by homicides and accidents (Tal et al., 2017). Another US study compared overdose loss with loss by suicide and sudden-natural deaths, and found more acute symptoms of prolonged grief among bereaved people following suicide and overdose loss (Bottomley et al., 2021). Thus, understanding the sociocultural context seems essential for understanding the life situation and consequences for those bereaved after a loss. The stigma of drug use and DRDs is often more pronounced due to repressive policies, jurisdiction and a judgemental culture and discourse (Corrigan et al., 2017). For example, a study from the US found that people's attitudes towards opioid overdose decedents were more discrediting compared to suicide decedents (Kheibari et al., 2022), and a Norwegian study on DRD-bereaved people found that many of them had experienced stigmatizing attitudes and utterances directed at the deceased (Dyregrov & Selseng, 2021).

Extensive register-based studies, particularly in Scandinavian countries, have also demonstrated an elevated risk of adverse consequences and mortality risk for individuals bereaved by suicide and DRDs. A Swedish retrospective cohort study identified a greater likelihood of offspring suicide after parental suicide (Wilcox et al., 2010), and another follow-up study from Sweden found a clear association between sibling suicide and the greater likelihood of suicide among the remaining siblings (Rostila et al., 2013). A study from Denmark showed that suicidal risk was elevated in parents who had lost their child through suicide, compared to parents who had lost their children through other manners of death (Qin & Mortensen, 2003). Finally, a Swedish study found that parent suicide was significantly associated with a young person's suicide attempt (Mittendorfer-Rutz et al., 2008). To our knowledge, only one register-based study on the mortality of DRD-bereaved people has been conducted. This Norwegian study found that overdose deaths were associated with a higher mortality risk in parents, compared with parents bereaved through other manners of death, even those bereaved by other external causes (Christiansen et al., 2020). On the other hand, a Norwegian study involving 232 parents, bereaved by a sudden and traumatic death, did not find any significant differences in subjective distress between those bereaved by suicide and those bereaved by accidents (Dyregrov et al., 2003). Such divergent findings strengthen the assumption of the social context's central role, including stigma, discourse and attitudes in the culture where the death occurs.

Taken together, the impact of suicides and DRDs on the bereaved can be profound, affecting them both in the long- and short-term. Moreover, the social context in which the deaths occur seems to play a crucial role. Understanding the social context surrounding DRDs can be especially important, as it places many of the bereaved in unique circumstances where pre-loss stress factors and a pervasive stigma significantly influence their situation. A user representative in the END project group stated that what sets DRDs apart from other traumatic deaths is not only the manner of death, but also the experience of living with drug-related problems so closely for many years (Lindeman, 2021). In the following section, I will present literature concerning the experiences of family members affected by a relative's problematic substance use that sheds light on this statement.

1.4.2 The stress and strain of living with substance use in the family

Many family members affected by a relative's substance use suffer from prolonged stress related to the substance use (Orford, 2017). A recent meta-ethnography, reviewing the international qualitative literature on the subject, coined the term "an unknown invisible intrusion" to capture the impact of substance use on family life (Lindeman et al., 2021). The reviewed studies revealed that many family members felt overwhelmed by their circumstances, and the effects of substance use permeated every aspect of their family life. Family members tried to adapt to a constantly unpredictable environment; many families withdrew from their extended social network and many family members experienced loneliness and a lack of support (Lindeman et al., 2021). Similar findings were reported in a meta-ethnography on families living with a young person's problematic substance use, describing that the substance use caused overarching family changes across cultures (Lindeman et al., 2023). Recent research in the form of a scoping review reinforces and provides additional insights into the stress and challenges experienced by family members affected by a relative's substance use.

Many family members in the scoping review's studies reported relational and emotional problems, problematic family interactions and a disrupted lifestyle and social life (Di Sarno et al., 2021). More than half of the affected family members reported negative mental health consequences like depressive symptoms, anxiety, loss of sleep or death wishes (Di Sarno et al., 2021). The included comparative studies showed that poorer mental health was associated with having a substance-using relative (Newton et al., 2016; Ray et al., 2007; Ray et al., 2009). Concerning social and relational adjustment, and quality of life, the review found that the affected family members reported lower scores than community participants, and women had consistently higher scores in terms of family impact and burden, as well as mental and physical health issues (Di Sarno et al., 2021).

The qualitative findings in the review were related to emotional and psychological stress, where guilt, self-blame and shame, hopelessness, grief and anger were frequently experienced (Di Sarno et al., 2021). Furthermore, many reported experiences of being stigmatized, being socially isolated and blamed, having financial problems, experiencing difficulties finding support and being preoccupied with family conflicts and the substance user's aggression (Di Sarno et al., 2021). Findings from research carried out in Norway (Dyregrov et al., 2022; Titlestad et al., 2021b), the UK (Valentine, 2017), Ireland (Lambert et al., 2021), Brazil (da Silva et al., 2007), the USA (Feigelman et al., 2020; Nowak, 2015) and Denmark (Biong & Thylstrup, 2016) on people bereaved by alcohol and/or drugs also support the above findings that the experiences before death affect the experience of bereavement and grief on intra- and interpersonal levels (see Titlestad et al., 2021a for a review).

In addition to the more direct impact of substance use, many family members have reported frustrating experiences with support services, when the substance-using family member is alive. Across different cultures, families with a young substance-using family member "seemed to be disappointed by the lack of assistance or the quality of support provided" (Lindeman et al., 2023, p. 10), and families with an older family member using substances experienced a lack of understanding from health and social services. They perceived it as impossible to seek and receive support in their own right (Lindeman et al., 2021). Similar experiences were also found in a study from Norway, comprising 14 DRD-bereaved parents (Titlestad et al., 2021b). Many parents expressed anger towards the health- and social services regarding the way in which they had treated their child when alive and rejected the parents when they asked for information or help (Titlestad et al., 2021b). Thus, in many cases of DRD-bereavement, the relationship between the bereaved individuals and professional health- and social services may have been compromised before the death. In other types of bereavement, negative experiences with the support services provided to the deceased individual have been associated with self-destructive behaviour and depression (Beernaert et al., 2017), a decreased likelihood of seeking help (Pettersen et al., 2015a) and a lack of trust in healthcare services among those who are grieving (Pettersen et al., 2015b).

1.4.3 Psychosocial aspects of DRD-bereavement

This thesis emphasizes the social health, that is, the quality of relationships, the sense of belonging in a community, and the capacity to manage the social life of those bereaved. Hence, I will focus mostly on the social element of the psychosocial aspects of studies on DRD-bereavement. The studies include parents (Lambert et al., 2021; O'Callaghan et al., 2022; Titlestad et al., 2021a; Titlestad et al., 2021b), siblings (Dyregrov et al., 2022; Lambert et al., 2021; Løberg et al., 2022; O'Callaghan et al., 2022), extended family members (Lambert et al., 2021; O'Callaghan et al., 2022), close friends/partners (Selseng et al., 2023a; Selseng et al., 2023b), and adolescent children (Grace, 2013).

Studies from Norway and Ireland have shown that DRD-bereaved people often have to navigate a complex social context. In studies that were part of the END project, Titlestad et al. (2021b) found that many parents, in a sample of 14, experienced complex relationships and challenging communication relating to the loss, while another study within the same project, comprising 93 parents, found that withdrawal from other people was strongly associated with symptoms of prolonged grief (Titlestad et al., 2021c). Findings from an Irish study supported and contributed to the findings from the Norwegian studies. This qualitative study included multiple relations to the deceased: parents, siblings, one daughter and two nieces (Lambert et al., 2021). All families experienced complex interactions with family members, friends and other community members before the death (Lambert et al., 2021). After the death, family dynamics became even more complicated, and some connections were severed. Certain family members reflected on how they had withdrawn from the family system after the loss, and many struggled to integrate their grief into existing family dynamics. They reported that the distancing from one another within the family often was related to unresolved conflicts, exacerbated by the death (Lambert et al., 2021). Hence, studies of parents and various relationships with the deceased in DRD-bereavement show that social relationships are complex, and experiences of social withdrawal have been reported in both the Norwegian and Irish context.

DRD-bereavement can place siblings in a demanding position in the family. As part of the END project, a study interviewed 10 siblings who had lost a loved one to DRD. The findings revealed several common experiences among these siblings, including a lack of support from family and friends after the death, complex and challenging family relationships, a pervasive silence that often served as a form of protection, difficulties in seeking support due to feelings of shame associated with the deceased's drug use, feelings of blame and guilt regarding the circumstances of the death, and a devaluation of drug users by their social network members (Dyregrov et al., 2022). Although most siblings wanted openness and mutual closeness, they often adopted a "strong" sibling role in order to cope, despite the adversity in the family (Dyregrov et al., 2022). This way of coping was probably related to the situation before the death, as another Norwegian study found that siblings often tried to balance the family environment and maintain family functioning by not taking up a significant space in the family (Løberg et al., 2022).

Considering bereaved partners and close friends who use drugs themselves, a qualitative study from Norway comprising 13 persons of both genders concluded that many used drugs to cope with grief, had difficulties approaching loss-oriented tasks together with other people, and tended to use avoidant coping strategies (Selseng et al., 2023b). They described a fear of talking to others about the grief during periods of abstinence, dreading that they might not cope with the emotions that could arise (Selseng et al., 2023a). Many struggled with guilt concerning their role and responsibility for their close relative's death. They described a double stigma with regard to the manner of death and their coping strategies that "(...) creates a silence around their own grief experiences, leaving no room for processing the grief with the help of social networks (...)" (Selseng et al., 2023b).

To our knowledge, only one previous study has explored the experiences of children and adolescents in relation to DRDs and substance-related deaths. Based on in-depth interviews with four British girls aged 14-16, Grace (2013) found that the children's experiences were highly challenging, for example, concerning belonging and security in a home environment. The social context in which they coped was often unstable, for example, changing relationships and care homes. The children struggled to "find a way both to make sense of themselves within their pasts and to find a way forward into the future" (Grace, 2013, p. 145). Other studies on parentally bereaved adolescents, who experienced an expected parental death have shown that poor family cohesion is more likely to be reported by the parentally bereaved youth than their non-bereaved peers (Jessop et al., 2022). Furthermore, less satisfactory parent-child communication, measured by parents and children, is associated with psychological health problems among children and youth self-injury (Jessop et al., 2022). Thus, it appears significant that the family relationships of adolescents who have experienced parental bereavement become considerably challenged.

To summarize the above studies, complex social interactions in the grieving process are reported across different relationships with the deceased in DRD-bereavement, notably parents, siblings, intimate partners, close friends and adolescent children, relationships which, apart from adolescent children, form part of the quantitative enquiries of this PhD thesis. Poor and complex social relationships, support and interactions interfere with the coping process and adaptation to life after the loss.

1.5 Coping with bereavement and the role of social support

Although bereavement can be devastating, many people, over time, adjust to their loss with adequate help and support, although the circumstances may be dire (Zisook et al., 2014). The majority of all bereaved people have a resilient course, denoting the person’s “ability to maintain relatively stable, healthy levels of psychological and physical functioning” when exposed to a highly disruptive event like the death of a close person (Bonanno, 2004, p. 102; Bonanno et al., 2005; Bonanno et al., 2012). We know that intra-personal variables are important in coping with bereavement, for example, emotion regulation strategies (Eisma & Stroebe, 2021). However, as this thesis focuses on the social health of those bereaved, the social and relational dimensions in coping with bereavement are highlighted here.

These social dimensions are often termed “social support” in the literature, which, subjectively rated, can be defined as the perception of having access to others, who are willing to listen, who provide support in emotional and practical ways when necessary and who do not make the person feel worse in any way (see Andrews & Brown, 1988; Elklit et al., 2001). Social support has consistently been found to be an important variable that correlates with positive and negative bereavement outcomes: lower ratings of perceived social support are associated with symptoms of PTSD (Scott et al., 2020) and a risk factor for complicated grief reactions (Burke & Neimeyer, 2013), while higher ratings of perceived social support have a consistent and clear positive association with posttraumatic growth, denoting the positive changes resulting from the struggles of experiencing a traumatic life event (Michael & Cooper, 2013; Ning et al., 2023; Tedeschi & Calhoun, 2004).

The findings that social support is important for coping with bereavement are consistent with the kind of support bereaved people, in general, report as being most helpful. A cross-sectional Australian study found that family and friends were unparalleled sources of help and support for bereaved people (Aoun et al., 2018). Most found this support quite or very helpful, while professional help was rarely used and had a considerably higher rating of perceived unhelpfulness (Aoun et al., 2018). Similar findings on the importance of family and friends were found in a longitudinal study in Sweden (Benkel et al., 2009). The study concluded that help from professionals for those bereaved seemed to be needed in two cases: when the grieving persons did not want to burden members of their network or when the social network was “dysfunctional” (Benkel et al., 2009). The function and nature of the relationships seemed to matter more than the number of social network members (Benkel et al., 2009); in other words, the perception of the quality of the support experienced by the bereaved was of higher importance than the number of people providing the support.

The case for social support following a traumatic death is often more complex than the support provision following expected or “orderly” deaths. When summarizing the findings from several studies on traumatically bereaved people in Norway, Dyregrov and Dyregrov (2008) found that most of those bereaved viewed the support and care of family and social network members as valuable and irreplaceable. However, they also found that many social network members, especially those outside the immediate family, displayed ineptitude in terms of meeting and dealing with those closest to the deceased. This ineptitude was associated with mutual social withdrawal and, consequently, a loss of potential valuable support (Dyregrov, 2004; Dyregrov & Dyregrov, 2008). The ineptitude appeared in three dimensions, 1) anticipated support that failed to appear, 2) people suddenly withdrawing from the bereaved and 3) unhelpful advice and support being offered (Dyregrov, 2004). Furthermore, the ineptitude was associated with the network members’ insecurity relating to the intense and frightening reactions they observed among their loved ones. Mutual openness between the closest bereaved and the social network members, that is, speaking frankly, actively communicating thoughts, discussing insecurities and clarifying needs, helped alleviate this ineptitude and maintain or increase social contact (Dyregrov, 2004).

Social support from family and friends has also been reported as being very important in studies on DRD-bereaved people. In the aforementioned study on 14 Norwegian parents, Titlestad et al. (2020) found that being needed by others and receiving support through their social network was important in the way that parents adjusted to life after their child’s death. Close network members were the most helpful in adjusting to life, and family members were the most important in grieving the loss (Titlestad et al., 2020). Moreover, the two qualitative studies from Ireland that included 17 DRD-bereaved family members reported the importance of

opening dialogue with other families as part of the coping process (Lambert et al., 2021; O'Callaghan et al., 2022).
Bereavement, especially when it is traumatic, can significantly impact a person's health and functioning. However, individuals can also adapt to these life-changing events and sometimes experience positive personal growth. Whether one goes through adaptation or growth depends on various factors, and a prominent one appears to be the perceived availability, functionality and utilization of social support – an element of social health. Nevertheless, many people who have experienced a traumatic bereavement may still require professional assistance in addition to the support of their social relationships. In the following section, I will delve into the literature concerning the provision of professional psychosocial help after a bereavement.

1.6 The role of professional psychosocial bereavement care

While many bereaved individuals can adapt without professional psychosocial help after a loss, those who have experienced traumatic deaths face a higher risk of maladjustment. For instance, a recent meta-analysis, suggests that 34%-65% of those bereaved by traumatic deaths, report clinically significant levels of prolonged grief symptoms (Djelantik et al., 2020). Dyregrov and Dyregrov (2008) propose that in the case of such deaths, professional psychosocial help should automatically be offered since this situational risk factor results in long-term affliction for so many people, and many are not able to ask for help (Dyregrov & Dyregrov, 2008). Furthermore, other factors like finding the deceased or being present at the scene, sense impressions, age of the deceased, individual and family circumstances, and support and reactions from the surroundings are relevant for the considerations of professional psychosocial bereavement care (Dyregrov & Dyregrov, 2008).

Nevertheless, receiving professional psychosocial help is not guaranteed to lead to better long-term outcomes. Some forms of assistance improve the situation of those who are bereaved, while others do not, and certain types of psychosocial help may even have negative effects (Neimeyer & Currier, 2009). Furthermore, professional help can encompass various interventions, including those aimed at preventing maladjustment or treating complicated grief reactions. These interventions may be structured or just loosely structured and may involve individual, group, family or network-based approaches. The field is heterogeneous, and it is challenging to differentiate between what works and what does not. However, several reviews and meta-analyses have been published for psychosocial interventions after bereavement in general, specifically interventions aimed at treating or preventing complicated grief reactions. These studies also have relevance for DRD-bereavement, as high levels of prolonged grief symptoms have been reported by those bereaved (see Article I).

In a review of studies investigating the effect of therapeutic interventions after a loss, Neimeyer and Currier (2009) divided the interventions into different categories depending on which group of bereaved people they included. These categories were (1) universally targeted interventions (i.e., targeting anyone who had suffered a loss), (2) selective interventions, aimed at grievers who are at a higher risk of developing complicated grief trajectories, such as parents who have lost a child to a traumatic death and (3) indicated interventions, provided for those who have had difficulties in adapting to the loss (Neimeyer & Currier, 2009). The review's findings suggested that grief therapy had significant average effects at the follow-up stage, but only among individuals assessed as having difficulties adapting to their loss (i.e., the "indicated" group). Participants in universally targeted interventions and even those in the selective interventions group did not necessarily show better outcomes, on average, eight months after the intervention (Neimeyer & Currier, 2009).

These findings were supported by a meta-analysis conducted by Wittouck et al. (2011), who investigated the effects of preventive and treatment interventions for complicated grief in adults. They found that preventive interventions, on average, were not effective, while treatment interventions, on average, were effective (Wittouck et al., 2011). A recent meta-analysis of psychological treatment interventions for grief largely replicated these findings (Johannsen et al., 2019). Factors linked to improved outcomes included individual intervention delivery, intervention initiation six months or more after the loss and participants with higher baseline symptoms, such as prolonged grief symptoms (Johannsen et al., 2019).

On the other hand, a recent meta-analysis of 19 controlled trials of professional bereavement support for adult family caregivers in palliative care found outcomes that partly contradicted the aforementioned meta-analyses (Kustanti et al., 2021). The results showed that bereavement support significantly reduced grief, depression and anxiety, and that a group format recorded better outcomes than an individual format. However, these studies were not controlled for baseline grief symptoms and the findings were also inconsistent (Kustanti et al., 2021). For example, one study found that participants in a structured grief group, led by professionals, did not have better outcomes than non-participants who would have wanted to participate (Näppä et al., 2016); another study concerning family therapy for cancer, which continued into bereavement, reported very favourable results (Kissane et al., 2016), and a third study indicated favourable outcomes in terms of reduced grief following individual, structured, writing disclosure exercises (Lichtenthal & Cruess, 2010). The above meta-analyses include both individual, group and family-oriented interventions. Given the focus of this thesis on social health, studies exploring family- and network-based approaches are particularly interesting.

A systematic review of studies on the effect of support programmes on parentally bereaved children and their caregivers found that the programmes positively affected the remaining caregivers' and children's health (Bergman et al., 2017). Relatively brief interventions could reduce the likelihood of developing complicated grief and mental health problems in children (Bergman et al., 2017). Furthermore, two articles reviewed studies on programmes promoting parenting skills (Sandler et al., 2015; Sandler et al., 2011). These articles found such skills to be an important mediator for several long-term, internalizing and externalizing psychosocial outcomes in children and parent-children relationships after adverse events, including bereavement. Thus, interventions that include family members or focus on the interaction between family members, promoting positive parenting and family cohesion, have been proven to be helpful.

Finally, while there are no controlled studies on interventions specifically for DRD-bereaved people, a systematic review of interventions for suicide-bereaved people concluded that evidence indicating effectiveness was scant in the field (Andriessen et al., 2019). However, the authors drew some conclusions from the findings, namely, that interventions should include supportive, therapeutic and educational aspects, as well as the involvement of the social environment of those bereaved, that the length and number of sessions must be sufficient and that the facilitators need appropriate training (Andriessen et al., 2019).

The reviews mentioned above can make it difficult to draw any firm conclusions concerning psychosocial interventions for bereaved people who struggle with grief. Several psychosocial interventions after bereavement fail to yield statistically significant effect sizes. Still, they can have a value and a significant effect at an individual level (cf. Wittouck et al., 2014). The studies included in all reviews were also highly heterogeneous. For example, in the reviews of Neimeyer and Currier (2009) and Wittouck et al. (2011), the type of intervention and time since the loss varied widely, and those who received a preventive intervention often received it quite a long time after the death - on average, 14 months later, as shown in the review by Neimeyer and Currier (2009). Thus, a cautious conclusion is that professional psychosocial help, when needed, is often of benefit to bereaved people. However, experienced helpfulness depends on a range of variables concerning the context and form in which the professional help is offered, the existing relationship between the help services and those bereaved, the persons that are included in the help provisions (e.g., individual, group, family), the stage at which the bereaved person is in the bereavement process and so forth. Hence, when providing professional psychosocial support for traumatically bereaved individuals, a humble and a need-adapted approach appear to be sensible choices. This type of attitude seems to resonate with the needs of traumatically bereaved people.

1.6.1 Bereavement care requests of traumatically bereaved people

Studies from different countries in Western cultures show that most traumatically bereaved people call for professional help at an early stage post-loss, and often prefer that this help is provided pro-actively, that is, that services initiate and repeat this contact and provide flexible, need-adapted help over time (see Dyregrov, 2011; Dyregrov et al., 2015; Ligier et al., 2020; Wilson & Marshall, 2010). These wishes also echoed findings from smaller Norwegian exploratory studies on DRD-bereavement (Biong et al., 2015; Biong & Thylstrup, 2016), as well as a recent, more extensive study involving participants from the END project (Fjær & Dyregrov, 2021). In a systematic review of postvention after suicide, pro-active and outreach work from services was found to be beneficial for the bereaved seeking support (Szumilas & Kutcher, 2011). Such findings are probably related to a common experience of many traumatically bereaved, often finding themselves severely functionally impaired and unable to seek out help services on their own (see Dyregrov, 2002; Dyregrov et al., 2016; McKinnon & Chonody, 2014; McMenamy et al., 2008). A study from the United States found that those with more severe health and functional impairment also reported greater barriers to seeking help (McMenamy et al., 2008). Another study conducted in the United States identified an underutilization of mental health services among bereaved caregivers with prolonged grief disorder (Lichtenthal et al., 2011). These findings suggest that early and proactive contact with bereaved individuals, who may require professional help the most, could be beneficial, either at the time of initial contact or later.

Taken together, those who have been bereaved by traumatic deaths are at risk of developing complicated grief reactions; most studies show that such individuals request professional help post-loss and often want help that is pro-active, need-adapted and lasts for some time. Studies concerning professional psychosocial interventions in bereavement care show high heterogeneity in interventions and inconsistent results, but interventions aimed at treating complicated grief and family-oriented interventions for parentally bereaved children generally yield favourable outcomes. However, only a few qualitative studies have explored the need for and experiences of professional help among DRD-bereaved people. We also know that professional bereavement care cannot replace informal social relationships and social support, which most bereaved people find more important than professional help. Thus, it is not a question of either-or, but both-and. Since social variables like informal social support are essential for coping with bereavement, the social health of DRD-bereaved people is an important indicator of their ability to cope and their help needs.

Furthermore, professional psychosocial help efforts can have varying impacts on the social support and resources available within the bereaved person's social environment. In some cases, professional help efforts might replace or weaken functions that could otherwise be managed within informal relationships. On the other hand, professional help efforts can alleviate difficulties in relationships after bereavement, mobilize social network members, and strengthen social support within existing networks. Therefore, the family processes that can help explain the social health and support situation of those bereaved, can also shed light on how professional help services can tap into the challenges and resources of the social environment when helping DRD-bereaved people.

Hence, this thesis aims to map and gain an understanding of the help needs and experiences of DRD-bereaved people and the state of their social health and family processes following bereavement. It also aims to derive the implications for help provision based on the findings. The overarching research questions were:

- Which needs for help and received help from professional services do DRD-bereaved people report?
- How do DRD-bereaved people rate dimensions of their social health?
- How can DRD-bereaved families' need for family-oriented help be understood through bereaved parents' reflections on family interactions post-loss?
- How can the findings from the above questions be explained, and which implications can be drawn regarding the help and support need of DRD-bereaved people?

These aims and questions have resulted in three articles. In Article I, we investigated the needs for help and the help that DRD-bereaved people received from professional services, and which variables were associated with participants' satisfaction with regard to the help received. In Article II, we investigated how DRD-bereaved people rated their social health and whether differences in social health were associated with different experiences of professional help. Finally, in Article III, we explored the need of DRD-bereaved families for family-oriented help and how this could be understood through the bereaved parents’ reflections on family interactions post-loss. The last research question, *How can the findings from the above questions be explained, and which implications can be drawn regarding the help and support need of DRD-bereaved people?,* is addressed in this synopsis.

2 Methodology

Kaplan (1964, p. 23) states, “the aim of methodology is to help us to understand, in the broadest possible terms, not the products of scientific inquiry but the process itself.” This doctoral project embraces a wide range of elements that have shaped its scientific enquiry, including ontological, epistemological, and axiological considerations. These questions are integral to the philosophy of science within this project.

Furthermore, the thesis’s theoretical framework plays a pivotal role in illuminating the scientific enquiry process. It not only guides the research focus but also influences the choice of research design. In addition, methodology involves detailing, explaining, and justifying the methods used for data collection and analysis (Carter and Little, 2007). Subsequent subsections will provide a more detailed exploration of these aspects.

2.1 Philosophy of science

The philosophy of science addresses ontological, epistemological and axiological questions (see Krumsvik, 2016; Polit & Beck, 2021). In other words, these are questions relating to the nature of reality, how our knowledge relates to reality, and the role of values in the enquiry.

This doctoral project’s ontological, epistemological and axiological framework is a critical realist philosophy of science. Critical realism’s ontological claim is that a reality exists independently of our knowledge of this reality (cf. Bhaskar, 1998). Reality consists of hierarchical and necessary laminated domains, where dynamics, mechanisms and interplay at one level causally generate phenomena that arise at another level (Archer et al., 1998). These domains are the real, actual and empirical domains. The real domain contains all parts of reality and is the only domain that contains the “mechanisms” or “causal processes” that generate phenomena in the world (Bhaskar, 1998). Our enquiries in the world are conducted within the actual and empirical domain. We can explore and represent empirical events through a language (e.g., mathematics, statistics or stories) and, through this language, infer the necessary conditions for the events to occur. Thus, our scientific explorations in the empirical domain aim to map the domain of the actual and explain processes, dynamics and mechanisms in the domain of the real.

Furthermore, critical realism posits that the world is stratified, with emergent powers and mechanisms hierarchically organized in different strata (Danermark et al., 2019). These strata are reality's social, psychological, biological, chemical and physical levels. Each stratum cannot be reduced to the underlying one, as new and qualitatively different phenomena emerge at one level, due to processes on the underlying one. Furthermore, stimuli and changes at a higher hierarchical level interact with the lower strata. For example, losing a significant person (an event in the social strata of reality) will affect all the lower mechanisms or systems of one's body. Psychologically, I might become sad or angry, my cognitive abilities could decline and I yearn for the lost relationship. Biologically, my immune system might be reduced and my blood pressure might rise (cf. Palitsky et al., 2023). Chemically, such processes are related to the release of hormones that carry messages through my blood to different organs. Physically, the loss affects the electrical signals between nerve cells, necessary for transmitting information within the body and in relation to my actions in the world.

This thesis explores the social world and thus demands an ontology of social interaction and structures. Critical realism posits a social ontology consisting of "agency" and "structure" as distinct ontological strata of social reality. Social structures are, for example, language, social classes, cultural norms and rites, and societal institutions of various kinds - "the ever-present condition and the continually reproduced outcome of intentional human agency" (Archer et al., 1998, p. xvi). Drug jurisdiction, the rules that guide drug jurisdiction and material prerequisites to enforce the drug jurisdiction are one type of social structure, and the framework and praxis for public health provisions in traumatic bereavement are another. These structures precede agency and condition us to certain ways of acting, feeling, thinking and evaluating actions. For example, at the outset of my doctoral project, the public health framework and methods for providing psychosocial assistance to individuals who had experienced DRD were already in place with a defined structure. However, the framework and praxis (structure) can be changed by generating knowledge and through my and other people's interventions in various public discourses (agency).

Choosing critical realism as the philosophy of science comes with axiological considerations. Agents within a society have agency despite living in a "world of structural constraints and possibilities that they did not produce" (Archer et al., 1998, p. xvi). Social science research can illuminate relations between agents and social structure, through "explanatory critique", thus raising consciousness and increasing people's agency and motivation for changing oppressive social structures (Gorski, 2013). Agents can then transform social structures (Danermark et al., 2019). In critical realism, an important purpose of research is to show where the potential for agency might lie for changing such structures, often referred to as the emancipatory potential in social science (Archer et al., 1998; Deforge & Shaw, 2012). For this thesis, this means that findings should be presented in a way that shows whether "oppressive structures" exist concerning DRDs and in the life situation of those bereaved, explain how these structures work, and propose ways that could facilitate people's agency in transforming those structures, if they are deemed to be harmful.

Critical realism implies a hermeneutical, epistemological position (Danermark et al., 2019). The empirical impressions are not directly accessible and must be interpreted. Critical realism also acknowledges that the social sciences have research subjects affected by how we collect data and present findings. They can change their being in the world due to the research process (Danermark et al., 2019). Furthermore, as social science studies subjects that are active meaning-makers, it demands a double hermeneutic, as we interpret meanings that people have already made of their experiences (Danermark et al., 2019). These insights have implications for methodological pluralism.

As used in this doctoral project, a combination of qualitative and quantitative methods is fully compatible with a critical realist framework (see Mukumbang, 2023). While quantitative methodology is necessary for certain purposes, for example, to map the domain of the actual based on empirical phenomena, the quantitative methodology also rests on assumptions about phenomena and their relations, which must be answered by qualitative enquiry. For example: “What do we mean by a need for help from professionals, when we ask whether respondents need help from professionals?” “When participants rate their social support as low, what happens in their relationships and how do they experience these processes?” “When they report that they have withdrawn from other people, how does this happen and how do they experience these processes?” Such questions are contextual, are subject to internal and external interpretations and should thus be explored through qualitative means. Hermeneutic analyses aim to generate contextualized and situational explanations rather than abstract generalizations independent of time and space (Bukve, 2016). These approaches are essential in evaluating whether a need to investigate the phenomenon is warranted and which internal relations the bereaved people have concerning this phenomenon.

A critical realist framework entails explaining events and processes as the overall aim of science (Danermark et al., 2019). This emphasis on explanation demands a view on inference: How can we conclude something based on something else? For this process, critical realism draws on four modes of inference: induction, deduction, abduction and retroduction (Danermark et al., 2019). Abduction denotes a likely but not a necessary explanation of why something is like it is. Abduction draws not only on strict scientific findings but also on creativity, imagination and the ability to draw connections from different knowledge to explain why and how a phenomenon emerges (Danermark et al., 2019). Retroduction is related to abduction but focuses on the conditions that must be present for the phenomenon to exist. The main questions in retroduction are “What are the conditions under which X occurs? What makes X possible?” (Meyer & Lunnay, 2013, p. 3). Retroductive logic implies interpreting the inductive, deductive and abductive conditions for the social realities and structures underpinning the findings and combining all four types of logic to inform one or more theoretical models (Meyer & Lunnay, 2013).

I have found that critical realism provides a purposeful ontological, epistemological and axiological framework for this doctoral project. The methodological pluralism embraces both this thesis’s quantitative and qualitative enquiries, in which the qualitative inquiries have explanatory value for the quantitative findings. Furthermore, the discussion of this thesis draws on all modes of inference - deduction, induction, abduction and retroduction, to build a theoretical model that proposes an explanation for the findings, and guides the implications and conclusion. Finally, the hermeneutical epistemological position suggests that our knowledge is always subject to uncertainty and can be incorrect. It recognizes the limitations in our ability to fully and precisely explain phenomena, implying that our understanding is partial and imperfect. However, the ontological basis means that some interpretations are closer representations of the real domain than others. This position aligns with the way in which I position myself in relation to the phenomena explored in this doctoral project. For example, although bereavement, grief, professional help, social support and withdrawal from others are ontologically subjective phenomena and only exist as long as someone experiences them, they are not merely social constructions.

2.2 Theoretical framework

The theoretical landscape of this thesis is mainly situated in microsociology, focusing on the face-to-face interaction of people (see Aakvaag, 2008), emphasizing the role of emotions, emotional sharing and intersubjectivity. The theoretical lenses are used within the research fields on which this thesis is focused: the research fields of bereavement by traumatic deaths and grief, drug-related problems and psychosocial help in crises (Figure 2).

The research field of bereavement and grief after traumatic deaths focuses on how individuals, families, communities and societies are affected and cope with sudden, violent, and/or stigmatized deaths. In contrast, the research field of drug problems explores how individuals, families, and communities are affected by their own or a close one’s drug use, either directly or indirectly. Finally, the research field of psychosocial help in crisis addresses aspects of professional psychosocial assistance provided to people affected by potentially traumatizing events, such as traumatic loss.

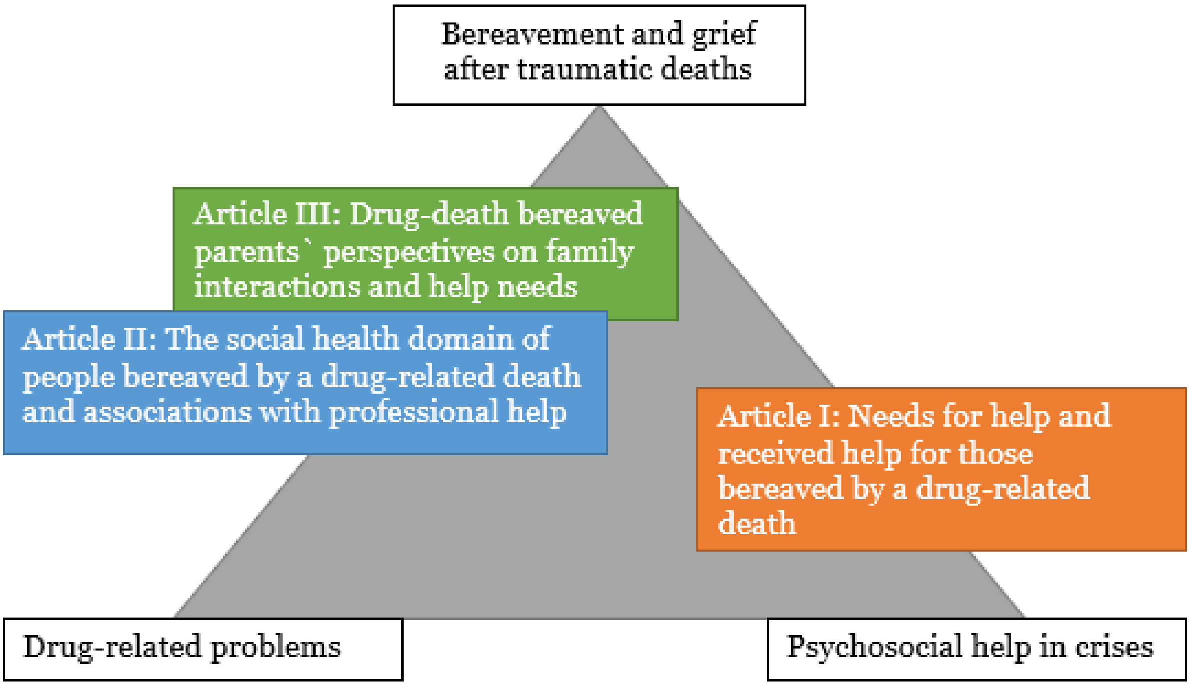


Figure 2: Positioning of the articles of the thesis in the research field

Articles II and III share common themes, focusing on the social health of individuals who have experienced drug-related deaths (DRDs). This places them in close proximity to the research field of bereavement and grief following traumatic deaths. Conversely, Article I is primarily concerned with psychosocial help needs after traumatic losses, aligning it closely with the particular research domain of psychosocial help in crises.

This chapter will first explore the theories of bereavement and grief, continuing with the theory of emotion, emotional sharing and intersubjectivity, which might explain much of the link between social health and mental health in bereavement. Stigma theory will be explored to help explain the obstruction in interpersonal processes crucial to adaptive coping. Finally, the values and theories from the perspective of a public health approach to bereavement care are presented in a cultural context.

2.2.1 Social and mental health aspects in bereavement and grief

Bereavement and grief

Bereavement can be defined as the state of a person having lost someone significant to death (Boerner et al., 2017) and encompasses the individual's emotional and psychological responses to this loss. These responses are often labelled as “grief.” Grief is generally defined as an emotion, but as grief lasts and consists of numerous feelings, for example, sadness, anger, anxiety, fear, guilt and shame, it is separate from our usual understanding of emotions (Gharmaz & Milligan, 2006). Furthermore, cognitive components, like trying to make sense of the death and one’s ongoing life; physical components, like loss of sleep and vitality; behavioural components, like an increased or decreased level of activity and social components, like talking with others about the loss, are all part of grief. Grief can thus be understood as consisting of a fan of emotions, as well as cognitive, social, behavioural and physical responses related to losing an attachment figure (cf. Boerner et al., 2015; Gharmaz & Milligan, 2006).

A micro-sociological theory of coping with bereavement suggests that when someone experiences a loss, it creates a void in their social life (Maciejewski et al., 2022). The likelihood of mourners achieving a state of social well-being depends on their ability to fill these social spaces (Maciejewski et al., 2022).

Bereavement, grief and health

The void in a mourner’s social state is a profound experience that manifests both internally—through the loss of a social bond and the emotions of absence—and externally, as it involves the extinction of meaningful interpersonal interactions. This void can significantly disrupt a bereaved person’s sense of purpose and ability to function in their daily life and can be viewed as threats to health or as impairments to health. The Ottawa Charter for Health Promotion describes health as a resource for everyday life, emphasizing physical capacities, and social and personal resources (World Health Organization, 1986). In line with this perspective, Huber et al. (2011) define health as the capacity to adapt and self-manage, identifying three primary domains: physical, mental, and social health. Consequently, bereavement can constitute a loss of a health resource within the social health domain, but affects the bereaved person’s total health situation.

Figure 3 illustrates how the physical, mental and social health domains are intertwined. For example, low social integration, a phenomenon in the social health domain, is highly associated with increased mortality, rivalling prominent known risk factors like smoking and the excessive intake of alcohol (Holt-Lunstad et al., 2010).

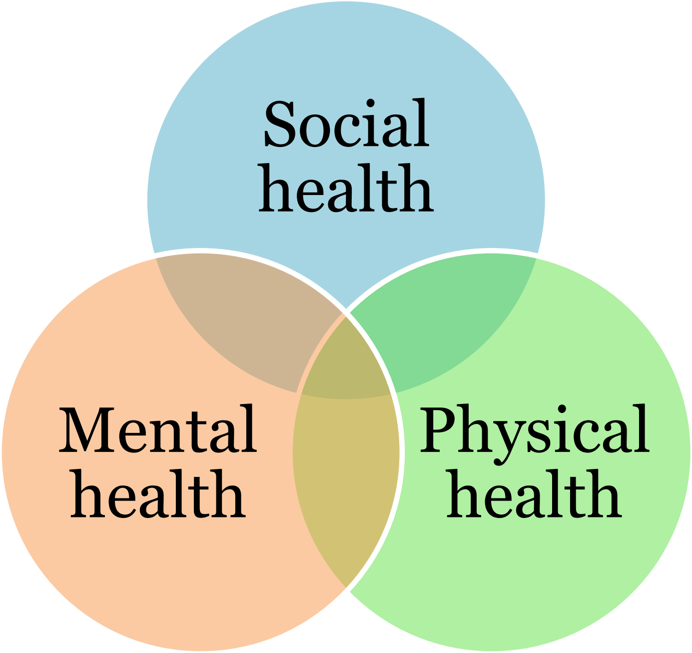


Figure 3: The connection between social, mental and physical health.

Furthermore, there is a well-documented connection between social relationships and the domain of mental health (Cacioppo & Cacioppo, 2014). Consequently, the social health domain of bereaved individuals is intertwined with the other health domains, and any changes in this domain, whether they are declines or improvements, are likely to influence the overall health status. For bereaved individuals, the implications for the mental health domain are particularly significant. Several theories attempt to elucidate the relationship between the social and mental health domains.

The relationship between the social and mental health domains

Andersen et al. (2021) provide a systematic review and a synthesis of the middle-range theories that explain the connection between the social and mental health domains. In synthesizing the theories, they focus on how interaction and belonging in smaller and larger social systems can provide potential benefits in times of adversities and irrespective of adversities. Regarding the latter, the link between social relationships and mental health is provided by fulfilling the need to belong, providing social identities, regulating emotions, enabling participation in life opportunities, being an arena for positive experiences and rewarding societal roles. In times of adversity, social relationships can provide support when an individual is dealing with a threatening or stressful situation by buffering stress, regulating emotions and being a source of strength and personal growth (Andersen et al., 2021). Furthermore, a potential benefit is that social relationships can help increase resilience to face future threats and challenges. Thus, there are several pathways between the social and mental aspects of health. One of these pathways is linked to the social sharing of emotions. To gain an understanding of this pathway assumes a foundational comprehension of the concept of "emotions."

Theory on the social sharing of emotions

Barrett (2017, p. 160) provides a constructionist understanding of emotions, asserting that *emotions are meaning*:

> They explain your interoceptive changes and corresponding affective feelings, in relation to the situation. They are a prescription for action. The brain systems that implements concepts such as the interoceptive network and the control network, are the biology of meaning-making. (…) To make meaning is to go beyond the information given. A fast-beating heart has a physical function, such as getting enough oxygen to your limbs so you can run, but categorization allows it to become an emotional experience such as happiness or fear, giving it additional meaning and functions understood within your culture.

Thus, emotions convey information about the body-environment state and guide us towards actions that help balance discrepancies within the body or between the body and the surrounding physical and social environment (Barrett, 2017). An important feature of Barrett's definition is the prominent place of categorization. Categorizing physical states allows it to become an emotional experience which gives additional meaning and functions to the present culture (Barrett, 2017). Categorization is meaning-making, and this meaning-making connects our emotional experiences to the social interactions and the culture of which we are part (Barrett, 2017). Hence, emotions are constructed based on how we express them, talk about them, and relate to them with other people, meaning they are intrinsically wired with our social surroundings.

Traumatic bereavement is an extreme emotion-eliciting event. The theory of the social sharing of emotions (Rimé, 2009) can help explain which “prescriptions for actions” grief emotions after bereavement provide. Rimé (2009) shows that the social sharing of emotions after an emotion-eliciting event happens exceptionally frequently, and higher emotional intensity yields a higher likelihood for frequent sharing. The social sharing of emotions has profound intra- and interpersonal effects, but the directions and manifestations of these effects depend on how social sharing occurs and how the recipient responds. These interactional components can roughly be divided into socio-affective and cognitive components of an emotion-sharing interaction (Rimé et al., 2020).

The socio-affective responses include empathy, validation, comfort and help, often leading to increased social connectedness through increased liking of one another (Rimé et al., 2020). The cognitive responses entail much of the verbally transmitted content in terms of sharing emotions and are likely to be necessary for emotional recovery (Rimé et al., 2020). Cognitive-dominated responses are also part of the socially shared meaning-making process, a factor many scholars consider essential to grieving (cf. Neimeyer et al., 2011). In short, Rimé’s (2009) theory that emotion elicits the social sharing of emotion, asserts that people who share intimate emotions start to like each other more. A greater liking can create stronger feelings of being bonded and references being made to “we” and “us,” which, in Maciejewski et al.’s (2022) words, can contribute to filling the void in the mourner’s social state. The combined socio-affective and cognitive aspects of the social sharing of emotions can lead to emotional recovery (Rimé et al., 2020). Hence, sharing emotions can be one key feature of the link between social and mental health, and consequently social and individual adjustment following bereavement.

An essential factor in the context of traumatic bereavement is that there are situations where the social sharing of emotions does not happen. These situations might be ascribed to different aspects of the emotional episode and the context and space for social sharing. Rimé (2009) suggests that the eludation of social sharing might take place due to at least three circumstances: a) when the emotions in question entail self-conscious emotions like shame and guilt, b) when the phenomenal nature of the emotions is highly intense or traumatic, and c) when there are "social constraints", often present when the emotions shared are likely to elicit strong or "harmful" emotions in the listeners. All these three components can be relevant to people bereaved by traumatic deaths.

The role of self-conscious emotions and stigma for emotional sharing

Self-conscious emotions encompass feelings such as shame, guilt, embarrassment, and pride. These emotions serve as valuable indicators of how we relate to others, helping us predict how others perceive us and the potential consequences of their perceptions. Additionally, they inform our decision-making by suggesting appropriate actions (Lewis, 2019). Shame is often defined as a pervasive sense of self-worthlessness and typically signals threats to social bonds (Scheff, 2003). It occurs in a social context, where we gauge our self-worth in relation to others and how we believe others perceive us (Scheff, 2006). Guilt and shame are closely related and belong to the same family of emotions, according to Scheff (2006). Guilt typically arises from a sense of violating a societal norm and motivates individuals to take responsibility for their actions, often leading to reparative behaviours (Lewis, 2019). In contrast, shame can prompt individuals to hide or withdraw to avoid exposing their perceived flaws to others (Lewis, 2019). However, it is important to note that these emotions often intermingle and fluctuate in various situations. In the case of perceived norm violations, in which we feel a deep sense of guilt, the distance to feeling bad about ourselves on a more global scale is often short. Thus, these emotions may lead bereaved people to withdraw from other people.

Stigma often serves as a societal obstacle that discourages individuals from openly discussing or sharing their emotions, and this societal obstacle is closely linked to intra-personal feelings of shame (Corrigan & Rao, 2012). Phelan et al. (2008) highlight two main functions of stigma on a social level – norm enforcement and disease avoidance. These primary functions are associated with creating boundaries between people: norm enforcement for keeping people "in" and disease avoidance for keeping people "away" (Phelan et al., 2008). Corrigan and Rao (2012) suggest disclosure as the first step to combat self-stigma and stigma, which harmonises with the theoretical framework concerning the social sharing of emotions. However, emotional disclosure always constitutes a risk for the person sharing. The person who discloses can be rejected by the person (s)he discloses to. This risk is related to the concept of intersubjectivity, the capacity for shared or coordinated experiences between people in joint activity (Mascolo & Kallio, 2020; Stern, 2005).

From an intersubjective point of view, the response of the one(s) with which the emotional disclosure takes place is essential. There is solid evidence that humans, from a very early age, are highly oriented towards other people's intentions and responses, for example, illustrated with the still-face experiment (see Trevarthen & Aitken, 2001). This orientation implies that we, as infants, get distressed when the response from a significant other does not synchronize with ours. When observing reactions after interactional episodes in which the responses of the significant other are out of sync with the infant, Trevarthen and Aitken (2001, p. 9) write: "Indeed, the infant's behaviour assumes the configuration and interpersonal timing of an expression of sad avoidance, an expression which, in an older person, we would not hesitate to call distressed embarrassment or shame (...)." This description echoes Scheff (2003) understanding of shame, an emotion signalling a threat to the most crucial human motive - the social bond. Thus, the intersubjective processes are linked to whether we develop a form of social synchronization - "we-ness" – through the social sharing of emotions. Conversely, the social sharing of emotions can lead to increased shame and loneliness - if the other person displays distance or fails to meet us adequately (Trevarthen, 2015). For traumatically bereaved people who experience stigmatization and may grapple with persistent feelings of shame and guilt, these dynamics can hinder their ability to express their emotions.

Furthermore, when a public stigma is present, the risk can also be more considerable for the “emotion-recipient” – the person another confides in. This risk can be understood by the simple notion that people who share intimate emotions often start to like each other better (see Rimé, 2009). When people start to like each other better, it is harder to distance oneself from the other person. This means that the emotion-“recipient” can become more closely affiliated with a stigmatized person, which might lead to being “contaged” with the stigma. Thus, the space for sharing emotions when stigma is present can be unsafe both for the “provider” and the “recipient.” For traumatically bereaved people, the consequences can be dire when the space for emotional sharing is unavailable. Rimé (2018, p. 69) asserts that:

> People with adverse destinies thus often face social constraints exerted on them by those who want to protect themselves from distressing emotion sharing (…) and are thus progressively dismissed from social communication. An increasingly large part of unshared experiences develop in their subjective life, feeding up social distancing, loneliness and loss of meaning. Though less often considered in this context, effects of this kind also explain the association linking social relationships and health.

Taken together, bereavement creates a social void in the mourner, and grieving after a loss is both an emotional and social process in which the social and emotional processes are intertwined. The social sharing of emotions can be risky, but also necessary for forging new or stronger social bonds and recovering from adverse events like traumatic bereavement. When emotions are not socially shared, they may feed rumination, loneliness, and distancing from close social relationships. In contrast, social sharing with adequate response can lead to increased social synchronization, forge stronger social bonds, and promote cognitive reappraisal and meaning-making processes. When stigma and self-conscious emotions like guilt and shame are present, they may restrain the space for the social sharing of emotions.

Processes of these kinds can be integrated with a relational view on resilience and the Dual Process Model of Coping with Bereavement.

2.2.2 Resilience and The Dual Process Model of Coping with Bereavement

Resilience, the capacity to withstand and rebound from adversity (Walsh, 2021), can be viewed from an individual or relational perspective. This thesis is embedded in a relational view of resilience, which encourages people to approach adversity as a shared challenge, in which their joint struggles, efforts and pride in prevailing can also strengthen their bond with others (Walsh, 2016, p. 104). For the processes of adapting after bereavement, the connections with other people, be they family members or friends, can thus be vital. A relational view of resilience aligns with The Dual Process Model of Coping with Bereavement - revised.

The Dual Process Model of Coping with Bereavement deals with coping, that is "processes, strategies or styles of managing (…) the situation in which bereavement places the individual" (Stroebe & Schut, 2010, p. 274). The ways of coping are divided into two categories of stressors associated with bereavement: loss- and restoration-oriented. The model suggests that the stressors of grief in these domains places demands on the coping processes depending on how much the loss has stressed the factor in question. For example, if the loss profoundly disrupts my role as a caretaker in the family, I need to cope with this stressor. A restoration-oriented coping would be to adjust this role or enter a new role. A loss-oriented coping would be to grieve and let go of the role I had. The oscillation between the domains is central to the model. The process of attending to and avoiding different stressors fluctuates, and the oscillation between coping with the two kinds of stressors is considered necessary for adaptive coping (Stroebe & Schut, 2010).
The Dual Process Model-Revised considers that the individual stressors and coping processes have their relational correlates and that the individual and interpersonal levels are intertwined (Stroebe & Schut, 2015). For instance, a wife and bereaved mother might cope with the loss of her son by sharing the grief with her husband. The husband's emotional needs and abilities do not synchronize with hers, and he prioritizes taking time off from the pain and grief. She experiences him as cold and turns to others to share her emotions. The intimacy in their relationship fades.

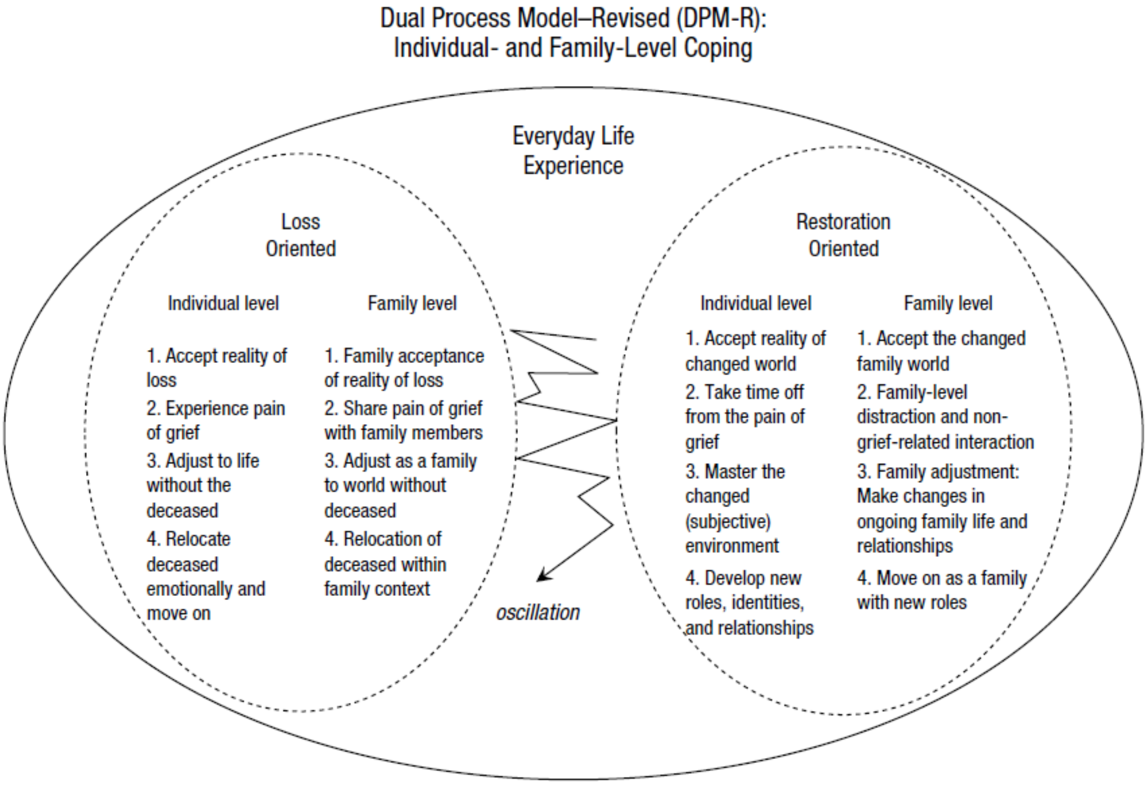


Figure 4. The Dual Process Model-Revised by Stroebe and Schut (2015)

A revision in 2016 added the concept of "overload" to the model, suggesting that too many stressors connected to everyday life, restoration-oriented tasks, or loss-oriented tasks can render the bereaved person unable to cope accordingly, which again might lead to mental and physical health complications (Stroebe & Schut, 2016). An overload of everyday life stressors could be related to quarrels and discordance within the family. An overload of loss-oriented stressors could, for example, be multiple losses in rapid succession, and an overload of restoration-oriented stressors could be having to deal with the significant increase in responsibilities as a consequence of the loss. The theoretical Dual Process Model of Coping with Bereavement, incorporating family coping and overload, can be useful for understanding the individual and interpersonal coping processes following a loss, also for traumatically bereaved people. Moreover, psychosocial bereavement care might help people in these coping processes.

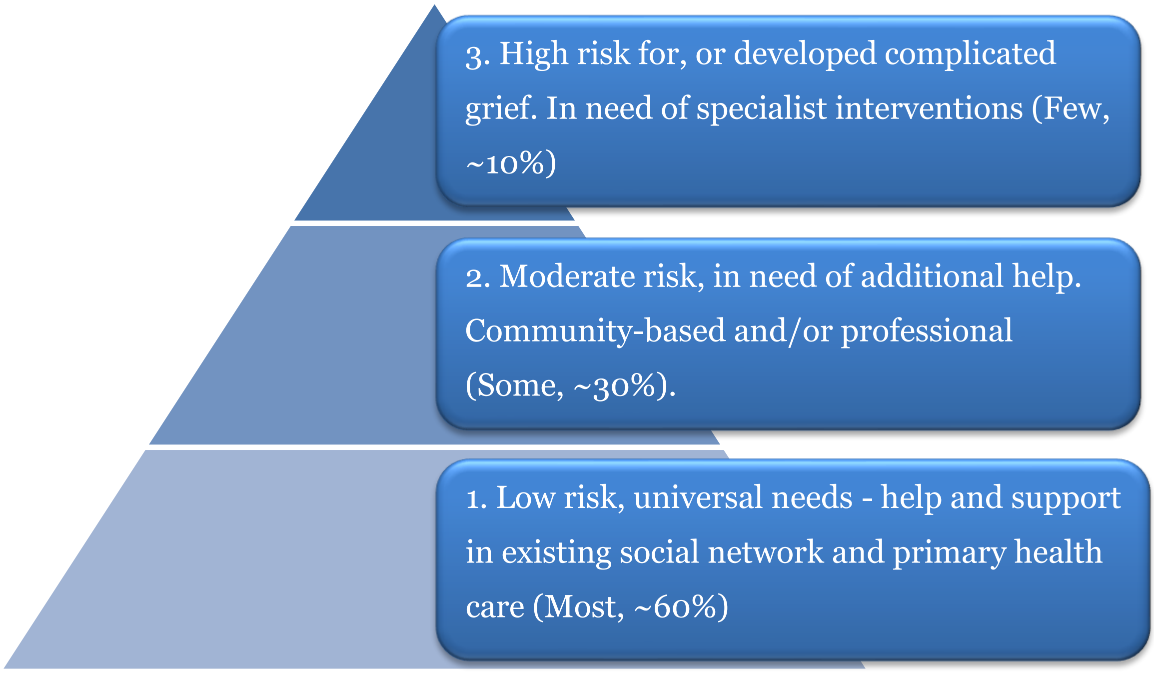
2.2.3 Psychosocial bereavement care

A central purpose of psychosocial help and bereavement care is to promote the health of those who receive it. In the Ottawa Charter, health promotion is defined as "the process of enabling people to increase control over and to improve their health" (World Health Organization, 1986, p. 1). The charter posits that an important task for public services is to "support and enable them (people) to keep themselves, their families and friends healthy through financial and other means, and to accept the community as the essential voice in matters of its health, living conditions and wellbeing" (World Health Organization, 1986). A framework for end-of-life and bereavement care that draws on the principles of the Ottawa Charter is "Compassionate Communities" (Hooker, 2022; Kellehear, 2005).

Compassionate Communities takes a public health perspective on end-of-life and bereavement care and posits the natural supportive network surrounding the bereaved person as the starting point for the help from public services (Abel, 2018; Kellehear, 2005). The Compassionate Communities philosophy for the relationship between health services and the community, is that health care should be participatory, something we do *with* others and not *to* others (Kellehear, 2005).

Rumbold and Aoun (2015) build on the architecture of Compassionate Communities and suggest that health and social services should have an asset-based approach to bereavement care, contending that most care comes from people already involved in the everyday life of those bereaved. Hence, supporting these "everyday assets" is considered the most effective way of providing bereavement care (Rumbold & Aoun, 2015). Consequently, a public health model based on Compassionate Communities needs to develop ways of working that create partnerships between formal and informal networks (Aoun, 2020). A public health architecture for psychosocial bereavement care, like Compassionate Communities, must consider different needs among the bereaved populations.

A tiered model of bereavement care based on an approximation of the different needs of the population, was first outlined in the cancer guidelines in the United Kingdom (NICE, 2004, pp. 160-161). The tiered model was later proposed and recommended in the bereavement literature in several Western countries (see McLoughlin, 2018; Penny & Relf, 2017; Rumbold & Aoun, 2015; Stephen et al., 2009; The Irish Hospice Foundation, 2020). The three levels are based on an approximation of the number of people at different levels of risk for persistent complicated grief reactions after death, with around 60 % estimated at low risk, 30% at moderate risk, and 10 % at high risk (Penny & Relf, 2017).



3. High risk for, or developed complicated grief. In need of specialist interventions (Few, ~10%)

2. Moderate risk, in need of additional help. Community-based and/or professional (Some, ~30%).

1. Low risk, universal needs - help and support in existing social network and primary health care (Most, ~60%)

Figure 5. A three-tiered public health model for bereavement care. Inspired by Aoun (2020), NICE (2004) and Penny and Relf (2017).

The higher tiers concerning support and care build on the lower tier. For example, the need for help and support from existing social networks and primary health care (tier 1) is also necessary for those with greater needs (tiers 2 and 3). The several different versions of the model all emphasise the central role of family and friends in coping with bereavement (see Aoun, 2020; Penny & Relf, 2017; The Irish Hospice Foundation, 2020), and the role of the family is especially stated in the tiered model for children (Childhoood Bereavement Network, 2017).

Abel et al. (2018) highlight the training and use of social network mapping and social network enhancement for all staff as essential in a public health system based on Compassionate Communities. Thus, if services should aim to strengthen the capacity for support and resilience of the inner and outer network of those bereaved, they would need to have a framework for and competence in engaging in dialogues with families and social networks. When we know that DRD-bereaved people often report complex social relationships, and most likely have risks and needs that position them in the two upper tiers of the bereavement pyramid (high-moderate risk), bereavement care where the service providers have competence in social network enhancement might be of particular importance for them.

Psychosocial bereavement care and traumatic deaths

If the goal of bereavement care is to mobilize and partner with social networks effectively, also in cases of traumatic bereavement, it is essential to address the question of "how." The Open Dialogue approach to psychosocial help offers a perspective and principles that could be adapted to this purpose.

Initially developed as a need-adapted treatment approach to tackle the issue of severe mental health difficulties in a community setting (Seikkula et al., 2011), Open Dialogue offers principles aligned with the service delivery ideals of Compassionate Communities (see Aoun, 2020; Kellehear, 2005) and structure of the Norwegian guideline on Psychosocial Measures in Crises, Accidents and Disasters (see Norwegian Directorate of Health, 2016). Open Dialogue emphasizes the strengthening and mobilization of the resources of the focal person together with his/her family or close social network and interdisciplinary collaboration from the start to the end of the follow-up process provided by the professional services (Ong et al., 2019). The approach builds on seven principles that were developed on the basis of training and research in Finland, where it was developed (Seikkula et al., 2006).

These principles are (1) the provision of immediate help, within 24 hours of the first contact with the service, (2) a social network perspective, where key members of the focal person's social network are invited to the first meetings, (3) flexibility and mobility regarding places to meet, changing needs and therapeutic methods, (4) responsibility, whereby the professionals first contacted are responsible for organizing the first meeting, (5) psychological continuity, to ensure that the professionals and social network members, who are involved at the beginning of the follow-up, are involved throughout the whole process, if possible (6) tolerance of uncertainty, by accepting the uncertainty of the process and the outcome of the follow-up and by building strong relationships in which everyone feels safe and (7) dialogism, where the focus in the interventions is “primarily on promoting dialogue and secondarily on promoting change in the patient or in the family” (Seikkula et al., 2006, p. 216).

Open Dialogue does not prescribe one specific kind of therapeutic intervention but provides a framework for psychosocial help in which different therapeutic methods can be used. The founding element of this framework is the dialogue within the clients’ social network. However, the need for individual help, for example, individual therapy, can and should be met and provided as part of the follow-up within the framework.

The principles of Open Dialogue can largely be considered an operationalization of important features of a Compassionate Communities public health framework for bereavement care for traumatically bereaved people. Open Dialogue aims to strengthen the potential resilience within the close social networks through involvement of the inner network from the beginning of contact with health- and social services (Seikkula & Arnkil, 2006). The social network meetings emphasize facilitating the social sharing of emotions (Seikkula & Trimble, 2005). Moreover, Open Dialogue provide a framework for tying together different levels of service provisions over time, addressing the complexity of a continuity of professional care when different service providers are involved in the follow-up (see Seikkula & Arnkil, 2006). Finally, the emphasis on early and flexible help fits well with traumatically bereaved populations’ reported needs for professional help.

2.3 Research design and methods

The data collection for the END project, and consequently for this doctoral project, began with a combination of purposive and convenience sampling methods to recruit participants for the cross-sectional survey. In the survey, participants were given a consent form that allowed them to agree to individual interviews. Based on this consent, a diverse sample of parents was strategically selected. Table 1 provides a chronological overview of the doctoral project's sampling, data collection, analyses, and outcomes.

Table 1: *Diagram of the project showing phase, procedure and product*

<u>Phase</u>	Procedure	Product
Data collection, quantitative and qualitative	Convenience and purposive sampling for survey, N=255 Strategic sampling of participants from survey, N=14 (parents)	Numeric data Audio data (sound files) Text data (transcripts)
Article I: The help needs and experiences	Quantitative analysis (n=124-255). Descriptive analyses of background data, support needs and received help Chi-square analyses of support needs and received help Logistic regression analysis of predictors of satisfaction regarding provision of help.	Frequencies and central tendencies on background characteristics and variables concerning needs and received help Dependency/independency of needs and received help from other variables Predictors of satisfaction regarding support
Article II: The social health	Quantitative analysis (n=124-255) Descriptive analyses of Crisis Support Scale (CSS) Work and Social Adjustment Scale (WSAS) Health-related quality of life (RAND 12) Social withdrawal (AQ-R) Comparison analyses (n=124-130), for example, T-test, ANOVA	Central tendencies on social health variables across whole sample and stratified in different relationships to deceased Differences in the social health variables dependent on satisfaction regarding help
Article III: The family interaction and help needs	Qualitative analysis, parents (N=14) Reflexive thematic analysis of interview data	Codes and themes of family interactions and help needs
Synopsis	Integration of the quantitative and qualitative results. Discussion, interpretation and explanation of the different findings	Synopsis with implications and future directions

Figure 6 shows that the first two parts of this doctoral project have a quantitative approach, using cross-sectional data from the survey to investigate the help needs, help experiences and social health of DRD-bereaved people with multiple relationships to the deceased. The third article is based on qualitative data from the in-depth interviews of 14 parents recruited from the survey. This article explores how family interactions and the family-oriented help needs of DRD-bereaved families can be understood through interviews with DRD-bereaved parents.

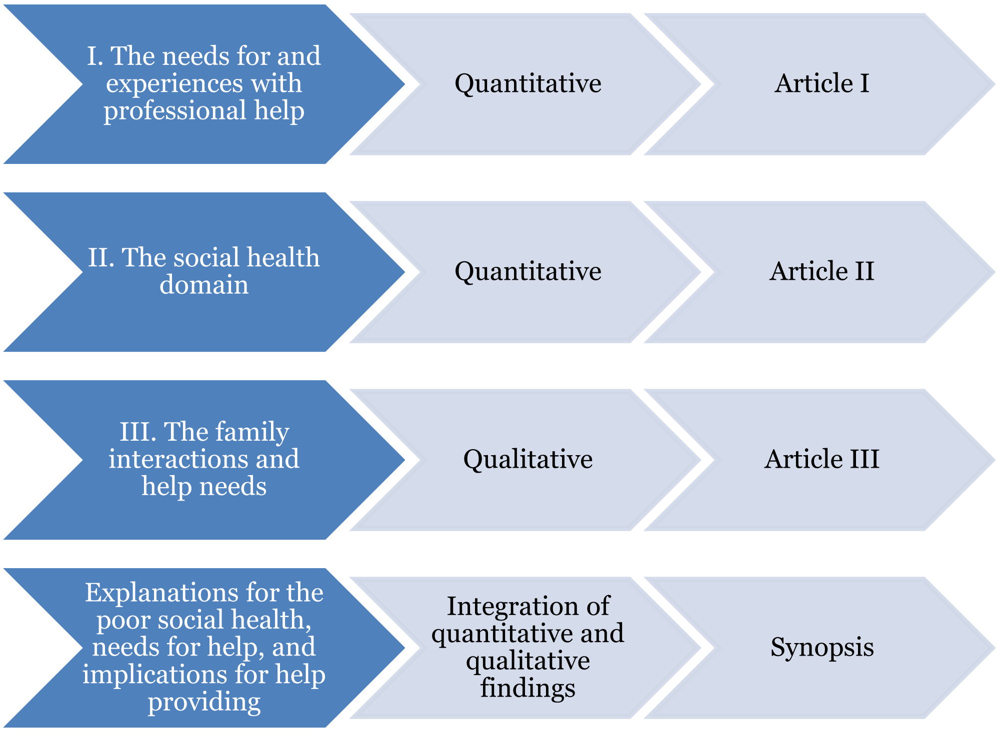


Figure 6: The foci and methods of the different articles and the synopsis

Article I investigates the help needs and experiences reported by those bereaved. The high reported need for assistance prompted an investigation into various dimensions within the social health domain of the participants. The hypothesis was that the population would, on average, report relatively low scores in this area. Subsequently, based on the findings indicating that the sample's scores on dimensions of social health were indeed relatively low (Article II), we explored the interviews with DRD-bereaved parents to delve into how they experienced family interactions. These analyses aimed to explore the dynamics of family interactions, which constitute one aspect of the micro-level of social health (Article III).

The doctoral project thus follows a variant of what Schoonenboom and Johnson (2017, p. 10) describe as "a combination of a quantitatively established effect and a qualitative description of the underlying process." The "effect" in this case is the need for professional help and the generally poor social health among those bereaved, and the "underlying process" is explored through the parents' descriptions of family interactions.

The doctoral project can be conceptualized as mixed methods research. An important feature of mixed methods research is that the quantitative and qualitative findings should make more of a statement about the study object than a purely quantitative or qualitative design could (Fetters et al., 2013). The study object is the social health and help needs of DRD-bereaved people. The quantitative articles document the help needs and the state of the participants' social health dimensions with considerable generalizing value. The qualitative exploration of family interactions and help needs adds an understanding of the participants' reported social health and help needs, as well as potential explanations. Hence, I argue that the mixed methods research design adds a greater validity to the quantitative findings and explanatory value in terms of answering the last research question.

The different methods can be connected and integrated into several phases of the research project in a mixed methods research design (Fetters et al., 2013). For this doctoral project, the qualitative data are connected with the quantitative data through the sampling frame (see Schoonenboom & Johnson, 2017). Furthermore, the results and discussion from the quantitative analyses provided the basis for the qualitative data selection, research question and data analysis. The qualitative data analysis has explanatory value for the quantitative findings, especially the quantitative findings of Article II. The data are merged in the synopsis, connecting the three articles' research questions and methodology. Thus, when using a mixed methods typology, this thesis would probably best be termed a quantitatively driven concurrent and explanatory mixed-method research design (see Schoonenboom & Johnson, 2017).

2.3.1 Recruitment and participants

Members of the END project group recruited the participants to the survey and interviews before this doctoral project started. The criteria for participation in the study was having been bereaved due to the DRD of a family member or a close friend. The assessment of the inclusion criteria was given to the participants: their own subjective experience of being bereaved by such a death (Appendix 1. In the survey, the alternatives for defining the manner of death were Drug overdose without intention; Intended overdose (suicide); Disease, accident or violence related to the intake of drugs, or Unknown cause (Appendix 2).

All the members in the END project group, which at the time consisted of two professors, four associate professors, three assistant professors, one PhD-student and four user consultants, were active in the recruitment process from March to December 2018. E-mails with a flyer (Appendix 3) detailing the aim of the project and how to participate were sent countrywide to central municipalities and specific health and social municipal services, relevant non-governmental organizations, treatment centres, large companies, hospitals, religious and non-religious foundations, universities and student colleges. Media (television, radio, and newspapers) and social media (Facebook and Twitter) were used to distribute information and make contact with potential participants. Furthermore, assembling the national “Drug-death bereavement and recovery” conferences in 2017 and 2018 were used to actively recruit participants, and snowball sampling was also an important means of recruitment.

During this period, 255 participants were recruited for the survey, which could be completed digitally or manually. The Regional Ethics Committee approved sending a reminder to all registered participants who had not completed the survey after 14 days, which was done. The survey contained a page with an enquiry concerning participation in individual interviews at the end of the survey. Many participants responded and agreed to be interviewed, including 75 of the 95 parents.

Out of the respondents, a total of 14 parents were interviewed. The selection of parents for these interviews was carefully considered, with the primary focus on variables such as gender, place of residence (including various regions of the country and distinctions between urban and rural areas), a wide range of ages (above 18 years), and varying durations since the loss occurred. Additionally, the inclusion criteria encompassed the parents of deceased children of both genders. Consequently, we conducted interviews with seven mothers and seven fathers.

2.3.2 Phase 1, quantitative design

Articles I and II are quantitative studies, and different parts of the same cross-sectional survey were used in both articles. The cross-sectional design enabled both descriptive and analytical analyses to explore associations between variables, such as the differences between various groups included in the sample, for example, parents, siblings, etc. or whether the help from certain service providers was related to a greater degree of satisfaction. The cross-sectional design does not allow for causal inferences. However, associations can indicate a possible causal relationship that can later be studied with other designs or inferred through abduction or retroduction.

The survey comprised a total of 109 questions and 23 sub-questions (number of questions on each theme in parenthesis, includes sub-questions): Background variables (22), "The Special Grief Questions" (19), RAND-12 (12), Work and Social Adjustment Scale (5), The General Self-Efficacy Scale (5), The Crisis Support Scale (7), Prolonged Grief Disorder PG-13 (13), The Posttraumatic Growth Inventory Short Form (10), Assistance Questionnaire – Receivers (36). In addition, one question from the General Health Questionnaire concerning suicidal thoughts and two questions on own substance use were included in the survey. The survey was piloted by three user representatives from the END project group, and corrections and additions were made based on their feedback.

Both quantitative articles used background variables reported in the first part of the survey, for example, gender, place of residence and number of DRDs experienced. In

Article I, most other variables were taken from the Assistance Questionnaire – Receivers (Dyregrov, 2003b). This questionnaire was developed by grief researcher Kari Dyregrov and colleagues in relation to a Norwegian research project on traumatically bereaved people starting in 1996 - The Support and Care Project (see Dyregrov & Dyregrov, 2008). The questionnaire was later adapted and used in various contexts with the traumatically bereaved in Norway (Dyregrov, 2002; Dyregrov et al., 2015) and Australia (Wilson & Clark, 2005). Furthermore, two independent variables, used in the starting steps of the logistic regression analysis, were taken from the "Special Grief" Questions in the survey. Kari Dyregrov developed this questionnaire with grief researchers William Feigelman (US), Margaret Stroebe (Netherlands) and Christine Valentine (UK). The questions concern to what degree those bereaved experience the fear of death and anticipated grief pre-loss and ambivalence, guilt, shame/stigma and disenfranchised grief post-loss (Dyregrov et al., 2020; Titlestad, 2021). The variables, included in the statistical analysis in Article I, concerned the pre-loss fear of death and loss of sleep.

Most instruments in Article II were validated in their country of origin and have been quite frequently used, making comparisons with populations from other studies possible. Most of them have also been used and measured for internal consistency in studies in different countries, including Norway or similar countries (i.e., Scandinavian or Nordic countries), namely the Health-related quality of life - RAND-12 (Farivar et al., 2007; Gandek et al., 1998), the Work and Social Adjustment Scale -WSAS (Pedersen et al., 2017), and the Crisis Support Scale – CSS (Bodvarsdottir & Elklit, 2004; Elklit et al., 2001). Two single Likert items from the Assistance Questionnaire were also used in this study, concerning whether the participant had withdrawn from others, or that others had withdrawn from the participant after the death. Table 2 shows the instruments and their content, and where they are used in this doctoral project.

Table 2. *Survey instruments and single items used in quantitative articles*

Instrument name	Measures	Description	Ref.
Assistance Questionnaire – receivers (AQ-R)	Bereaved people's ways of coping, need for help and social support, and experiences of help and social support.	AQ-R consists of 22 questions and a mix of response options – free-text, nominal, ordinal, and five-point Likert items. In this doctoral project, items were used in both quantitative articles. In Article I, 12 items addressing questions on needs and experiences of professional help were used. Article II used two single items concerning one's own or the others' social withdrawal level after death.	Dyregrov (2002) Dyregrov et al. (2015)
Crisis Support Scale (CSS)	Perceived and obtained social support after the death.	CSS consists of seven items measured by seven-point Likert scales. The sum score of the first six items, reversing the score on the sixth negative item, measures the level of social support. Higher scores=higher social support In this doctoral project, six scale items were used for the descriptive analysis, and the five positive support items for the correlation and group comparisons tests (ANOVA and non-parametric) in Article II.	Elklit et al. (2001) Joseph et al. (1992)
General Self-Efficacy Scale, Short Form (GSE-SF)	General self-beliefs regarding own coping with difficulties and challenges.	GSE-SF consists of five Likert items, scoring 1-4 from "Not at all true" to "Exactly true", for example, "I can solve most problems if I invest the necessary effort." Higher scores=higher self-efficacy. In this doctoral project, the scale was used as one of the predictor variables in the logistic regression analysis concerning predictors of satisfaction regarding help from professional services.	Schwarzer and Jerusalem (1995) Tambs and Røysamb (2014)
PG-13	Symptom levels of prolonged grief.	PG-13 consists of 13 items on grief reactions following a loss, including separation distress, cognitive, behavioural and emotional symptoms, frequency, and a duration and impairment criterion. Except for the duration and impairment criterion, all other 11 variables concerning frequency or distress are rated on five-point Likert scales. Higher sum scores = higher levels of grief symptoms In this doctoral project, the sum score of the 11 variables measuring frequency or level of distress was used in Article I.	Prigerson et al. (2009)

Table 2 *Survey instruments and single items used in quantitative articles* (continued)

Instrument name	Measures	Description	Ref.
RAND-12 health survey	Health-related quality of life.	The RAND-12 health survey consists of a mix of nominal variables and Likert items regarding the health-related situation for the last four weeks. Examples of questions are "have you felt downhearted and blue?," "how much of the time have your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?" Higher scores=better health-related quality of life. For this doctoral project, the mental health component of the scale, using the oblique scoring method, was used in Article II.	Farivar et al. (2007) Gandek et al. (1998)
The "Special Grief" Questions (SGQ)	Fear of death and anticipated grief, ambivalence, guilt, shame/stigma, anticipated grief.	The SGQ consists of 17 five-point Likert items measuring to what degree those bereaved have experienced complex emotions, relationships, stigma and self-stigma. For this doctoral project, two items were used as independent variables in the logistic regression analysis in Article I: Worry before death and Fear disturbed night sleep.	Dyregrov et al. (2020)
Work- and Social Adjustment scale (WSAS)	Impaired work and social adjustment following an adverse incident.	The WSAS consists of five nine-point Likert items, and higher sum scores = higher levels of impairment related to the loss in the last four weeks. The measured domains include work, home management, social and private leisure, and social relations. In this doctoral project, the scale was used in Article II. The full scale was used in the descriptive analyses, while the two items that tap social relations were used in the analyses comparing groups (ANOVA and non-parametric)	Mundt et al. (2002) Pedersen et al. (2017)

Statistical analysis

All statistical analyses were conducted using IBM SPSS Statistics Version 27. A codebook for the data matrix was made, and a continuously updated log to track changes was kept. Frequency and chi-square analyses were used to investigate the purpose of Article I, which concerned help needs and experiences. For the chi-square analyses, the dependent variables were the following questions (Appendix 2):

- Did you receive help from professionals/help services after the death? (yes/yes, earlier/no).

- Did you experience a need for assistance from professionals/help services soon after the death? (five-point Likert scale, high degree-not at all)
- How was the contact with the help services initiated? (I was contacted/I initiated contact myself/others initiated contact on my behalf).

Logistic regression analysis was applied to question b) “which variables are associated with the participant’s satisfaction with regard to the provision of help?” The dependent variable, “satisfaction with regard to help,” was collapsed from a five-point to a dichotomous variable, to the two options “high” and “low” satisfaction regarding the provision of help. The middle alternative, “satisfied to a certain degree,” was put in the “high” satisfaction category. The purposeful selection of relevant and possible confounding variables was applied (Hosmer et al., 2013). In the first step of the analysis, 24 independent variables were included, based on the theoretical assumptions of variables that could impact satisfaction with the provision of help: nine background variables (e.g., education level, relationship to the deceased), seven variables concerning the strain before or surrounding the death (e.g., fear of a disturbed night sleep, duration of substance use) and eight variables concerning the service provider or service provision (e.g., home visits). A detailed description of the steps in the logistic regression analyses can be found in Appendix 4.

Article II aimed to a) find how DRD-bereaved people rated dimensions of their social health and b) whether there were differences in social health between DRD-bereaved people with different experiences of professional help.

Question a) was investigated with frequency analyses and question b) was investigated with analyses comparing groups, namely T-tests, Mann-Whitney U-tests, ANOVAs and the Kruskal-Willis H test. A linear regression and correlation analysis provided part of the foundation for choosing these methods as, theoretically, time since death was considered a co-variate that should be included in the ensuing analyses of variance. However, it was not included because the time since death showed no correlation with the dependent variables in these analyses. Hence, the initial assessment of using a statistical method that could control for confounding (e.g., ANCOVA) was changed.

2.3.3 Phase 2, qualitative design

The qualitative study, Article III, is based on the in-depth interviews conducted with 14 parents recruited from the survey. The research question was: *How can DRD-bereaved families' need for family-oriented help be understood through bereaved parents' reflections on family interactions post-loss?*

Data collection

At the beginning of the doctoral project, all data collection approved by the Regional Committee for Medical and Health Research Ethics had been conducted. This data collection included in-depth interviews with siblings (10), friends/partners (18) and parents (14) concerning the period before and after their loss. I discussed options with my supervisors, and decided to use the interviews with the 14 parents as the qualitative data material for the last article (see also section 2.5.1).

Semi-structured, in-depth interviews

Three researchers of the END project conducted the interviews between August and December 2018: clinical social educator Kristine Berg Titlestad, sociologist Kari Dyregrov and psychologist Sonja Mellingen. A checklist was developed, ensuring a common standard, including re-informing the participants of the END project's aim, how the data would be stored, consent form, etc. The interviews took place between 27. August and 4. December 2018 in private settings selected by the participants. Nine interviews were conducted at the participants' homes, four at their work office and one in a hotel.

The interview guide consisted of five themes, a) the period before the death, including the relationship to the deceased and the impact of the drug use b) the period after the death, including factors impacting the grief, c) stigma and self-stigma, including how and to whom they could talk about the grief, d) support from family and friends and help from professional services and e) coping and posttraumatic growth (Appendix 5). Although all the interviews included the themes mentioned, the questions were fairly open after the initial question asking who the deceased was and the nature of the interviewee's relationship with that person.

The interview guide was calibrated through a pilot interview with a DRD-bereaved parent, conducted by the END project's senior grief researcher, Kari Dyregrov, with the two other interviewers present, followed by a discussion with the interviewee and the interviewers. The interviews, which lasted 1.5-3 hours including breaks, were audio-recorded and later transcribed verbatim by a research assistant. Each interview ranged from 20 to 39 pages, and the transcripts covered 431 single-spaced pages. When half of the interviews had been conducted, the interviewers exchanged experiences and calibrated future interviews based on notes and experiences.

Reflexive thematic analysis

I analysed the interviews using a reflexive thematic analysis framework described by Braun and Clarke (2022). Reflexivity denotes the disciplined practice of critically interrogating the whats, the hows and the whys of the research, including one's preconceptions and situatedness in relation to the phenomena in question (Braun & Clarke, 2022). The thematic analysis was based on a primary experiential framework, grounded within the life-world of the participants, in which I aimed to understand their help needs based on an intimate understanding of how they experienced the phenomena of family interactions (see Braun & Clarke, 2022). However, the hermeneutical element is epistemologically essential, as texts always require interpretation from the one who utters and interpretation from the one who reads (Lindseth & Norberg, 2004). Moreover, the hermeneutical element was essential for answering the research question of how family help needs could be understood through the parents' descriptions of family interaction.

Reflexive thematic analysis is conducted in six phases (Braun & Clarke, 2022). Some phases partly overlap, and some are recursive. These phases are 1) familiarization, whereby the researchers immerse themselves in and gain an in depth understanding of the data content, and make notes of any ideas and potential patterning, 2) coding, whereby patterning of meaning is explored and the associated codes are developed, 3) initial theme generation, in which codes are clustered into possible themes, i.e., larger meaning patterns in the data, 4) development and reviewing of themes, whereby themes are scrutinized, evaluated and changed, 5) refinement, where themes are defined and named and 6) writing up, involving the write up of the article with the generated themes (Braun & Clarke, 2022).

I listened to the audio recordings and read the transcripts during the familiarization phase. This combination of sensory inputs provided me with enriched information regarding the conversation, such as when the interviewees seemed to touch on something they regarded as important, and my own emotional reactions to passages in the interviews. In addition, the use of audio helped me sense and understand the interaction and co-construction between interviewer and interviewee, which provided context for the data interpretation. The ensuing process started linearly but became more and more recursive as the analysis progressed in phases 2-6. For example, from phase 3, I returned to phase 2 after a discussion with the co-authors, as I did not consider the developed codes to be in line with the research question. From phase 5, I went back to phase 4 and developed new themes on the basis of the codes, as the themes, following a discussion with the main supervisor, Kristine Berg Titlestad, were deemed too deductively oriented. The exact wording of the final themes was reviewed and changed throughout the writing process (phase 6), until the final article was ready.

Writing down your experiences of how you as a person and professional researcher are situated in relation to the data, context and research aims is a critical recommendation in reflexive thematic analysis (Braun & Clarke, 2022) and phenomenological-hermeneutic research (Lindseth & Norberg, 2004), hence I wrote a reflexivity note before reading the interviews and listening to the audiotape. It increased my self-awareness of what I brought to the analysis, and where my experiences “stood” concerning the phenomena I investigated. Moreover, as prescribed in reflexive thematic analysis (Braun & Clarke, 2022), I kept a continuous reflexive journal throughout the project, writing about analysis progress, ideas and assumptions, and reflecting on the interpretations and paths in the analysis process.

2.4 Ethical approval

The Regional Committee for Medical and Health Research Ethics (REK) approved the END research project in February 2018, reference number 2017/2486/REK Vest (Appendix 6). Due to an extension of the END project beyond the time frame approved by the REK, extended approval for the storage and usage of existing data until 2026 was applied for. In addition, the application requested that four doctoral students, with their doctoral projects, be added to the research project. This doctoral project was one of these studies. REK Vest approved this application in November 2020, reference number 11121 (Appendix 7 & 8), provided that the participants were informed of the extension. This information was written and sent to the participants by myself and a fellow doctoral student in February 2021, guided by our supervisors. We logged this work in detail.

The data management plan entailed that participants' qualitative and quantitative data were deidentified and stored in the Western Norway University of Applied Sciences' research server. Identifiable names were replaced with a code, and the code keys connecting the deidentified forms and interviews with the directly identifiable personal information were stored in a different secure area in the research server, to which only the END project leaders had access rights. The data storage in the secure research server followed the standards of The European Union's General Data Protection Legislation, as incorporated in The Personal Data Act (2018) in Norway. The Western Norway University of Applied Sciences' (2021) guidelines for processing personal, identifiable and health data in research provided the detailed, practical management of the data processing in the doctoral project.

2.5 Methodological and ethical considerations

The empirical studies in this doctoral project consist of two quantitative articles and one qualitative article, and I have argued that the research design of the doctoral project can be termed mixed methods research, quantitatively driven, concurrent and explanatory (see Schoonenboom & Johnson, 2017). In the current chapter, I will describe important choices I have made concerning research questions, the use of methods, and the strengths and limitations these methods imply for the findings in the doctoral project. Moreover, ethical considerations will be addressed.

2.5.1 The choice of research questions and data for the qualitative phase

Choosing the research question and data for the last article posed a challenge, as it involved considering how a qualitative approach could add value to the findings from one or both of the quantitative articles. I commenced my doctoral project with access to data already collected and ethically approved by the Regional Ethics Committee, including interviews with 14 parents, 18 friends/partners and 10 siblings. All interviews included significantly more topics than what my research focus addressed: dimensions of family- and social life and the interplay between help services and social relationships after the deaths. Hence, I decided to screen all interviews to select the most relevant research focus and sample.

Considerations related to the selection of the research questions and sample were continuously recorded and discussed in the reflexive journal during this screening, for example, concerning the information power on this subject in the different interviews, the relationship between the quantitative and the qualitative sample, the participants' experiences of professional help and the advantages and disadvantages of including a mix of different relationships to the deceased in the qualitative sample. I realized that including multiple relationships could be challenging because the participants had highly diverse life situations and connections with the deceased. Since I wished to understand the participants' experiences in depth instead of covering a wide range, focusing on one type of relationship with the deceased made the most sense.

The screening concluded that the interviews with parents seemed most informative on the topic of interest. All parents had participated in the survey, and the sample selection was the most comprehensive regarding various background characteristics like gender, location, etc. Furthermore, an important aspect was that in terms of family relationships and family-oriented help, parents are often in an empowered position to seek out or accept such assistance, both for themselves and for other family members (see Andriessen et al., 2019; Rickwood et al., 2015). Therefore, I chose to use the parent interviews, with the option of including interviews with siblings if there was a need for more data to gain adequate information power.

During the familiarization with the data in the autumn of 2022, the research question underwent several revisions in consultation with the supervisors. I also presented this part of the doctoral project for systematic feedback from members of the END project's advisory board, and this feedback served to refine the final research question to "How can drug-death bereaved families' need for family-oriented help be understood through bereaved parents' reflections on family life."

It proved a challenge that all the qualitative data had already been collected following the END project's concurrent mixed-method approach. The qualitative research question in this doctoral thesis, built upon the quantitative analyses' findings, would have prompted interviews focusing on delving deeper into those topics. However, although the interview guide did not specifically address the research question, reflections about family life and help needs emerged prominently in all interviews with parents. During the analysis, we thus determined that there was sufficient information to address the research question.

2.5.2 Validity, reliability, transferability and generalizability

Considerations concerning validity, reliability, transferability and generalizability are differently treated within quantitative versus qualitative research projects. Before delving into the specific quantitative and qualitative considerations, it is essential to address overarching concerns regarding the validity of the mixed methods research project as a whole. In both quantitative and qualitative methodologies, validity revolves around the fundamental concept of ensuring accuracy in the investigation of the phenomenon under examination, ensuring that the methods employed capture essential aspects of the phenomenon in a useful and believable manner (see Carter & Lubinsky, 2015; Creswell & Clark, 2018; Maxwell & Loomis, 2003). The identification of these central aspects and thus selection of methods depend on the research question guiding the study. The overarching research question for this thesis is "How are the social health and help needs of DRD-bereaved people, how can they be explained, and what implications can be drawn for help provisions?"

A fundamental question regarding the validity of the mixed methods research design arises: Does this approach enhance the validity of insights pertaining to the research question, and what limitations in terms of validity might still exist? The validity of the findings related to the social health dimensions of DRD-bereaved individuals is notably bolstered by the qualitative exploration of DRD-bereaved parents' experiences. Their accounts of family interactions expand our comprehension of nuances and complexities within constructs such as "withdrawing from others" and "social support." Furthermore, these qualitative insights contribute significantly to explaining the phenomena under investigation, and they are instrumental in the ensuing discussions and the derivation of implications for help provisions.

However, it’s crucial to acknowledge the limitations to validity inherent in this approach. Primarily, the qualitative data enrich and add depth to the quantitative findings from the perspective of parents, not the perspective of other family members. Furthermore, the qualitative exploration remains limited in scope to the domain of “family life.” The broader extended network of DRD-bereaved individuals is not covered in the qualitative exploration. Hence, the explanations for the low ratings in social health dimensions and the implications drawn for assisting DRD-bereaved people should be understood on these premises.

The quantitative studies

Regarding quantitative studies, Carter and Lubinsky (2015, p. 76) define validity as “the extent to which the conclusions of that research is believable and useful.” While “internal validity” addresses issues of causal relationships, the most important dimensions of validity for these articles are a) construct validity, concerning the *meaning* of variables in the study, and whether the operationalization of a construct is a good indicator for the construct, and b) external validity, concerning “to whom, in what settings, and at what times the results can be generalized” (Carter & Lubinsky, 2015, p. 88). Reliability, on the other hand, concerns “the degree to which the measurement is free from measurement error” (Mokkink et al., 2010, p. 743). I will first address the considerations of reliability in both quantitative studies, subsequently exploring the construct validity and internal consistency (a feature of reliability).

In terms of reliability, we must consider the time gap between the DRD and the data collection in our project, as it gives rise to concerns about recall bias. The period between the death and the survey ranged from 0 to 35 years for the participants, with an average of 8.1 years. Specifically, when it comes to questions about the early support individuals received after the loss, a central theme in Article I, we need to acknowledge the potential for interference. As time passes, people’s life experiences can shape their perception of their own needs and their satisfaction with the assistance they received. This introduces a possible decrease in the reliability of these responses.

For Article II, the situation is somewhat different, as the analysed variables predominantly gauge participants' perceptions of their current circumstances. This is evident in instruments like the RAND-12, The Work and Social Adjustment Scale, and The Crisis Support Scale. However, it is worth noting that the Work- and Social Adjustment Scale also prompts participants to assess their present functioning in light of how the loss has impacted them. Similarly, the two Likert scales in the Assistance Questionnaire enquire about changes in connections with others *following* the loss. Consequently, participants' evaluations of whether the loss has caused these changes may be less precise, especially for those who experienced their loss a long time ago compared to more recent losses.

In Article I, in which we investigate the needs and experiences of professional help, the primary questionnaire is the Assistance Questionnaire – Receivers (see table 2). This questionnaire was developed in a Norwegian context by Kari Dyregrov with fellow grief researchers and clinical specialists at the Center for Crisis Psychology in Norway. The questionnaire has been employed in various studies on traumatically bereaved populations in Norway, apparently yielding believable and useful results (see Dyregrov, 2002; Dyregrov, 2003b; Dyregrov et al., 2015). However, it is important to note that the questionnaire's measurement properties have not yet been tested.

The General Self-Efficacy Scale – Short Form (Article I) is translated and cross-culturally validated into Norwegian (Leganger et al., 2000; Tambs & Røysamb, 2014). Thus, the association between the score on this scale and satisfaction with help should be quite valid. The measurement properties of the PG-13 instrument have been assessed in other countries, but not in Norway. The Norwegian version has been translated by grief researchers Atle Dyregrov and Pål Kristensen. As the instrument is not evaluated cross-culturally, the accuracy of the results in this Norwegian context must be considered with some caution (cf. Huang & Wong, 2014).

Article II used three generic measures: the Work and Social Adjustment Scale (Mundt et al., 2002), the Crisis Support Scale (Elklit et al., 2001) and the RAND-12 health survey (Farivar et al., 2007; Gandek et al., 1998). Generic measures purport to be broadly applicable across populations, demographics and cultural contexts (Patrick & Deyo, 1989). In addition, two single Likert items from the Assistance Questionnaire were used in this article. The measures included questions operationalizing relatively universal human experiences, for example, “When you need to talk, how often is someone willing to listen to you?” from the Crisis Support Scale. The single Likert items also share this trait. In this article, we argued that the included variables inform different dimensions in the social health domain. This is our conceptualization, not originating from the different instruments and variables in question. See more about the rationale for this decision in the background section of Article II.

The measurement properties of all generic measures included in Article II were originally tested in their respective countries of origin and have been used in previous studies in Norway (e.g., Andersen et al., 2022; Kristensen et al., 2010; Pedersen et al., 2017). It is important to note that only the RAND-12 instrument has undergone cross-cultural validation for use in a Norwegian context, while translations of the Work and Social Adjustment Scale and the Crisis Support Scale, to my knowledge, have not. Nevertheless, it is worth recognizing that both of these instruments have been employed in numerous studies conducted in Norway and other Scandinavian countries. In these studies, they have demonstrated acceptable levels of internal consistency, a dimension of reliability (e.g., Arnberg et al., 2012; Dale et al., 2020; Pedersen et al., 2017). The Crisis Support Scale has also undergone comprehensive testing and validation in Denmark (Elklit et al., 2001), a cultural context similar to that of Norway. Consequently, while more thoroughly adapting these two scales to the Norwegian context would have been preferable, we consider the results reasonably valid and reliable.

Finally, an important issue for Article II is construct validity, that is, whether the instruments measure what they claim to measure. This question concerns, for example, perceived and obtained social support and other relational processes like withdrawing from other people. The measuring of these phenomena using self-report instruments, rests on the assumption that social support and social health, to a large degree, can be measured from “the eye of the beholder” - the participants’ subjective experience. Conversely, Lakey and Orehek (2011) argue that social support should be considered a continuously changing entity, depending on day-to-day social interactions with unique people.

Following their view, the cross-sectional survey design and measurements used in this article do not capture the core of perceived social support or other social health variables and cause effect sizes with “unknown mixes of recipient personality and social influences” (Lakey & Orehek, 2011, p. 490). On the other hand, this way of quantitatively measuring perceived social support and other relational variables is essentially the only one used in the literature in this field, and it can be argued that recipient, provider, and relational influences might be impossible to isolate from each other. Thus, this article captures the participants’ subjective perception of their social support and other variables concerning relational processes, with the same limitations as most research on the topic, that recipient personality and social influences are confounded in the results. Moreover, deeper insights into the processes concerning social relations, social support, social withdrawal are gained in the qualitative article.

From a quantitative viewpoint, the final validity dimension is external validity which concerns to what degree the results can be generalized - to whom, in what settings, and at what times (Carter & Lubinsky, 2015). This dimension is closely linked to the representativity of the study sample. The sampling of the END project and, consequently, this doctoral project, is based on a mix of purposive, convenience and snowball sampling. Such sampling may be necessary to reach populations that cannot be sampled from registers (Taherdoost, 2016), which is the case for this population.

The condition for inclusion in the category “bereaved after a DRD” in this project was that the bereaved person felt close to someone who had died either in connection with or as a consequence of illicit drug use. The criterion for the death to be classified as a “DRD” was that the bereaved person defines the deceased’s death as being associated with illicit drug use. This is a different criterion, but not a different procedure from the registration of deaths carried out by a medical doctor and coded according to the guidelines of the Norwegian Institute of Public Health and the World Health Organization (cf. Norwegian Institute of Public Health, 2023). This recruitment process made it possible to include extended family members and friends in the sample, thus representing the various impacts a DRD might have on different relationships.

Regarding the sample in the quantitative studies, the demographic background data of the participants for both quantitative studies is presented in Table 3 (p. 93). Overall, these data show a high diversity among participants, suggesting that we included a close to representative part of the study population, hence increasing the external validity. However, there are some clear limitations in relation to the study’s generalizability and target population. The heterogeneity of the sample population is both a strength and a weakness. While capturing diverse experiences from the different relationships to the deceased, the weighting of the different relationships constitutes a problem. Parents constitute 37% of the sample, siblings 31%, while children, other kin and close non-kin-relations constitute around 10% each. Also, 82% of the sample have female gender. Thus, the experiences of parents, siblings and females are disproportionally highly represented compared to the other relationships to the deceased. Moreover, an inclusion criterion was the ability to speak Norwegian fluently, which is highly likely to have led to the inclusion of fewer immigrant and refugee populations.

Furthermore, the socio-economic variables of education and household income are generally a bit higher in our sample than the population norm in Norway (cf. Statistics Norway, 2020a; Statistics Norway, 2020b). Considering that lower scores on socio-economic variables are associated with higher risks of opioid-related overdoses (van Draanen et al., 2020), it is likely that our sample deviates from the study population in this regard. As studies have shown that low education level is a risk factor for complicated grief reactions (Nielsen et al., 2019; Nielsen et al., 2017), this skewness in the sample suggests that the target population might be more challenged than our findings show. Thus, we might have missed the proportional representativity of DRD- bereaved people who are the most challenged regarding social and mental health. Finally, some of the participants were related, and reported on basis of the same deceased person (i.e., “dependent observations”). However, it was impossible to discern which participants this applied to in retrospect. These issues regarding validity are also discussed in the strengths and limitations in Articles I and II.

The sample size is too small to give a confidence level of 95%, based on the calculation of around 110,000 people having been bereaved by a DRD in Norway over the last 30 years. This calculation is based on the United Nations’ estimation that more DRDs occur as a result of indirect causes than direct causes attributable to drugs, such as hepatitis C and HIV (United Nations, 2019). Therefore, a modest calculation is that drug-induced/overdose deaths account for a maximum of 2/3 of the DRDs in Norway, aligning with the distribution in the study sample. With a mean number of 267 overdose deaths per year, the annual number of DRDs would be 400. Considering this mean annual number for the last 30 years, with nine unique, living bereaved persons after each death, the sample size for a confidence level of 95% should be 383 or more, not including the design effect. This sample size calculation is based on the formula: $n = [DEFF*Np(1-p)]/ [(d2/Z21-\alpha/2*(N-1)+p*(1-p)]$.

Additionally, some questions in Article I are more relevant in a Norwegian or similar cultural context, such as enquiries about specific service providers and preferences for professional help from public services. While this questionnaire’s use within the Norwegian context allows for relatively reliable comparisons between different bereaved populations in Norway, its applicability for cross-cultural comparisons requires careful consideration of what the responses signify within the specific culture and context.

Finally, in addition to interpreting our results and considering external validity, it’s essential to examine the types of deaths experienced by the bereaved participants.

The survey categorized these deaths into four groups: a) overdose without intention, b) overdose with intention, c) disease, accident, or violence related to drug use, and d) uncertain cause (Appendix 2). The primary concern lies within category c), which encompasses both sudden and expected deaths. In retrospect, I would have made a distinction in the survey between sudden, violent deaths and expected deaths, such as those caused by diseases.

If we had made this distinction, it is possible that the results of our analyses of the help needs after the death (Article I) might have shown some variations. For instance, when we conducted chi-square analyses, there was a noticeable difference in the reported help needs between those bereaved by intentional or unintentional overdoses compared to the other groups ($p<.001$). However, considering what we know about help needs following traumatic deaths, it is quite likely that a smaller percentage of those bereaved by disease would have reported needing help compared to those bereaved by accidents or violence related to drug use, if they had not been grouped together. Therefore, this grouping may have introduced certain imprecisions into our analyses, and it is a factor that must be taken into account when interpreting the results: if we had focused only on those bereaved by sudden deaths, the number of individuals reporting the need for help would probably have been higher. Conversely, if we had included a larger proportion of those bereaved due to disease, the reported need for help would likely have been somewhat lower.

Taken together, these aspects of the quantitative studies' reliability and external validity suggests that the results cannot be generalized to the study population of DRD-bereaved people in Norway without precautions, and several considerations must also be made regarding generalizations to the target population, namely, DRD-bereaved people worldwide. These include, among others, cultural differences in relation to drug use and discourse, cultural differences concerning rituals and customs in bereavement, differences in legislation, socio-economic differences and differences in systems and expectations for health- and social services in the country in question. Last but not least, the population characteristics of those dying from a DRD can also change, and thus, most likely, the characteristics of those bereaved by a DRD. This development is an issue in Norway at the time of this doctoral project, where the number of overdose deaths as a result of heroin is declining, while overdose deaths caused by pain medication are increasing (Stave, 2022). On the other hand, there is a noticeable scarcity of quantitative studies worldwide focusing on this population, and it's worth noting that our sample is exceptionally extensive – the largest, as far as I am aware, up to the current date. Also, the recruitment process presented distinct advantages in accessing a diverse population that might otherwise have only been accessible through official death registries, which would have posed limitations in terms of which relationships to the deceased we would have reached and reliance on the accuracy of such records.

The qualitative study

Creswell et al. (2018) define qualitative validity as "accuracy" that should be viewed from three perspectives: the researcher, the participants and the readers. They argue that qualitative researchers should employ at least two validation strategies within each lens.

From the researcher's lens, I corroborate research evidence through triangulation through the mixed-method design. Furthermore, I have clarified my biases and have engaged in reflexivity through a self-reflexivity note, reflexive journal and discussions with supervisors. This reflexivity is primarily present in the qualitative article but should also be adequately present within this synopsis. Validity from the perspective of the reader's lens is achieved through peer reviews in the process of publishing articles and supervision during the process of analysis and writing. For the synopsis, collaboration with the supervising team has been the primary validation in relation to the reader's lens. Regarding the participant's lens, validity was increased by the user representatives' role in developing the qualitative interview guide. This increased the likelihood of the interviews having been effectively designed for their intended purpose. Validity from the perspective of the participants' lens would have profited from using some kind of member checking as part of the data analysis (Birt et al., 2016). The interpretations and findings derived from the transcribed interviews could then have been confirmed or modified, and new data could also have been added. Consequently, the qualitative interpretations and findings have not been "refined" through a post-interview dialogue with participants. They are thus more likely to be more distanced from the original or the meaning they intended to express.

For sample selection and size, we drew on Malterud et al.’s (2016) proposals of criteria for determining information power. According to Malterud et al. (2016), information power depends on the study aim, sample specificity, use of established theory, quality of dialogue and analysis strategy. The interviews explored several topics, and only some related to the research question. The sample specificity was high, as the parents clearly belonged to the specified target group but still had considerable variations in terms of experiences. At the time of the interviews, the study did not relate to a strong theoretical background, suggesting the need for a larger sample to obtain sufficient information power. I perceive the quality of the dialogues of the interviews as ranging from medium to very high, thus reducing the demands in sample size. Finally, the in-depth and primarily phenomenological-hermeneutical analysis strategy within the reflexive thematic framework requires fewer participants than, for example, a cross-case analysis. We thus judged the chosen interviews of 14 parents to provide sufficient information power for the analyses and claims made in the third article.

Concerning the transferability of the study, several variables have been considered to ensure that the heterogeneity and, thus, representativity of the 14 individually interviewed parents recruited through the survey are high. However, several considerations for transferability exist. While most parents were divorced from their former partners, the varying quality of their relationships with their ex-partners is likely to have impacted the parents’ situations differently. In addition, although the sample was heterogeneous in some aspects, it was homogeneous regarding ethnicity, sexual orientation and the parents’ household income and education, which were somewhat above the Norwegian norm. Thus, regarding the transferability to similar populations, all these considerations and other aspects of Norwegian culture must be considered.

The transference of findings from Article III to populations outside Norway has to consider the local discourse and culture surrounding family life, parents’ tasks and caring for children in the country in question. Still, as the findings were analysed and discussed using theories developed in other Western countries such as the Netherlands (The Dual Process Model of Coping with Bereavement by Stroebe & Schut, 2015) and the United States (Family Resilience by Walsh, 2016); this suggests that the knowledge derived from these findings may also have relevance beyond Norway.

2.5.3 Research ethics

The word “ethics” comes from the Greek term “éthos,” meaning habit or custom (Caprona, 2013, p. 934). Ethics entail thinking systematically about what is morally right, just and fair (Eide & Aadland, 2008). Following The Norwegian National Research Ethics Committees (NESH) (2022), the core scientific ethic norms consist of a) the search for truth, integrity and honesty; b) methodological norms, including factuality, accuracy, transparency and accountability and c) institutional norms, securing openness, independent and critical research.

The formal ethics following these norms are mainly achieved through the END project’s design. The design includes the overall research aims, the methodology, the way in which the recruitment was conducted, how information was given to participants and followed up on in case of need, consent for the provision of data, data storage and data analyses, etc. These factors are also essential in the Helsinki Declaration of ethical principles for medical research (World Medical Association, 2013) and provide the basis for the approval of the END project by the Regional Ethics Committee.

The published articles have also followed ethical guidelines concerning co-authorship, where all authors have made substantial contributions in one or more of the four criteria stated in the Vancouver Recommendations (Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals (International Committee of Medical Journal Editors, 2023)).

Another research ethic factor is the level and form of user involvement in research. User involvement can strengthen the quality of research, promote democratic rights, and create ethical challenges (The Norwegian National Research Ethics Committees, 2022). Throughout the END project, members of the study population were actively involved in the preparatory, execution, and translational phases. However, most of the project has been researcher-driven, situating the user involvement in a consultation and collaboration position (see Shippee et al., 2015). To my knowledge, this positioning has been adequately collaborative, so as to be ethically sound and enriching for the research foci, analyses and findings. It has also facilitated a robust research design, including for my doctoral project.

Furthermore, as both the Helsinki Declaration and the Vancouver Recommendations highlight that vulnerable groups and individuals should receive specific integrity protection, I will elaborate on this principle for this doctoral project. Throughout the thesis, I frequently reference prior research, highlighting the role of stigma both before and after a person's death as a significant contributing factor to the pronounced need for assistance and the diminished social health reported by many bereaved individuals. Consequently, I have been particularly attentive to the language employed in this thesis and the associated articles. In my writing, I have adopted a person-centred approach, striving to employ respectful language and avoiding stigmatizing terms such as "drug abuse" (see Kelly et al., 2016).

The findings of both quantitative articles were systematically discussed with the user representatives before writing the article's discussion chapter. This discussion allowed them to provide input, viewpoints and possible explanations for the presented findings, for example, why many bereaved people were more satisfied when they received help from a psychotherapist and why so many lacked help from such service providers. These inputs were consequently used as inspiration for the writing of the discussion chapter. I would have liked to use a variant of member checking to validate and enrich the findings of the qualitative article (see Birt et al., 2016). However, this was impossible when the doctoral project started, as consent for such contact was not a topic explored with the participants during the interviews. Thus, I have used the best of my own and my co-authors' competence to strive to ensure that results are presented in an ethically justifiable manner, doing justice to the experiences the participants' have conveyed.

Finally, the possible downstream effects of the research and dissemination of findings demand ethical awareness. There are several instances where these downstream effects have diverged from the intended outcomes envisioned by the research and researchers, leading to negative consequences, for example, the implications of increased family burdens and the blaming of parents related to the "double-bind" hypothesis of schizophrenia (Beels, 2011; Lefley, 1998). Such effects are also highly relevant in the research field of this doctoral thesis. Hence, I find it important to depict members of the study population without doing them an injustice by portraying them solely as victims or attributing excessive responsibility to them for the challenges they face due to DRDs. I have aimed to strike a balance in alignment with the critical realism axiology, which examines the interplay between structure, agency, and emancipation. Thus, I have sought to acknowledge and emphasize the participants' agency while also recognizing the significance of social structure and the need to allocate resources to support those marginalized and in need of assistance.

2.5.4 Researcher's ethics and self-reflexivity

Researchers' ethics concern the researcher's responsibility in relation to research and the research community, for example, transparency and reflexivity (Kalman & Lövgren, 2019). Self-reflexivity denotes "thoughtful, conscious self-awareness" (Finlay, 2002, p. 532) and can increase the validity and reliability of the research, as it provides transparency and context to the preconceptions/prejudices the researcher brings forth to the research project.

Self-reflexivity has solid traditions in qualitative research, in which the researcher's background and preconceptions are vital. Data gathering through interviews, for example, means that the researcher's demeanour with others and the way in which s/he continuously interprets and responds to their utterances are of utmost importance (see Finlay, 2012). However, in quantitative research projects, self-reflexivity is also of importance. The researcher's background influences the research question, the chosen methodology and measurements, and the interpretation and discussion of the findings. The note below on self-reflexivity and the process of situating to the data are relatively general and are a compressed version of notes I made before analysing the individual interviews.

I am a native Norwegian man, married, with children and grew up in a rural community until my teens, before moving to the second largest city in Norway. Although my parents had a strained financial situation when I was growing up, my socio-economic situation has always been quite secure and privileged in recent years. I have not had experiences of problematic substance use among my closest relations or had this problem myself. My family structure and relationships when growing up were relationally rich but somewhat fragmented due to my parents' early divorce, their new romantic relationships and siblings from previous and later relationships. These experiences have probably impacted the high value I have placed on family in my adult life.

In my professional life, I have worked with people with problematic substance use or addiction. I have also trained as a family therapist, and have applied much of this professional perspective to my practice through the years. This way of working has been very important with regard to my dedication to focus on social relationships during mental health, substance use and addiction treatment. The involvement of family and network members is crucial to the potency of social relationships in problem development and recovery. This perspective has mainly stemmed from experiences with affected family members and substance users in joint conversations and in numerous meetings with affected family members in their own right.

From a personal perspective, my second oldest brother died as a result of suicide some years ago. This experience certainly affected me the most concerning bereavement and grief. His death and the way in which it occurred was a shock for me and the whole family, and the experience of the practical, relational and emotional havoc during the initial days and weeks after the death have been profoundly life-changing. Moreover, I experienced how some difficult relational situations within the family in the early days post-loss were never consolidated later, making lasting changes to our family relations. My feelings, reactions and way of coping, and the differences between my family members, have affected the way in which I approached this research project, dealing with bereavement from DRDs.

Hence, the combination of my professional and personal experiences have impacted the doctoral project in terms of the research questions, contributing to the focus on social health, the intersection between social and mental health and the intersection between professional help and social relationships.

3 Findings

The following section outlines the findings from the different articles in the doctoral project. Table 3 shows the sample characteristics of the participants in all articles, and Table 4 summarizes the research design, aim, and findings from the three articles in this PhD.

Table 3. *Sample characteristics presented with (min-max), mean (sd) or n (%)*

Survey (N=255)			**Interviews (N=14)**	
Variable (min-max)	mean (sd)	n (%)	mean (sd)	n (%)
Sociodemographic characteristics				
Age at time of survey (18–80)	48 (14)		58 (8)	
Age at time of loss (5–76)	40 (15)		55 (8)	
Sex. Female		208 (82)		7 (50)
Educational status				
College/university		125 (49)		11 (79)
Senior high school		97 (38)		3 (22)
Primary school		32 (13)		-
Relational status. Married/cohabiting		162 (64)		12 (86)
Residency. Urban		156 (62)		6 (43)
Part of country. South		231 (92)		10 (64)
Employment				
Working (full- or part-time)		155 (61)		9 (50)
Retired		29 (11)		3 (7)
Student		14 (6)		1 (7)
Other		58 (23)		1 (7)
Household income. USD				
≤50,000		85 (34)		1 (7)
50,000–100.000		121 (48)		9 (64)
≥100,000		45 (18)		4 (29)
Relational characteristics				
Years since death (0–35)	8 (7)		4 (4)	
Relationship to deceased				
Parent		95 (37)		14 (100)
Sibling		79 (31)		
Child		25 (10)		
Other kin		28 (11)		
Partner (n=13) or friend (n=15)		28 (11)		
Perception of relationship. Close/very close		222 (88)		13 (93)
Characteristics of deceased				
Sex. Male		192 (75)		10 (71)
Age at time of death (15–68)	31 (10)		27 (9)	
Years of drug use (0–42)	13 (9)		12 (9)	
Manner of death				
Unintentional overdose		160 (63)		9 (64)
Intentional overdose (suicide)		19 (8)		1 (7)
Drug-related disease, accident, violence		47 (19)		2 (14)
Manner uncertain		27 (11)		2 (14)

Table 4. *Research design, aim, findings and conclusions from articles in the thesis*

<table>
<tr><td colspan="6">Title of thesis: The social health and help needs of those bereaved by a drug-related death</td></tr>
<tr><td colspan="6">Aim: To map the social health of DRD-bereaved people, gain knowledge of help needs and experiences with professional help</td></tr>
<tr><td colspan="6">Research Question: How are the social health and help needs of DRD-bereaved people, how can they be explained, and what implications can be drawn in relation to help provisions</td></tr>
<tr><th>Art</th><th>Title</th><th>Method</th><th>Research questions</th><th>Findings</th><th>Conclusions and implications</th></tr>
<tr><td>I</td><td>Needs for help and received help for those bereaved by a drug-related death</td><td>N=255
Quantitative cross-sectional survey
Descriptive & logistic regression</td><td>1) Which needs for help and received help from professional services do DRD-bereaved people report?
2) Which variables are related to participants' satisfaction with the help received?</td><td>>80% of the sample reported the need for professional help post-loss. Those bereaved by overdose deaths reported a greater need for help. An older age and psychosocial help were associated with a higher level of satisfaction. Parents received help more often. Few were satisfied with the help available for children in the family.</td><td>Most DRD-bereaved people call for help from professional services post-loss.
Needs of younger age groups, including children, should be recognized, and therefore it is essential with a family perspective from services.
Acknowledge the needs of bereaved people with psychological closeness to the deceased in addition to family ties</td></tr>
<tr><td>II</td><td>The social health of people bereaved by drug-related deaths and associations with professional help</td><td>N=255
Quantitative cross-sectional survey
Descriptive, correlation, ANOVA, T-test and non-parametric</td><td>1) How do DRD-bereaved people rate dimensions of their social health?
2) Are there differences in social health between DRD-bereaved people with different experiences of professional help?</td><td>Low average scores across various social health dimensions. 67% reported substantial withdrawal from other people. The social health dimensions did not correlate with time since death. Satisfaction with professional help was associated with higher scores across most social health dimensions.</td><td>DRD-bereaved people score poorer on social health dimensions than comparable populations. Reduced social health after bereavement might become chronic.
Reduced social health might be mitigated through satisfactory professional help, interventions that include social network members might be beneficial.
Research is needed on help to improve the social health of people bereaved by traumatic deaths.</td></tr>
<tr><td>III</td><td>Drug death-bereaved parents' perspectives on family interactions and help needs</td><td>N=14 parents
Qualitative individual interviews.
Reflexive thematic analysis.</td><td>How can the families' needs for family-oriented help be understood through the bereaved parents' reflections on family interactions post-loss?</td><td>I. Considerable needs in the family become our responsibility
II. Conversations that are important for family connections are obstructed
III. As parents, we can strengthen family connections.</td><td>The findings demonstrate families' inherent resilient capacities, and areas where some families could need professional help to increase their resilience. These areas were a) the family's need and ability to adapt roles and relationships to new tasks, and b) the space and environment for emotional sharing and joint meaning-making processes.</td></tr>
</table>

3.1 Summary of articles

3.1.1 Article I

The aim of Article I, *Needs for help and received help for those bereaved by a drug-related death: a cross-sectional study,* was to map the need for professional help, help received and satisfaction with the help on the part of those bereaved by a DRD. Descriptive and regression analyses were deployed to answer the research questions 1) *Which needs for help and received help from professional services do DRD-bereaved people report,* and 2) *Which variables are related to participants` satisfaction with help?*

The analyses found that most DRD-bereaved individuals reported needing professional help after the death; 57% reported a considerable need and 24% required help to a certain degree. Furthermore, 52% reported to have received help, and 45% reported a high satisfaction with this help. Most participants also wished that help provisions lasted from six months to a year or more.

We found few differences that were significant at p<.05 concerning the need for help and help received in the sample, but those bereaved through intentional or unintentional drug overdose reported a significantly greater need for help than those bereaved through disease, accident, violence or uncertain circumstances (p<.001). Regarding the received help, parents reported more often to have received help, while siblings and extended family members seldom received help (p<.004).

A higher age and help from a psychosocial crisis team or psychotherapist were associated with a higher rate of satisfaction. Moreover, only 26% reported that children in the family had received help. Of those having received help for children, only 29% reported a high satisfaction with this help and 37% reported having lacked help for children to a considerable degree.

This article discussed why overdoses were associated with a greater need for help on the part of the bereaved rather than those bereaved by other DRDs. We concluded that these explanations may be due to a) the suddenness of the death, b) the level of stigma and c) the level of self-infliction. We also discussed the finding that professional help was unequally distributed, hypothesizing that this might be due to the grief hierarchy and the accessibility of services.

When discussing why the help from some service providers was associated with a higher level of satisfaction than others, we hypothesized that this might be due to the type of help given by the service providers in question. Psychotherapists and psychosocial crisis teams focus on psychological and emotional needs, and the psychosocial crisis teams also provide early and flexible help.

Finally, we discussed the needs of the young bereaved, based on the finding that the bereaved of a younger age were more often dissatisfied with the help received than those of an older age, and that many participants reported unmet needs in relation to the help measures for children in the family. We drew on the empirical findings that older age often comes with better emotion regulation capacities and that parents might have reduced capacity to care for their children's needs because of the emotional and practical impact of the loss on their own life. We also discussed that the lack of help available to children could be related to the general individual-centred focus within Norwegian health- and social services and the lack of recognition of children in policy documents until recent years.

We concluded that professional help services should recognize relationships of both psychological and biological closeness to the deceased. Furthermore, as the findings showed a gap in terms of adequate help for younger age groups and children, we recommended that a family perspective was necessary to provide for their needs.

Questions this article does not answer

We do not know why the need for help from professionals is stated in this way among this specific population, and the study does not provide clear answers about what kind of help the bereaved require and how soon it should be provided. Concerning the children in the families, we do not know what the children themselves wish for, lack or need concerning professional help. Furthermore, we do not know what kind of help the participants would like for the children in the family.

3.1.2 Article II

The aim of Article II, *The social health domain of people bereaved by a drug-related death and associations with professional help: A cross-sectional study*, was twofold: 1) to map dimensions in the social health domain of those bereaved by a DRD and 2) to investigate the associations between different experiences of professional help and the scores on social health dimensions.

Our sample reported low average scores across different social health dimensions relative to other traumatically bereaved populations, and almost two-thirds of the participants described substantial withdrawal from other people. The social health dimensions did not correlate with time since death, suggesting that these dimensions do not improve with time. Higher satisfaction with professional help was associated with higher scores for almost all social health dimensions. We discussed three aspects of the findings: a) strain, stigma and shame before and after the death, b) the circular causality of social health and c) professional help and social health.

Strain, stigma and shame before and after the death is one possible explanation as to why the social health of this population is compromised. Before death, the strain of problematic drug use on family members can affect all health dimensions and lead to feelings of shame and guilt for being closely related to the drug-using person. Furthermore, many distance themselves from social relationships outside the family. This distancing is probably partly due to the process of stigmatization of the drug-using person, and stigma and shame are closely linked phenomena. Withdrawing from others is one way of coping with stigma and shame. These processes might explain in part why the social health domain of DRD-bereaved people is often compromised.

The circular causality of social health explored the interactional aspects of social health, where mutual failure to communicate intentions and needs may lead to misunderstandings and unbalance in relation to the distance between those bereaved and their social network members, possibly leading to less connection and less perceived social support. Openness from both parties regarding feelings, needs and dilemmas is necessary but difficult to manage. Finally, we discussed how the improvement of social health as a result of satisfactory professional help might mitigate the impairing potential of strain, stigma, shame and withdrawal, and facilitate openness between the bereaved and their social network members.

Based on the results and discussion, we recommended that professional services emphasize ways of working with the bereaved to improve social health dimensions, and that interventions including more than one individual at a time are likely to be the most effective. We also concluded that there is a need for more research on these types of support interventions.

Questions this article does not answer

The article does not consider which dynamics cause or maintain poor social health, or the nature of the association between satisfaction with the help provided and social health variables. The social health variables are subjectively rated, and thus do not give an overview of the actual availability of positive social interactions, arenas and communities or the nature of the social interactions in which the individual participates.

3.1.3 Article III

Article III, *Drug-death bereaved parents' perspectives on family interactions and help needs: A qualitative study*, explores how DRD-bereaved parents experienced family interactions post-loss in order to better understand social processes and family-oriented help needs. We recruited 14 parents from the survey sample for individual in-depth interviews. The interviews were analysed through reflexive thematic analysis, and three themes were generated: I. Considerable needs in the family become our responsibility, II. Conversations that are important for family connections are obstructed and III. As parents, we can strengthen family connections.

Theme I captures how parents try to mend the disrupted family system and provide adequate care for those who struggle after the death. Theme II encompasses how the space for emotion-sharing conversations is obstructed, and how family members sometimes seem afraid of grief emotions and try to protect one another by not talking. Finally, theme III encapsulates how parents create space to talk, listen to one another in the family and navigate relational challenges in ongoing relationships. Based on these findings, we developed a model heavily inspired by family resilience theory and the Dual Process Model of Coping with Bereavement - family level. Our model divides the help needs of the DRD-bereaved families into two main paths.

The first path deals with sharing vulnerable and difficult emotions after the death, both for intrapersonal and interpersonal reasons. Grief comes with a cascade of emotions, and these emotions need to be shared socially for one's own emotion regulation and for the sake of connections between family members. If these conversations, important for family connections are obstructed, the family might need help facilitating emotional-sharing conversations, which may lead to increased family connections.

The second path deals with the structural dynamics in the family after the family system is disrupted after the loss. An important restoration-oriented task on the family level is to assess the family's and family members' needs and renegotiate interaction and roles in the family. If this task is adequately tended to, family flexibility will be balanced. If not, the family might need help facilitating the conversations on the topics required to balance family flexibility. Furthermore, we suggested a professional help approach based on a family-resilience framework, strengthening the family's immanent capacity to withstand and rebound from disruptive life challenges.

Questions this article does not answer

We did not explore other family members' experiences of family interactions and do not know whether these parents describe family interactions that are transferable to most of the population. We do not know what kind of family-oriented help parents or other family members would find acceptable.

4 Discussion

The main research question of this doctoral project is “What are the social health and help needs of DRD-bereaved people, how can they be explained and what conclusions can be drawn for help provisions?”

The main findings are that most DRD-bereaved people request help from professional services for themselves and the children in the family at an early stage post-loss, services with a focus on psychosocial dimensions are rated higher than others, few children in families received help and the majority of participants reported low-medium satisfaction regarding the help provision for children (Article I). Article II shows that the participants’ reported social health dimensions are poor, on average, regardless of the time since the loss. Article III, comprising parents’ descriptions of family life, might explain certain processes important for the social health dimensions of DRD-bereaved people. The parents highlighted the considerable psychosocial needs of many family members, especially the siblings and children of the deceased, and that they often felt that it was difficult to reach them emotionally. Furthermore, many parents experienced obstructions to family conversations concerning the loss and the deceased, conversations that could have strengthened family connections. However, several parents felt that crucial support came from their families and that they could strengthen family connections in the wake of their loss.

Based on the findings, we discussed and recommended foci from professional services when caring for those bereaved. In Article I, we recommended a family perspective to adequately meet the help needs of children. In Article II, we recommended that professional services emphasize ways of working with the bereaved to improve social health dimensions, and that interventions including more than one individual at a time are likely to be the most effective. In Article III, we suggested a professional help approach based on a family-resilience framework, strengthening the family’s immanent capacity to withstand and rebound from the disruptive life challenges. Based on the parents’ descriptions of family challenges, relevant family-oriented help could focus on a) family structure and flexibility, and

b) the space and environment for sharing emotions relating to the loss among family members.

Figure 7 summarizes the most important findings from the different articles in light of the thesis' research question: *How are the social health and help needs of DRD-bereaved people and how can they be explained?* Furthermore, the lines propose connections between the findings.

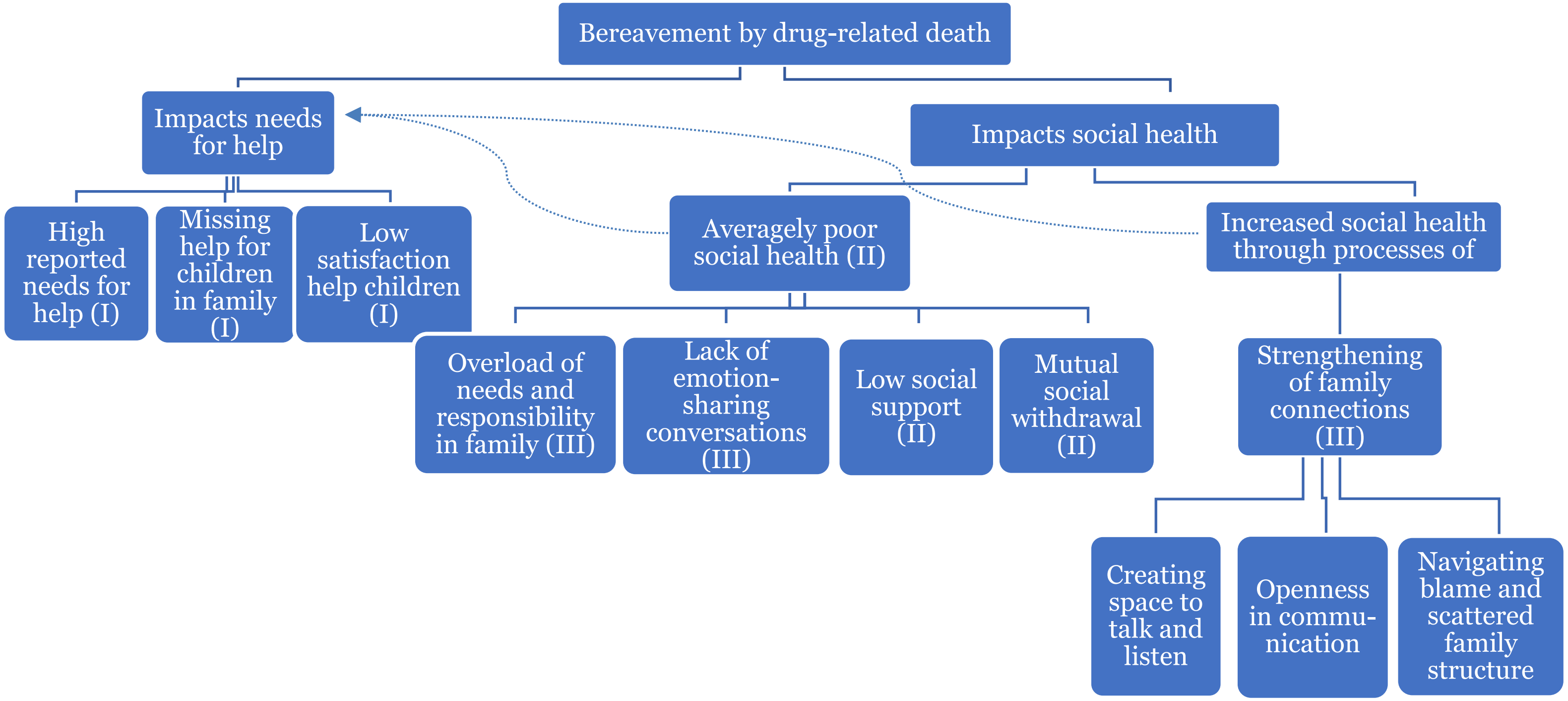


Figure 7: Results from Articles I, II and III and suggestions regarding the connections between them. The stippled arrows show that social health might impact the need for help from professionals. The numbers denote the article with the finding.

An explanation for the averagely poor scores in dimensions of social health and the reported help needs of the participants, can illuminate social processes that stakeholders might influence, thus possibly promoting agency. Hence, based on Figure 7, I will discuss how the averagely poor social health of DRD-bereaved people could be explained in light of social processes, and how this explanation might affect the need for professional help.

4.1 Under which conditions does poor social health occur?

In this discussion, I suggest that various processes occurring both before and after the death, in addition to the event of death itself, are pertinent to the diminished social health frequently reported by individuals who have experienced DRDs. Therefore, the discussion encompasses the processes of strain, social stigma, and withdrawal experienced prior to the death, as well as emotional sharing and family connections following the loss. These processes may increase the demand for professional assistance following the death.

The findings from Article II and III add to other studies that enquired into the social/relational situation of DRD-bereaved people that were published while the research for this project was taking place. These studies, explored in the literature review, generally show that complex social interactions in the grieving process are reported across different relationships with the deceased in DRD-bereavement, notably by parents, siblings, intimate partners and close friends. These relationships are part of the sample in the quantitative enquiries of Articles I and II in this doctoral project. While there is limited research on children's experiences in relation to DRD-bereavement, studies on different types of bereavement from a child's perspective have revealed common complex family and parent-child relationships after a death in the immediate family, such as a parent or sibling. When comparing these findings to the results of the two quantitative studies in this doctoral project, which involved 255 participants and had multiple relationships with the deceased, it becomes clear that a substantial portion of DRD-bereaved individuals encounter significant challenges to their social health.

Which dynamics might contribute to this phenomenon? Following the critical realism emphasis on providing explanations, I will propose an explanation that focuses on the social aspects of reality. While this explanation has its limitations, it might still guide us in developing measures and policies to improve the situation for those who have experienced a DRD. The explanation builds on a retroduction of the findings from this doctoral project and other research evidence and literature on the topic and includes:

1. The strain of problematic drug use in the family
2. The aspect of stigma
3. The aspect of guilt and shame
4. The individual impact of losing a close person to DRD
5. The social sharing of emotions
6. An emotional and/or practical overload
7. Macro-level moderating factors before and after the death

1. The strain of problematic drug use in the family

It is documented that many families and family members of people who struggle with substance use are severely strained (Di Sarno et al., 2021; Lindeman et al., 2021). This strain is often long-lasting and affects multiple relationships and the family unit as a whole. These processes are, for example, expressed through changes in the family structure and roles, problematic communication within the family system and between the family and its extended social network (Lindeman et al., 2021), as well as social isolation, loneliness and increased mental and somatic illnesses in family members (Di Sarno et al., 2021). Pre-loss mental illness is a risk factor for complicated grief reactions (Nielsen et al., 2017), and the social environment impacts mental health and illness. The heightened prevalence of mental illnesses of family members affected by substance use in the family (Di Sarno et al., 2021) indicates that problematic drug use is a factor in the causal dynamics that affects the family members' mental health and social functioning. Studies show that such situations often persist for years (Lindeman et al., 2021). It is fair to assume that this particular pre-loss context negatively affects the situation of those bereaved, an assumption that has been confirmed and nuanced by empirical findings. For example, Titlestad et al. (2021b) generated a theme of emotional overload in their qualitative study on parents' grief process in DRD-bereavement. This overload was highly related to constant preparedness, that is, organizing your own life according to another person's unpredictable needs, stepping up at any time to manage emergencies; and lack of acknowledgement from psychosocial help services before the death (Titlestad et al., 2021b).

2. The aspect of stigma

In most societies, people who use drugs excessively are subjected to stigmatization. Corrigan et al. (2009) have shown that those who use drugs are ascribed more negative attributes than people with mental or physical disabilities, and argue that this is likely to be due to the culturally sanctioned stigma regarding drug use and drug users as opposed to mental illness (Corrigan et al., 2017). In Norway, where this study took place, the legislation and discourse on drugs and drug use have been dominated by a repressive policy until recently (NOU 2019: 26, 2019). In recent years, there has been a significant change in the discourse and the legislation on the use of drugs as well as in the help- and follow-up services available to this group (NOU 2019: 26, 2019). Still, there are reasons to believe that drug users and family members of drug users in Norway and other countries like United States have a higher risk for the burden of stigma than those bereaved by suicides (see Corrigan et al., 2009; Dyregrov & Selseng, 2021).

3. The aspect of guilt and shame

Norm enforcement is a significant function of stigmatization (Phelan et al., 2008). When drug users are stigmatized, the associated feeling imposed on the individual drug user, and potentially those close to them, is guilt and shame-like feelings, as the individual's norms largely depend on society's general norms (see Scheff, 2006). Titlestad et al. (2021b) showed that guilt and shame were two of the most striking feelings expressed by the 14 interviewed DRD-bereaved parents. Moreover, emotions of guilt, shame and blame have also been shown to be prevalent in bereaved siblings (Dyregrov et al., 2022) and close friends who use or have been using drugs themselves (Selseng et al., 2023b). For some, ruminations on guilt and shame have severe health consequences. In a sample of Chinese bereaved adults, Li et al. (2019) showed that guilt was associated with higher levels of complicated grief reactions and depression, and a sample of suicide-bereaved German citizens showed similar results: guilt feelings were highly associated with depression, post-traumatic stress syndrome and prolonged grief symptoms (Wagner et al., 2021). Moreover, feeling guilt is also one of the criteria for prolonged grief disorder in the ICD-11 (World Health Organization, 2019/2021).

4. The individual impact of losing a close person to DRD

Sections 1.4.1 and 1.4.3 summarize studies that show how losing a close person to DRD can be devastating for those bereaved, creating complex emotions and reactions and increasing the likeliness of reporting high levels of complicated grief reactions (see also Bottomley et al., 2021; Feigelman et al., 2011; Kalsås & O'Connor, 2023, in press; Titlestad & Dyregrov, 2022; Titlestad et al., 2021a; Titlestad et al., 2021c). This association is also confirmed in this thesis's Article I. On an individual level, the research is clear that sudden and violent deaths are prominent loss-related risk factors for developing complicated grief reactions (Djelantik et al., 2020), as well as finding, seeing or identifying the dead body in cases of violent death (Burke & Neimeyer, 2013). These are factors that are relatively frequent in cases of DRD.

5. The social sharing of emotions

Based on the theory that emotion elicits the social sharing of emotions, emotions ought to be socially shared, acknowledged and explored through social sharing in order to regulate and adjust after an emotional episode and to increase social connection and cohesion (Rimé, 2009; Rimé et al., 2020; Rimé et al., 2010). Feelings of guilt and shame are harder to share than many other emotions, and the processes of stigmatization can put further social constraints on this social sharing. Many of those bereaved reported withdrawal from other relationships, and that others had withdrawn from them (Article II), indicating that social sharing is not a common occurrence. Furthermore, the findings from the qualitative study of this doctoral project (Article III) show that the social sharing of emotions is halted in many families, a finding supported by other studies on the same population or other DRD-bereaved populations (see Dyregrov et al., 2022; Selseng et al., 2023, in press; Titlestad et al., 2021b). Thus, the social sharing of emotions for DRD-bereaved people is often compromised. When this social sharing is compromised, the likelihood of guilt and shame ruminations increases (cf. Selseng et al., 2023b; Titlestad et al., 2021b)

6. An emotional and/or practical overload

In line with the Dual Process Model of Coping with Bereavement, overload can impede coping after a bereavement (Stroebe & Schut, 2016). Stroebe and Schut (2016, p. 100) define overload as "the bereaved person's perception of having more than s/he feels able to deal with – too much or too many activities, events, experiences and other stimuli." For many living with a person with problematic substance use, the "substance use problem" displaces almost all other foci and tasks in the family (see Lindeman et al., 2021). Many family members have few people or no-one to talk to and share their burden. After the death, limited social support (quantitatively documented in Article II) and loneliness and frustration, stemming from the silence surrounding these phenomena, affect this overload (cf. Titlestad et al., 2021b). Parents' feelings of responsibility for family members and the family unit and a lack of supportive interactions in the family might contribute to the overload (Article III).

7. Macro-level moderating factors before and after the death

Macro-level background factors related to discourse and jurisdiction on drug use (cf. Corrigan et al., 2017), as well as general socio-economic factors (cf. Orford, 2017; van Draanen et al., 2020), are assumed to moderate the described dynamics before the death. Concerning the processes after death; culture including discourse, customs and rituals concerning dying, death, bereavement and grief are assumed to moderate the variables on the micro-level (cf. Kellehear, 2005). Also, the public health- and welfare system and the populations' general expectations concerning help and welfare services are likely to have an impact (cf. Anvik et al., 2020).

Through this inferential retroduction, I suggest that these factors might be necessary for the poor social health and high help needs of those bereaved. Figure 8 shows a theoretical model that highlights the social processes discussed above.

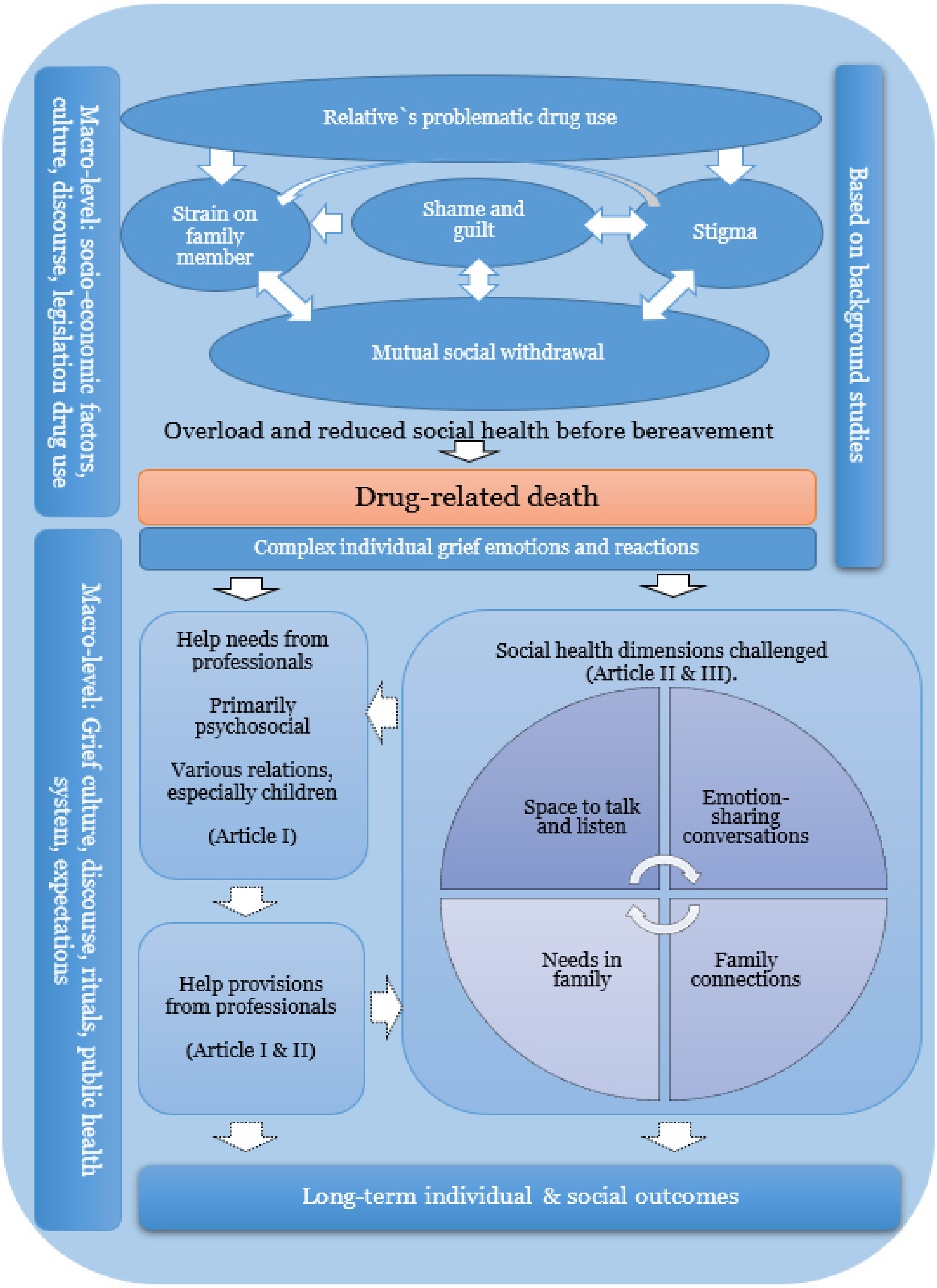


Figure 8. Expanded theoretical model of help needs and social health after a DRD.

The model suggests that dynamics contributing to poor social health before death involve the relative's problematic substance use before death, having a direct impact on the strain of the family member (or partner/friend). This impact is also mediated through processes of stigma, shame, and guilt, which, in addition to having a direct effect on the strain of the family member, also contribute to social withdrawal between the affected family member and other people. These dynamics can contribute to poor social health and overload before bereavement. The illustrated dynamics contributing to poor social health and overload before death are based on empirical findings and theory from referred literature in the above discussion.

The boxes following the death with ensuing complex individual grief emotions and reactions, show findings from the articles of this doctoral project. On the left-hand side, findings from Article I concerning the needs and experiences for professional help after death are presented. On the right-hand side, findings from Article II concerning the challenged social health of those bereaved are presented. In addition, processes in family interaction that can help explain the level of social health is presented in the circular matrix (Article III). The stippled arrows between the boxes suggest possible relationships between the needs for help and received help from professionals, and the participants' social health and/or family interaction. Finally, the stippled arrows to long-term individual and social outcomes suggest that both the availability and quality of bereavement care *and* the social health factors are important for the outcome.

Considering the boxes on the right side, the low scores on the various instruments used in Article II are in other empirical studies associated with complicated grief reactions and psychosocial distress after bereavement, including (a) lack of perceived social support in family/network, (b) social withdrawal from other people, (c) impairment of work functions and social adjustment. Furthermore, qualitative findings in Article III show important aspects of intra- and interpersonal adjustment in bereavement. C*onsiderable needs in the family become our responsibility* shows that many parents experience an overload of worries and/or responsibilities in line with the "overload" concept in the Dual Process Model of Coping with Bereavement (Stroebe & Schut, 2016). C*onversations that are important for family connections* *are obstructed*, entails a fear of heightened emotions, difficulty of finding words and lack of social sharing of emotions, which in other empirical studies have been shown to have an intra- and inter-personal impact on adjustment during the bereavement process. For example, communication concerning emotions, perspectives, priorities and actions is important for the way in which parents who have lost a child cope individually *and* as a couple (see Bergstraesser et al., 2015; Dyregrov & Dyregrov, 2017; Stroebe et al., 2013a). These phenomena are thus assumed to be related to the significant need for professional help documented in Article I.

Qualitative Article III was the only article that explored the relationship between higher family cohesiveness and lower help needs. Several parents who perceived family relationships as safe and supportive were considerably less likely to need help from professional services. The findings in Article III, replicating those in other studies relating to better adjustment after bereavement, are (a) the social sharing of emotions, (b) closer social connections and (c) the reorganization of and readjustment to life with one's significant others.

What are the implications of these explanations for help provision? Based on the discussion so far, I deduce the following:

Many who have lost loved ones to DRD experience poor social health. The circumstances leading up to the loss can contribute to ongoing social challenges in the aftermath. Poor social health is associated with reduced mental health and complicated grief reactions, which, in turn, tend to result in poorer adjustment and consequently increased need for professional assistance among the bereaved. Therefore, it is crucial to consider professional interventions to enhance the social health of affected family members and close friends/partners before and after the loss. Such measures have the potential to promote better coping and adjustment to bereavement. Additionally, it is likely that improving social health, as demonstrated in section 2.2.1, has positive ripple effects on the other health domains.

4.2 Compassionate Communities and DRD-bereaved people

In the following discussion, I will focus on the period after death, and how psychosocial bereavement care that might improve the social health of DRD-bereaved people could be structured and offered. This doctoral project addresses bereavement within a specific population, DRD-bereaved people. Still, I believe that psychosocial bereavement care in DRDs and other traumatic deaths should be part of a broader public health structure. In section 2.2.3, I presented Compassionate Communities as a possible overarching framework for a public health approach to bereavement care. Compassionate Communities considers the bereaved person's natural support network as the initial source of assistance from public services (see Aoun, 2020; Kellehear, 2005).

The three-tiered public health model can help differentiate psychosocial service efforts within a Compassionate Communities structure for bereavement care (Rumbold & Aoun, 2015). The three different tiers of the bereavement pyramid are based on an approximation of the number of people at different levels of risk of developing complicated grief reactions after death among the general population, with 60% placed at low risk, 30% at moderate risk and 10% at high risk (Penny & Relf, 2017). Figure 9 shows that most DRD-bereaved people should be considered in the moderate-high risk group in this tiered model. This suggestion is based on the findings from Article I and II, which, in addition to showing the sample's general social health and help needs, also showed that the mean score of Prolonged grief symptoms reported by our sample who had been bereaved the last two years, was 33.7 (Article I). A preliminary cut-off for a diagnosis of prolonged grief disorder is ≥35 (Pohlkamp et al., 2018). Hence, people bereaved by DRD can be assumed to have the same risk for complicated grief reactions as people bereaved from other types of traumatic losses (cf Aoun et al., 2015; Djelantik et al., 2020)

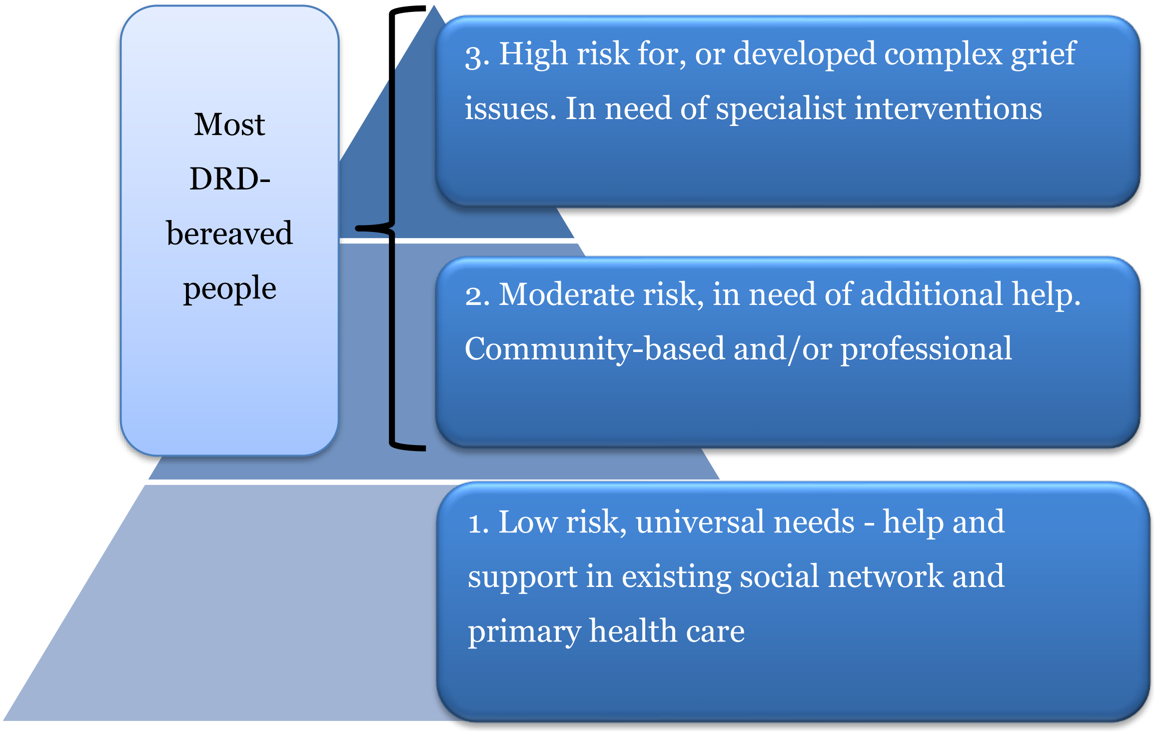


Figure 9. The three-tiered public health model for bereavement care with findings from Articles I and II places most DRD-bereaved people in the two upper levels of the pyramid (Inspired by Aoun (2020), NICE (2004) and Penny and Relf (2017)).

The three-tiered public health model for bereavement care suggests that natural support networks are the initial source of assistance but not the sole one, especially for individuals with needs in the higher tiers. Those falling into the third tier would require specialised and personalised professional help, indicating that many DRD-bereaved individuals may benefit from both forms of assistance. As discussed in section 2.2.3, the higher tiers of support and care build upon the foundation of the lower tier. Therefore, the need for support from existing social networks and primary health care (tier 1) remains crucial for those with more substantial needs (tiers 2 and 3). Consequently, during a workshop in the UK focusing on ideal bereavement care, key stakeholders emphasised that facilitating social adjustment and “improving family-based support, enabling bereaved people to be better supported by their existing networks” (Scott et al., 2022, p. 6) should be an integral part of psychosocial bereavement care.

This is in line with a central argument in this thesis, that close network members, often family, might need help from professionals to connect and thus be able to help each other cope and adjust after losing a loved one in traumatic circumstances like DRD. By providing professional assistance to the bereaved person and their "significant others" - family and/or close network members - it could be possible for the professional helpers to tap into the potential support within these relationships that could promote coping and adjustment in the short and long term.

The Norwegian guideline concerning psychosocial measures in Crises, Accidents and Disasters acknowledges this possible need for those bereaved in traumatic circumstances. It emphasises a family perspective and the active involvement of family and/or network members by the professional helpers who shall provide care for the traumatically bereaved people (Norwegian Directorate of Health, 2016). Also, the guideline highlights that crossdisciplinary psychosocial crisis teams, a core concept in the guideline, should have competence with children- and families (Norwegian Directorate of Health, 2016, p. 36).

The competence required for professionals providing bereavement care, particularly in cases of DRDs and other traumatic losses, is extensive. While this thesis does not aim to provide an exhaustive list of these competencies, it does advocate for establishing overarching guiding principles for professionals to focus on bereaved individuals' family and social relationships, in addition to individualized help. Core competency requirements should accompany such principles for the professional service providers. In the following section, I will explore how drawing inspiration from "Open Dialogue" principles customised for individuals who have experienced DRDs, could improve practice.

4.2.1 Open Dialogue in bereavement care

Section 2.2.3 outlined how Open Dialogue could serve as a concrete psychosocial therapeutic approach that aligns with the philosophy of Compassionate Communities. However, it is essential to note that Open Dialogue principles were developed within a community mental health context (Aaltonen et al., 2011). Therefore, when considering its application to bereavement care in cases of DRDs, it becomes necessary to adapt and contextualise these principles. This adaptation should take into account the findings presented in this thesis as well as other empirical material.

From Article I, we know that a high majority of the sample reported a need for psychosocial professional help post-loss, that this need applied to various relationships with the deceased, and that adequate help for children was lacking. From Article II, we know that many reported having withdrawn from others and experienced that others had withdrawn from them after the death, and that many experienced having few people to talk with and rely on. From Article III, we found that family connection was highly important for the parents to adjust to life, and that the sum of the family members' difficulties, complications in emotionally oriented conversations and family structure and flexibility suggested a need for family-oriented help in some families.

Together with other empirical findings of what help DRD-bereaved and other traumatically bereaved populations find helpful, such as early help, pro-active help, broad-spectrum help and need-adapted help over time (see Article I and Fjær & Dyregrov, 2021), I propose that the most important when adapting principles from Open Dialogue to bereavement care for DRD-bereaved people might be the following:

a) Proactive professional help at an early stage after bereavement.

This adaptation of the original principle of "Immediate help" (Aaltonen et al., 2011) builds on the wish and need for early and proactive help that DRD-bereaved people call for (see Article I and Fjær & Dyregrov, 2021). This wish parallels the needs and wishes of other traumatically bereaved populations (Dyregrov, 2011; Dyregrov et al., 2015; Ligier et al., 2020; Wilson & Marshall, 2010). In Norway, this principle is embedded in the official government guideline for Psychosocial Measures in Crises, Accidents, and Disasters (Norwegian Directorate of Health, 2016).

b) Involvement of key social network members, preferably from the first meeting.

This principle, included in the original writings on Open Dialogue (see section 2.2.3), means that the first meeting with those bereaved *is* primarily a social network meeting. Involving social network members from the first contact can, according to Seikkula (2012), be instrumental in preventing social withdrawal from important family or network members in times of crisis. However, it is essential to recognise that this principle should be applied flexibly, as seen in descriptions of Open Dialogue (see Olson et al., 2014). In practice, this means that sometimes "key social network members" consist of only one other person in the bereaved person's core social network. In other cases, individual conversations would be the most professionally sound.

A flexible approach might be particularly important for individuals who have lost loved ones to DRDs. The existing literature highlights the complexity and strain often observed in family relationships among those bereaved by DRD (see section 1.4.3.). Moreover, the tendency for many DRD-bereaved individuals to withdraw socially can result in a limited number of close relationships being available to provide emotional support. Additionally, the circumstances can vary significantly between a parent's experience, documented in Article III, and that of a partner or friend who also uses drugs (see section 1.4.3). While family relationships might take precedence for a parent, a bereaved person who uses drugs may prioritise their relationship with a friend as their primary source of support. Nevertheless, the limited availability of supportive relationships also underscores the significance of reinforcing the supportive bonds that do exist.

Following a principle like this from the start of the contact in an early intervention is probably demanding. The first days after a traumatic loss can be chaotic and induced by extreme emotions (see Dyregrov, 2001; Dyregrov, 2003a), and conversations involving family and/or close social network members may seem hard and uncontrollable. However, most importantly, a principle like this would nudge the professional help provision towards a family- and network-centred perspective, even though it might not always be feasible to facilitate these talks together immediately. A shift in the focus from the predominant individual-centric approach that currently guides service provision in Norway (see Article I) and many other Western countries to a perspective centred on networks and families would still be a pivotal step.

c) Encouraging dialogue in social network meetings, where individuals share experiences, emotions, and listen to others.

This principle, based on the original principle "dialogism" in Open Dialogue (see section 2.2.3), posits the role of the psychosocial service provider primarily to facilitate dialogue between the present network members and co-create a language in which all voices can be heard (Olson et al., 2014; Seikkula, 2002). Providing advice, information, and other assistance might also be important, but it is secondary. Following the theoretical basis in section 2.2.1, emotion leads to the social sharing of emotions, and in these exchanges, the connection between the people can be strengthened and individual adjustment promoted. The effectiveness of this process, however, relies on how sharing takes place and the responses it receives. For this purpose, the professionals have an essential role, and this professional task is not easy.

In Open Dialogue, the dialogical focus of family and social network meetings is emphasised, and the professionals must thus be able to organise and lead such meetings in ways that increase the likelihood of an enhanced dialogue between the family members in a crisis. This task presupposes thorough training, particularly so in cases of traumatic loss, illustrated by Dyregrov (2003a) when describing the family relations of a family bereaved by suicide: "I will not for a minute want somebody without experience and proper training to walk into a minefield like this." Such experiences are echoed in the writings of the exchanges in social network meetings in Open Dialogue; here, the team members' challenges entail supporting the expression of emotion and, at the same time, tolerating the intense emotional states that can be induced in such meetings (Seikkula & Trimble, 2005). Empirical studies have also confirmed these points of view, as social network meetings often involve demanding work for both therapists (Schubert et al., 2020) and clients

(Buus & McCloughen, 2022), and tensions can be experienced as difficult and unsafe by the family or social network members (Florence et al., 2021).

Thus, proper training is necessary for professional helpers to be able to meet these challenges adequately. In the original development of Open Dialogue, the training of therapists was a three-year part-time training in family therapy (Seikkula et al., 2011). In contrast, the increase in projects and research on developing Open Dialogue approaches in mental health care worldwide has developed several training programs of different duration and content. The duration of the courses ranges from about six days (Jacobsen et al., 2021) to one year for education to practitioners of peer-supported open dialogue (Stockmann et al., 2019) to extended training of two or three years part-time, depending on the base education level of the participants (see Buus et al., 2022; Wates, 2019). In addition, bereavement care for DRD-bereaved people and other traumatically bereaved populations also presupposes knowledge and skills in dealing with traumatic bereavement, grief reactions and substance use problems (see Fjær & Dyregrov, 2021). Hence, solid training would be needed to work this way with DRD-bereaved people.

Early and proactive family- and network-centred assistance, following the adapted principles of Open Dialogue, might effectively address crucial issues in bereavement care for individuals affected by drug-related deaths (DRD) and potentially other traumatic deaths. These issues revolve around the importance of the social sharing of emotions, social connectedness, the risk of social withdrawal from essential relationships, and the need to understand and communicate about interpersonal processes in close relationships following a loss. Thus, such assistance might yield enriching and sustainable benefits for bereaved individuals and families. Implementing a practice like this would also place significant demands on the training of professionals and could necessitate a shift in their perspective.

In the Norwegian context, this way of organising the system for psychosocial bereavement care for traumatically bereaved people would align with the recommendations in Psychosocial Measures in Crises, Accidents, and Disasters guideline (see Norwegian Directorate of Health, 2016). The suggested principles for a family- and social-network approach from services would mean a need for additional competence of those involved in psychosocial bereavement care. Specifically, the members of the psychosocial crisis teams would need to develop competence and skills in a family- and network-centred way of working.

5 Conclusion and future perspectives

This doctoral project has explored the help needs and experiences of DRD-bereaved people , dimensions of their social health, and family interactions and help needs. The quantitative findings documented that most of the sample reported the need for psychosocial help from professionals at an early stage after the death and over time (Article I), and that the investigated dimensions of social health were averagely poor compared to other traumatically bereaved populations (Article II). The qualitative findings showed that parents bereaved by DRD emphasized the importance of family relationships and support for their adjustment after the loss. They also pointed out that barriers to loss-oriented conversations and feeling overwhelmed by responsibilities complicated family life, connection and support (Article III). In this synopsis, I have, based on findings and previous literature, argued that the likeliness for DRD-bereaved people to develop complicated grief reactions is heightened, placing many of them in the “moderate and high risk – increased needs”-group in a tiered model for bereavement care.

A previous PhD thesis in the END project focused on understanding parental grief and their needs following DRD (Titlestad, 2021). The conclusions of that thesis highlighted that parents often would require individual-level professional help in the form of immediate, comprehensive, and need-based assistance over an extended period. Additionally, the thesis advocated for group-level support, such as participation in support groups, assistance from social networks, and access to web-based support resources (Titlestad, 2021). I argue that the current thesis expands the understanding of the help needs of those affected by DRD. It does so not by negating the need for individual assistance as highlighted by Titlestad (2021), but by contextualizing individual help within a family- and network perspective.

Through inferences from empirical findings and theory, I decided to explore psychosocial bereavement care focusing on family and social networks. Hence, the synopsis has primarily focused on the social health dimensions of individuals bereaved due to DRD, examining whether and how professional services can contribute to enhancing this aspect of their well-being. I have contended that service providers should adopt a family and social network approach, and I outline how this approach can draw from adapted principles found in the Open Dialogue model within a Compassionate Communities architecture for bereavement care. In the Norwegian context, these perspectives are largely integrated with the present framework in the guideline concerning psychosocial measures for those bereaved by traumatic deaths (see Norwegian Directorate of Health, 2016). However, I argue that this guideline could profit on an even clearer stand of the professional services need for competence when adopting a family-and network-centred approach in the bereavement care, as this is the base tier in a public health model to bereavement care (see Figure 9).

Through research in the END project and other countries, I have demonstrated that many of those bereaved by DRD experience considerable strain, that should be seen in relation to the stigma and strain pre-loss. I have also demonstrated that a majority of the experiences that DRD-bereaved people convey are transferable to other traumatically bereaved populations, such as those bereaved by suicide deaths. Thus, the proposed principles for psychosocial help are also relevant for other kinds of traumatic deaths in Norway and other countries, not only those bereaved by DRD.

5.1 Implications for practice

The findings from this doctoral project underscore the importance of offering consistent professional psychosocial bereavement care to those who have lost loved ones to DRD. Given the needs identified among different family members, including children, and the observed decline in the social health of those bereaved, I would recommend that this psychosocial bereavement care adopts a family- and network-centric approach. This approach aligns with the guideline for Psychosocial Measures in Crises, Accidents, and Disasters in Norway, which advocate for proactive outreach teams responsible for providing psychosocial bereavement care (Norwegian Directorate of Health, 2016). These teams, referred to as psychosocial crisis teams, should comprise professionals from various disciplines and aim to establish early proactive contact with those affected following a DRD.

In order to ensure a family- and network-centred focus from the start of the bereavement care, the initial contact from a crisis team member with a bereaved individual could involve asking questions that assume the presence of one or more family or social network members from the first meeting. Involving more than one person in the first meeting can strengthen those social connections and facilitate mutual assistance and support (cf. Olson et al., 2014; Seikkula & Arnkil, 2006). The first questions asked to the focal bereaved person, for example, on the telephone, could be:

- *Who else affected by the loss, who could need assistance or be of assistance, would you feel comfortable participating in a meeting?*

- *Who should make contact with this or these persons? Would you prefer that we make the contact?*

In situations where it may not be feasible or advisable to involve multiple individuals in the initial meeting, it becomes essential for professionals to ask questions that can help identify other individuals within the bereaved person's social network. These individuals may either require assistance themselves, serve as a source of social support for the bereaved person, or both. To identify other bereaved individuals in need of assistance, a pertinent question could be, "Who else has been significantly affected by this loss and may require someone to talk to?" To identify potential sources of support, an appropriate question might be, "Who could you rely on when you need someone to talk to or when you need someone to be there for you?"

For both these scenarios, this contact could be followed by a consultation following principles of a dialogical network meeting, first and foremost aiming to generate a dialogue between the present bereaved and family/social network members (see Olson et al., 2014). From this first consultation, additional follow-up could be tailored in a need-based approach, ensuring continuity of care throughout the clinical contact. This design of psychosocial follow-up and assessments are in line with original Open Dialogue principles and recommendations in the guideline for

Psychosocial Measures in Crises, Accidents, and Disasters (see Norwegian Directorate of Health, 2016; Seikkula & Arnkil, 2006).

Overall, this design for bereavement care has the potential to seamlessly combine professional assistance with a community-based approach on a micro-level. Such an approach could enhance the resilience of families and communities both nationally and globally. Considering the vulnerable position many DRD-bereaved people are in, there is a clear need for systems for help provision that professionally meet their help needs but also help strengthen the assets and potential resilience in their existing social networks.

5.2 Implications for research

Table 5 summarizes the proposals for further research areas described in article I-III. In Article III, we also proposed a variant of a participatory action design as the perhaps most ethically sound and flexible method for developing family-oriented therapeutic help practices that meet the population's needs. The trace from Article III will be further elaborated in this section.

Table 5. *Implications for research, Articles I-III*

Article	**Potential research directions**
Article I: Needs for help and received help for those bereaved by a drug-related death	Who are the people bereaved by DRD who report a high need for help but do not receive it, and how can relevant services reach them? How do DRD-bereaved people experience relationships with professional services? How can children be acknowledged and helped in their own right and as part of help efforts for grief-stricken families?
Article II: The social health domain of people bereaved by a drug-related death and associations with professional help: A cross-sectional study	How can early helping interventions that aim to improve the social health of bereaved people be designed and carried out? A naturalistic study design is proposed as the probably most feasible. Social health outcomes of bereaved populations from different geographic areas could be compared.
Article III: Drug death-bereaved parents' perspectives on family interactions and help needs: a qualitative study	Investigations with a focus on family-oriented needs and help interventions should be conducted. Possibly, explore feasibility of screening for family functioning and coping in bereaved families, for example using the Circumplex model or the Walsh Family Resilience Questionnaire. Analyses of help interventions' outcomes could be done at dyadic, parental and family levels.

This thesis has argued that many of those bereaved by a DRD need professional psychosocial help at an early stage after the loss, and the service provision should have a family- and network-oriented approach, emphasizing the facilitation of dialogue between the inner network members of those bereaved, followed by a need-based continuity of care, the latter in line with recommendations by Titlestad (2021). Nonetheless, the literature review focusing on interventions for bereaved populations and complicated grief prompts us to ask more questions, particularly regarding the most suitable form of early intervention, the optimal timing and the sustainable framework required for providing care to individuals dealing with DRD and other forms of traumatic bereavement. The family- and network-centred approach I have suggested throughout this thesis should thus be seen as a potential step towards the further development of and research into the help practices in these situations.

The literature review and the discussion of this thesis concerning early help efforts for those bereaved show that providing early psychosocial bereavement care that is need-adapted, lasts over time, is broad-spectrum, and adheres to a continuity of care, is not a straightforward dilemma to solve. In many ways, it has the features of a “wicked problem”, highlighting issues where “stakeholders disagree about the nature of these problems, about possible solutions, and about the values or principles that should guide improvements” (Head, 2022, p. 21). Death and bereavement are universal, shared human experiences characterized by deeply entrenched emotions and strong cultural values that shape customs and practices related to death and the grieving process, and significant regional disparities in rituals, customs, and beliefs exist. Additionally, the organizations and values that inform public health practices for traumatic bereavement and psychosocial crises vary among nations. Framing the problem as a wicked problem has implications for the type of research that might be necessary to develop solutions.

Lawson (2015) points out that participatory action research is appropriate for wicked problems. *Participation* concerns the involvement of essential stakeholders in the research process in all phases – from the definition of the problem, the study’s design, the implementation of interventions/change of practice, the analysis of results and the implications, etc. *Action* ensures that the research is situated in natural settings, intervening in the real world. *Research* denotes the systematic, rule-bound research process and methodology that defines research as research and not a "straightforward" change in practice (Lawson, 2015).

Thus, I would argue that the need for research into early helping interventions should seek inspiration from participatory action designs, as the needs, cultural context, and local public health framework are of essential importance in implementing feasible and sustainable help efforts in the area in question. One example of such work is described in the findings by Hill et al. (2022), where local stakeholders in Perth, Australia, collaborated on designing a model to provide early, proactive outreach help to people bereaved by suicide. The study described favourable outcomes and areas for improvement (Hill et al., 2022) and provides inspiration for the development of projects adapted to different local contexts.

From my point of view, the presented proposals in table 5 are all relevant, and I believe the direction of early psychosocial bereavement care with a family and network orientation is the most pertinent. Therefore, if I were to propose *one* concept for crucial further research into this field, it would be to conduct longitudinal research focusing on early family- and network-centred public health interventions for traumatically bereaved populations within a participatory action research framework.

5.3 Implications for policy

The implications for policy, focusing on official strategies and efforts related to DRD and other traumatically bereaved populations, will be drawn from both a Norwegian and an international perspective. I will discuss the Norwegian viewpoint and then extend the conclusion to an international context.

At the national societal level, the formerly mentioned thesis by Titlestad (2021), emphasized the importance of reducing stigma, recognizing individuals affected by DRDs, coordinating services, and fostering a commitment to further research. Following the current thesis's discussion and previous points, I broadly support the implications of Titlestad (2021). DRDs should be acknowledged as traumatic deaths that make those bereaved vulnerable to serious, adverse psychosocial consequences and thus, in need of need of immediate, broad spectrum, proactive crises help post-loss and over time. Findings from articles I and III suggest that it might be especially important to focus on the needs of children. That means there is a need for a policy that ensures that people bereaved by DRDs have access to relevant psychosocial bereavement care from early on after the death, individually, as families and social networks, and as a group.

In Norway, the guideline for Psychosocial Measures in Crises, Accidents, and Disasters contains many of these policy recommendations for traumatically bereaved people in general (Norwegian Directorate of Health, 2016). Also, the guideline acknowledges that organizing holistic bereavement care for traumatically bereaved people does not fit into one box within the welfare state model (Norwegian Directorate of Health, 2016). Thus, it advocates cross-sectorial collaboration through cross-disciplinary crisis teams for professional psychosocial bereavement care. I consider that this way of organizing services in these situations represents a good model. Nevertheless, achieving effective cross-sectoral collaboration has proven a formidable challenge for welfare services, with over four decades of inconsistent progress documented (Norwegian Ministry of Health and Care, 2015). Consequently, the development of policies related to psychosocial bereavement care should recognize cross-sectional collaboration as a distinct professional skill. It should be accompanied by comprehensive training and educational programs for all relevant service providers, complemented by system-level recommendations and incentives.

In the conclusion of Article I, we underscored the significance of each country establishing a legislative and guideline framework to effectively assist those bereaved by DRD and other traumatic events. Norway has already laid the groundwork through the Psychosocial Measures in Crises, Accidents, and Disasters guideline (Norwegian Directorate of Health, 2016). In numerous other countries, there may be a need for the development of similar service provision guides. Furthermore, I contend that these frameworks should be rooted in values supporting a public health approach to ensuring quality bereavement care across various bereavement experiences.

I have proposed that such foundational ideas can be found in Compassionate Communities. Within the philosophy of Compassionate Communities, psychosocial bereavement care should be grounded in a relational view of resilience and a family- and network-centred orientation (Kellehear, 2005). This approach necessitates cultivating partnerships between formal helpers and informal network members. Principles from Open Dialogue, for example, can facilitate this collaboration on the micro-level in concrete cases.

Therefore, in light of the findings from this doctoral project, I strongly encourage initiating a national and international discourse on the values and guidelines governing public bereavement care, with a specific focus on those who are at risk for experiencing or have experienced traumatic loss like DRD. From my perspective, and as argued in this thesis, these foundational values should include a family- and network-centred approach. Hence, there is a need for education and training programs in family- and network-centred approaches for the professionals responsible for assisting those bereaved by DRDs and other traumatic deaths.

6 Literature

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ARTICLES AND APPENDICES

Articles I-III

Appendices

Articles

Article I: Needs for help and received help for those bereaved by a drug-related death: a crossectional study

Article II: The social health domain of people bereaved by a drug-related death and associations with professional help: A cross-sectional study

Article III: Drug Death-Bereaved Parents’ Perspectives on Family Interactions and Help Needs: A Qualitative Study

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Needs for help and received help for those bereaved by a drug-related death: a cross-sectional study

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Abstract

Background and aims: Individuals bereaved after sudden and unexpected deaths can benefit from professional help to cope after the loss, and the bereaved call for proactive, early and flexible help from professional services. Most drug-related deaths (DRDs) happen suddenly and unexpectedly. DRDs are a significant public health issue, yet few studies have examined DRD-bereaved people's needs and experiences with professional help. This article investigates the needs for help and received help reported by DRD-bereaved family members and friends, and suggests improvements in services based on the findings. **Data and method:** A heterogeneous convenience sample of DRD-bereaved family members and close friends (n = 255) were recruited for a survey from February to December 2018. Descriptive analyses were conducted for experiences

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with professional help, chi-square analyses to find predictors for help needs and received help, and logistic regression analysis to find predictors for satisfaction with the help provided. **Results:** Most DRD-bereaved individuals reported a need for professional help after the death regardless of family relation to the deceased, and about half of the participants received help. Nearly half of them were satisfied with the help. Our results indicated higher satisfaction with help among older bereaved, and the participants who received help from a crisis team or psychotherapist. The latter was particularly stated for younger participants. Few participants with children in the family reported that the children had received help, and less than one-third were satisfied with this help. **Conclusion:** The study shows that younger age groups and children need particular recognition, and a family perspective from services is essential. When assessing the help needs of the DRD-bereaved, relations of both psychological and biological closeness should be recognised. Help efforts should be tailored according to established knowledge of the provided help that bereaved populations deem effective.

Keywords

bereavement, cross-sectional, drug-related death, help needs, logistic regression, professional help, unexpected death, unnatural death

Bereavement is a part of life. Nevertheless, some losses are so hurtful that the bereaved need professional help to cope with everyday life. In those circumstances, bereaved people's needs may relate to a broad spectrum of life areas, from the spiritual (Silviken et al., 2015) and practical (Ross et al., 2021) to the economic (Fjær & Dyregrov, 2021) and psychosocial (Dyregrov et al., 2015). Unnatural deaths, as well as sudden and unexpected bereavement, risk affecting the bereaved person's life and health in profound ways, and even the prospect of premature death looms larger (Djelantik et al., 2020; Kristensen et al., 2012; Song et al., 2010, 2019). The affected relations may include parents, children, siblings, extended family, partners and close friends (Bolton et al., 2016; Liu et al., 2019; Rostila et al., 2012; Templeton et al., 2018). Studies show that most of those bereaved by unnatural deaths report a need for professional help; however, many do not receive this help, and their own capacity to initiate it is impaired (Dyregrov, 2002; Peters et al., 2016; Pitman et al., 2017). The bereaved generally want the professionals to initiate contact (proactive help) and provide flexible help over time (Dyregrov et al., 2015; Dyregrov & Kristensen, 2021; Ligier et al., 2020; Wilson & Marshall, 2010). Early connection with support services generally results in positive experiences (McKinnon & Chonody, 2014), and outreach and proactive services have shown to improve the bereaved person's likeliness to access help and support (Szumilas & Kutcher, 2011).

Drug-related deaths (DRDs) are unnatural deaths that tend to happen suddenly and unexpectedly (Titlestad, 2021). According to research, common experiences on such deaths include stigmatisation, complicated emotions and complex social relations (Dyregrov & Selseng, 2022; Titlestad et al., 2019), as well as struggles concerning meaning-making, shame and guilt (Titlestad et al., 2020a, 2020b). A study on DRD-bereaved parents in Norway found a high prevalence of complicated grief symptoms (Titlestad et al., 2021). In addition, a register-based study found a higher mortality rate among DRD-bereaved parents than with parents bereaved by other forms of death (Christiansen et al., 2020).

Internationally, the high number of DRDs is a significant public health issue (UN General Assembly, 2016). Since 1990, there has been a considerable increase in the number of people with drug problems worldwide (Degenhardt et al., 2018), and the number of deaths related to drug use has similarly increased (Murray et al., 2020). The World Health Organization (WHO; 2020, 2022) estimates that about 500,000 deaths annually are related to drug use, and about 182,000 of them are directly drug-induced. In the European Union countries, including Norway and Turkey, the annual toll of drug-induced deaths was estimated to amount to 5,800 in 2019 (EMCDDA, 2021). In Norway, an average of 275 individuals are annually registered as deceased by immediate drug-induced causes (Norwegian Institute of Public Health, 2021), and a total of at least 400 persons can be identified as deceased by both direct and indirect drug-related causes (including illness and drug-related violence and accidents). Thus, if we estimate that there can be eight close bereaved persons after each DRD, there will be 3,200 new bereaved in Norway each year, and about 60,000 persons can be defined as strongly impacted by a DRD in the last two decades. Based on the WHO estimates of total DRDs globally, the impact of DRDs affect four million bereaved people each year.

The few small studies concerning DRD-bereaved people's encounters with professional services have found mixed experiences. In a UK study on drug- and alcohol-related deaths, the bereaved experienced fragmented encounters, but compassion and kindness from professionals mitigated feelings related to stigma (Walter et al., 2017). Another UK study found the experience of meeting a non-judgemental counsellor especially important for DRD-bereaved people (Cartwright, 2019). Of two small studies in Denmark, one reported a lack of help, understanding and support from professionals as common experiences (Biong & Thylstrup, 2016), while the other found that the bereaved were most satisfied with proactive help (Tjagvad et al., 2014). In a Norwegian study, only one of 14 DRD-bereaved parents received proactive help from professional services, and the experiences with help were generally mixed (Titlestad et al., 2020a, 2020b).

In sum, the studies investigating bereaved people's needs and experiences with professional help after a DRD are small, mainly including participants with one or few relationships to the deceased (such as parents). However, together with research into help experiences after other forms of unnatural death, they do show the importance of the way professional services relate to the bereaved. This study is part of the END project, a sizeable Norwegian research project investigating DRD-bereaved people's situations, experiences with help and how professional services relate to the bereaved. This article aims to provide knowledge on the needs for help that DRD-bereaved family members, close friends and partners have, the professional help that they have received, and on the variables related to participants' satisfaction with the received help. Improvements in services will be suggested based on the findings.

Methods

In this study with a cross-sectional design, the reporting is guided by the STROBE Statement Checklist (Von Elm et al., 2007). All analyses were carried out using IBM SPSS Statistics Version 27.

Data collection

The data were collected through a survey answered by a sociodemographically and geographically heterogeneous convenience sample of DRD-bereaved family members and friends in Norway from February to December 2018. The recruitment strategy entailed information letters and cooperation with municipalities, hospital services, treatment centres and non-governmental organisations. In addition, recruitment was promoted through information letters to all Norwegian municipalities' public email addresses, advertising in various media, information at conferences and snowball recruitment.

Participants

To be eligible, the participants had to be aged at least 18 years and to have lost a family member or close friend in a DRD more than three months before answering the survey. In total, 255 DRD-bereaved family members, partners and close friends participated in a survey completed on paper or digitally via Questback. Table 1 presents descriptive data of the sample, the reported relations to the deceased and the characteristics of the deceased.

The vast majority of deaths the bereaved had experienced were sudden. The majority of the deceased died while actively using drugs (38%). A substantial group had died after relapse (22%) and after or during substance treatment or prison (21%), whereas 20% died in unclear or other circumstances. Drug use was known to the bereaved in almost all cases (95%), and in most cases, the deceased had started using drugs several years before the death.

Questionnaires and variables

The survey consisted of 109 questions, and the data for this article included background variables and responses from three questionnaires in the survey. Some Likert items and nominal variables with more than two categories were collapsed because of statistical requirements, e.g., for the logistic regression analysis. In addition, some were collapsed in the frequency tables; for example, "high" and "very high" were collapsed into "high" in Table 2.

Assistance questionnaire

The assistance questionnaire (AQ-R), addressing bereaved people's needs for help and received help, has been used in other studies with traumatised bereaved (Dyregrov, 2003; Wilson & Clark, 2005). It consists of 22 questions, 12 of which we used in this study. The response options are nominal, ordinal or 5-point Likert items. The respondents are asked whether they have received help (nominal), which services they have wanted and received help from (nominal, 12 options and free-text), whether proactive contact and home visits are included in the helping relationship (nominal), the degree of satisfaction with the help received (Likert item), whether contact was experienced as burdening (nominal), the need for help immediately after death (Likert item), ideal help duration (ordinal, five options and free-text), received help for children (nominal), satisfaction with help for children (Likert item) and wanted help for children (Likert item).

General self-efficacy scale, short form

Self-efficacy was measured using the generalised self-efficacy scale, short form (GSE-SF), which consists of five items, scoring 1–4 from "not at all true" to "exactly true". The α-coefficient for the sample in this study was .834. One participant in the relevant analysis had missing values and was not included.

PG-13

Prolonged grief symptoms were measured using the diagnostic tool PG-13 (Prigerson & Maciejewski, N.D.). The measure consists of 11 5-point Likert items that score the frequency and intensity of distress symptoms related to bereavement, which are then summed continuously to reach a total score of 11–55. Higher scores mean more severe symptoms, and a preliminary cut-off for a diagnosis of prolonged grief is 35 or more (Pohlkamp et al., 2018). Five participants had more than 25% missing answers on this measure and were not included in the analysis, leaving 250. Nine participants had one missing value, and one participant had two, which constituted 0.4% of the total items. These were imputed based on the mean score of the participant's reported inventory items. The α-coefficient for the sample was .898.

Statistical analyses

Frequency analyses were performed with variables related to the needs for help and received help for the whole sample. Next, we conducted chi-square analyses (χ^2) for needs for help, received help and whether services initiated contact after the loss (proactive help) as dependent variables. The independent variables were

Table 1. Sample characteristics (n = 255) presented with (range), mean (*sd*) or *n* (%).

Variable (range)	Mean (*sd*)	*n* (%)
Sociodemographic characteristics		
Age of bereaved at the time of survey (18–80 years)	47.5 (13.9)	
Age of bereaved at the time of loss (5–76 years)	39.9 (15)	
Female sex		208 (82)
Educational status		
College/university		125 (49)
Senior high school		97 (38)
Primary school		32 (13)
Relational status: married or cohabiting		162 (64)
Residency: urban		156 (62)
Part of country: South		231 (92)
Employment		
Working (full- or part-time)		155 (61)
Retired		29 (11)
Student		14 (5.5)
Other		58 (23)
Household income: NOK in thousands		
≤499’		85 (34)
500’–999’		121 (48)
≥1,000’		45 (18)
Clinical characteristics		
Prolonged grief disorder scores measured with PG-13		
0–2 years since loss (14–54)	33.7 (9.0)	74 (30)
2–5 years since loss (12–55)	29.1 (10.3)	38 (15)
5–35 years since loss (11–49)	25.0 (7.9)	136 (55)
Total sample (11–55)	28.2 (9.4)	
Bereaved excess substance use before or after loss: no		190 (75)
Relational characteristics		
Years since family member’s or friend’s death (0–35)	8.1 (7.4)	
Relation to deceased		
Parent		95 (37)
Sibling		79 (31)
Child		25 (9.8)
Other kin		28 (11)
Close non-kin relation: partner (n = 13) or friend (n = 15)		28 (11)
Perceived closeness: close/very close		222 (88)
Characteristics of deceased		
Deceased sex: male		192 (75)
Deceased age at the time of death (15–68 years)	31.3 (9.9)	
Deceased duration of drug use before death (0–42 years)	13.4 (8.6)	
Manner of death		
Unintentional intoxication		160 (63)
Intentional intoxication (suicide)		19 (7.5)
Disease, accident or violence related to drugs		47 (19)
Manner uncertain		27 (11)

Table 2. Needs for help from professionals, received help and experiences with help, *n* (%).

	high	partly	low/no
Needs for help right after death	57 (140)	24 (59)	19 (48)
Satisfaction with services	45 (58)	34 (44)	20 (26)
Satisfaction with help for children	29 (18)	37 (23)	34 (21)
Missed help for children	37 (57)	29 (44)	34 (52)
		yes	No
Received help after the death		52 (131)	48 (121)
Home visits by professionals		33 (43)	67 (88)
Proactive contact from professional services		14 (18)	86 (109)
Straining experience with prof. service contact		21 (27)	79 (102)
Children in the family received help		26 (40)	74 (114)

sociodemographic characteristics, relation to the deceased (parent, partner or friend, sibling, etc.), temporal variables (age of the deceased and the bereaved at the time of death, time since loss, duration of the deceased's drug use) and the circumstances (manner and context) of the death. Logistic regression analysis was used to see if any variables predicted participants' ratings of high or low satisfaction with help controlled for confounding. See details for the logistic regression analysis in the supplementary file.

Ethical considerations

The END research project has been approved by the Norwegian Regional Committee for Medical and Health Research Ethics (reference no. 2017/2486/REK vest). When consenting to participate, all participants were informed in writing about the project's aims. It was further explained that the data would be published in a non-identifiable manner and stored on the research server at the university (more details can be found on the END web page or ResearchGate).

Results

The needs for help and received help

Prolonged grief symptoms measured with PG-13 showed mean scores of 33.7 for participants bereaved within the last two years, 29.1 for those bereaved 2–5 years ago, and 25.0 for those bereaved >5 years ago.

Table 2 shows the answers of the bereaved concerning their reported need for help from professionals for their own sake and for children in the family. It also shows how many have received professional help, aspects of how the help was tailored, and their assessments of received help in terms of satisfaction and straining experiences.

Concerning the ideal duration of help, 20% reported 1–3 months, 36% stated 3–12 months, and 39% reported 12 months, or as long as needed. In addition, 10 (4%) participants were not sure, and one participant reported no need. Figure 1 shows the distribution of services from which participants received help, presented as a percentage of the total participants that had received help ($n = 131$). Most of those who received help did so from more than one service ($M = 2.6$). Figure 2 shows the services that participants missed help from as a percentage of the total sample who had responded on this item ($n = 238$).

Variables associated with needs for help, received help and proactive help

The χ^2 analyses show that the needs for help are relatively evenly distributed between the different relations to the deceased. Only the variable of death by intentional or unintentional intoxication yielded a significant association to higher needs for help, compared with death by disease, accident, violence or uncertain manner (2, N = 245, $\chi^2 = 19.499$, $\phi_c = .282$, $p < .001$). The Cramer's V (ϕ_c) of .282 suggests a medium correlation (Pallant, 2020). On the dependent variable of received help, we found a significant association between the needs for help and the level of received help (2, n = 247, $\chi^2 = 9.194$, $\phi_c = .193$, $p = .01$), which suggests a small to medium correlation. Relation to the deceased was also significantly associated with received help (4, n = 252, $\chi^2 = 15.458$, $\phi_c = .248$, $p = .004$), a medium correlation. The distribution of received help favours parents (adjusted residuals = 2.6) and disfavours the extended family (adjusted residuals = –3.0). The other relations showed minor deviations from the expected count. Being a parent was also significantly associated with the dependent variable of proactive contact from services (1, n = 127, $\chi^2 = 7.690$, $\phi = .269$, $p = .006$), a small to medium correlation (Table 3).

Predictors to satisfaction with received help

The logistic regression model yielded five significant predictor variables at $p < .05$ and one interaction term at $p < .10$. The results show that a longer time since bereavement predicted higher satisfaction. Those of older age at the time of loss and those with higher self-efficacy were more likely to be satisfied with the help. Furthermore, if the bereaved received help from a crisis team or a psychologist/psychiatrist, they were also more likely to be satisfied with the help. On the interaction term psychologist/psychiatrist by age of bereaved at the time of death ($p = .073$), the analysis shows that having received help from a psychologist/psychiatrist predicts a higher likeliness for satisfaction with the help given younger age (Figure 3).

Table 4 shows the odds ratios of the significant predictor variables associated with high satisfaction with help.

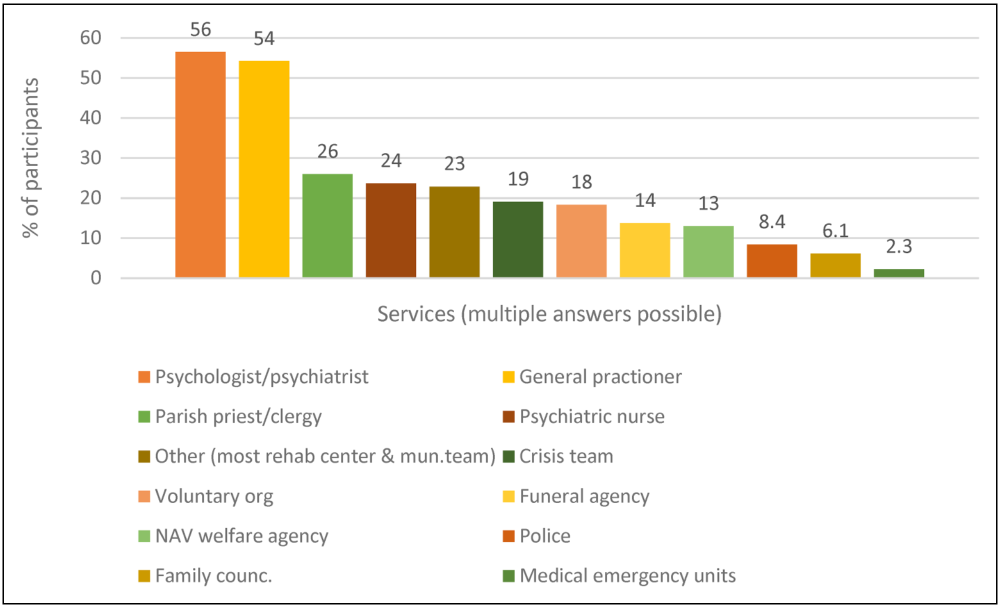

Figure 1. Received help after bereavement.

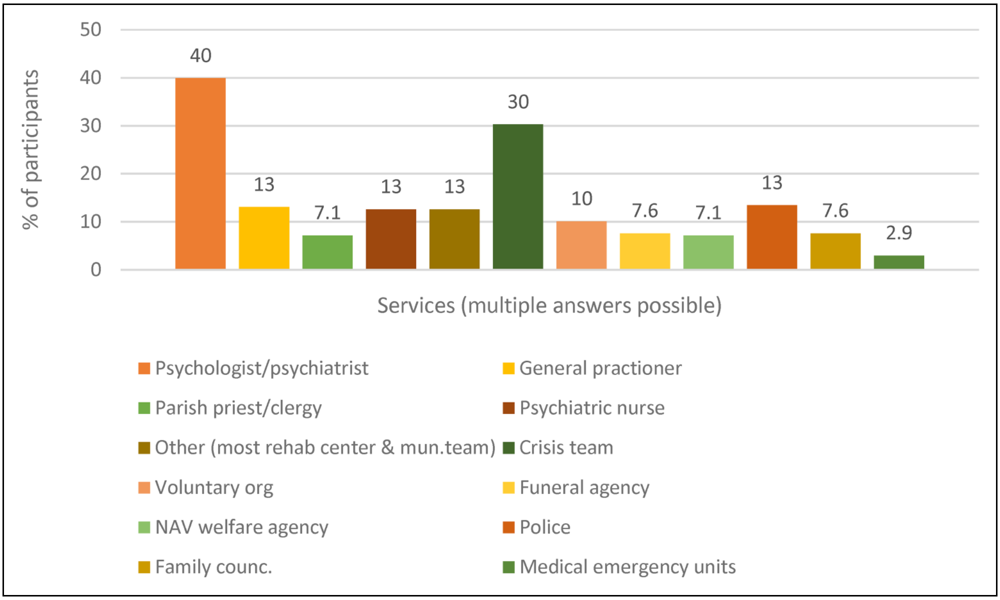

Figure 2. Missed contact with services after bereavement.

Discussion

This article aimed to provide knowledge of which needs for help and received help from professional services were reported by DRD-bereaved family members, close friends and partners, and which variables were related to participants' satisfaction with the help. Based on the findings, we suggest improvements in the services. Not only did most participants report a need for professional help after the death, but the mean scores of prolonged grief symptoms were high, in fact higher than in a study of Swedish parents who had lost an underage child within the last five years, comparing the same time since bereavement (Pohlkamp et al., 2019). Our sample is made up of heterogenous relations to the deceased, and as Titlestad and Dyregrov (2022) shows, there are group differences in mean scores in this sample depending on the relation. However, our sample's overall mean score indicates that grief levels are generally high across different relations, thus showing a population exposed and vulnerable to complicated grief trajectories (Boelen & Lenferink, 2020).

About half of the participants had received help, and nearly half of them again were satisfied with the help. Parents and those who reported a high need for help received help significantly more often than others. The most important predictors for satisfaction with help were a higher age of the bereaved at the time of death, having received help from a psychologist/psychiatrist, or having received help from a crisis team. Many received help from psychologists/psychiatrists, few from crisis teams, and these help services were also missed the most. Help from a psychologist/psychiatrist tended to predict satisfaction better for the younger age group than the older. Few participants with children in the family reported that the children had received help. A majority lacked help for children, and less than one-third of participants were satisfied with the help provided for children. Based on these findings, we will discuss the manner of death, relationship to the deceased and age of participants, with similarities and differences in help needs and received help within the population. Moreover, we discuss the differences in satisfaction with services and suggestions for improved services.

Table 3. Needs for help, received help and proactive help. χ^2 analyses.

Dependent variable						
Independent variable	Needs for help immediately after the death (% High need in group)					**p-value**
Sex	Female (59)		Male (49)			.489
Age of deceased at death (yrs)	≤30 (62)		> 30 (51)			.194
Cause of death	**Intox. unintentional/ intentional (65)**		**Disease, accident, violence, uncertain (35)**			**.001***
Residency	Urban (53)		Country (62)			.248
Time since loss (years)	0-2 (60)		2-5 yrs (53)		5-35 (57)	.523
Income (NOK, in thousands)	<500` (67)		500-999` (50)		≥1000` (55)	.172
Age of bereaved at death (yrs)	5-20 (52)		21-35 (56)	36-50 (63)	51-76 (53)	.705
Duration of dec. drug use (yrs)	<7 (67)		7-12 (47)	13-18 (55)	>18 (55)	.239
Relation to deceased	Parent (60)	Sibling (58)	Child (59)	Other kin (43)	Close non-kin (52)	.600
Context of death	post prison (53)	Post hosp (60)	Active use (54)	Relapse (65)	Uncertain/Other (49)	.712
Received help (% Yes in group)						
Sex	Female (51)			Male (57)		.503
Residency	Urban (50)			Country (56)		.427
Cause of death	Intox. unintentional/intentional (54)			Disease, accident, violence or uncertain (47)		.409
Income (NOK, in thousands)	<500` (56)		500`- 999` (49)	≥1000` (53)		.587
Time since loss (yrs)	0-2 (49)		2-5 (54)	5-35 (53)		.854
Needs for help right after death	**Great/significant (61)**		**Some (46)**	**Small/no (38)**		**.010***
Age of bereaved at death (yrs)	5-20 (75)		21-35 (47)	36-50 (37)	51-76 (57)	.055
Relation to deceased	**Parent (63)**	**Sibling (44)**	**Child (57)**	**Extended family (25)**	**Close non-kin (61)**	**.004***
Proactive contact from professional services (% Received proactive contact in group)						
Relation to deceased	**Parents (25)**			**Other relation (6)**		**.006***
Years since loss	<5,5 (16)			5,5 – 35 (12)		.664

Note. Significance levels on 2 × 2 tables reported as Yates continuity correction.
*Significant at $p < .05$ (in bold).

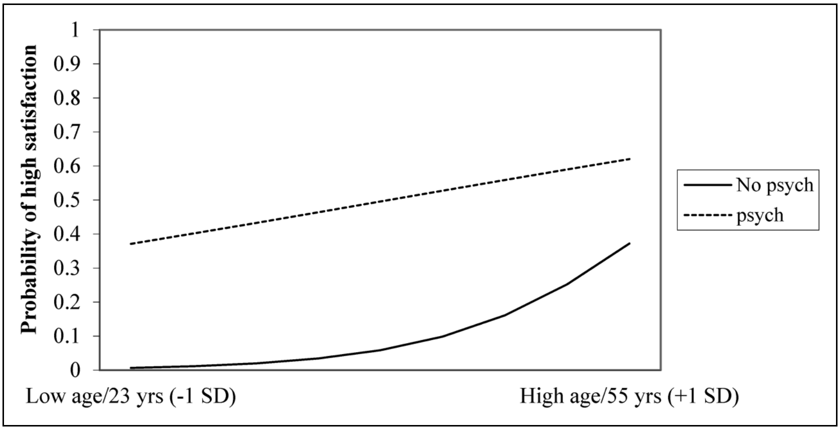

Figure 3. Interaction term psychologist/psychiatrist by age of bereaved at time of death.

Table 4. Final logistic regression-model for outcome high satisfaction with help (n = 124).[a]

	OR	95% CI
High vs low general self-efficacy (Z)*	1.6	1.0–2.5
High vs low age of bereaved at time of loss (Z)*	4.0	1.7–9.3
Long vs short time since loss (Z)*	1.7	1.1–2.8
Help from psychologist/psychiatrist vs no help*	4.0	1.5–10.9
Help from crisis team vs no help*	3.8	1.3–11.5
Help from psychologist/psychiatrist by age bereaved time of loss	0.4	0.2–1.1

Note. CI = confidence interval; OR = odds ratio.
[a] 24 variables included at the start of the analysis, e.g., education level, income, sex, relation to deceased, strenuous life experiences and home visits. See supplementary file for details.
* Significant at $p < .05$.

Sudden and self-inflicted death predicts increased needs for help

Participants who were bereaved through intoxication with or without intention reported a higher need for help than those bereaved through disease, accident, violence or uncertain manner related to drugs. While all deaths within the first category were sudden and self-inflicted, the second category consisted of both sudden and expected, violent and non-violent, self-inflicted and other-inflicted deaths. The death's suddenness can be one explanation for the difference in reported needs for help between these groups of the bereaved. There is considerable support in earlier research that sudden, unexpected and violent losses pose a higher risk for adverse health-related consequences for the bereaved (Djelantik et al., 2020; Kristensen et al., 2012).

The level at which self-infliction caused the death can be another part of the explanation. Self-infliction characterises both drug-induced deaths and suicides. In addition, the categories themselves overlap (EMCDDA, 2009). Although research findings differ on the consequences of suicide bereavement compared to other kinds of sudden and unexpected bereavement, experiences of stigmatisation and self-stigmatisation, meaning-making, shame and guilt seem to be more profoundly disturbing for many bereaved after suicidal deaths (Pitman et al., 2014; Shields et al., 2017; Wagner et al., 2021). These experiences are also documented in DRD bereavement, and the stigma and self-stigmatisation seem even more pronounced for those bereaved by such deaths (Dyregrov et al., 2020; Dyregrov & Selseng, 2022; Titlestad et al., 2019, 2020a, 2020b). Therefore, the suddenness, stigmatisation and level of self-infliction of the death can explain why this part of the population of DRD-bereaved people report a greater need for help.

Professional help is unequally distributed

There is an apparent discrepancy between reported needs for help and received help for participants: one-third of those who reported a need for help did not receive it. The discrepancy is higher for children, as only one-quarter of participants who had children in the family reported that they had received help. This discrepancy between the need for help and received help is higher than in other studies on traumatically bereaved populations in Norway (Dyregrov, 2002), especially compared to the follow-up after the terror attack in Norway on 22 July 2011, where 94% of the bereaved with different relations to the deceased received professional help (Dyregrov et al., 2015).

Our results show that reported needs for help did not differ significantly between relations to the deceased. A recent UK study also found that drug- and alcohol-related loss profoundly affected various relations to the deceased (Templeton et al., 2018). All these bereaved people needed recognition, and some needed more help than was available (Templeton et al., 2018). Furthermore, our results show differences in received help depending on the relation to the deceased, where parents received help significantly more often than did other relations. The difficulties for relations beyond the closest blood relatives in obtaining help parallels those recognised in the previously mentioned UK study (Templeton et al., 2018) and findings on other bereaved populations. In a study of psychosocial help to the bereaved after the 2011 terror attack in Norway where 77 people died, 25% of a sample of 67 bereaved reported rigidity in the professional services regarding who should and should not receive help (Dyregrov et al., 2015). Another study, based on interviews of bereaved friends after this attack, reported common experiences of not getting help or being acknowledged as bereaved (Johnsen & Tømmeraas, 2022). Thus, the experience of differing recognition of needs and access to help depending on relation to the deceased is a shared experience both for DRD-bereaved and other traumatically bereaved people.

The "grief hierarchy" following a death, which denotes the varying recognition and validation of grief and grief rituals depending on the relationship to the deceased (Robson & Walter, 2013), probably partly explains these differences. Which relative is contacted first after the death, which bereaved receive condolences, which bereaved organise and decide upon funeral arrangements and so on are informally and formally ordered in our culture (Cemetery Act, 1996 § 9-2; Robson & Walter, 2013). Extended family and friends do not have a prominent place in this order. A grief hierarchy provides predictability and order in circumstances of bereavement, but also creates barriers to recognising and acknowledging the help needs of the bereaved lower down in the hierarchy. Bereaved people's call for help from a psychologist/psychiatrist may also suggest that the bereaved do not find help adequately accessible or that their wish for help is rejected. Access to help from these services is mostly available within the specialised health services, where the criteria for receiving help include a cost/benefit analysis based on referrals from other professionals in the primary health system (Norwegian Directorate of Health, 2015). Therefore, these services are not easily accessible. Bereaved people with needs for help may restrain themselves from seeking this help because of the notion that their relation to the deceased disenfranchises them from needing or seeking help, or they may be rejected if their needs are not considered severe enough. Thus, the finding that the needs for help are only partially met and that help is unequally distributed can be explained both by the grief hierarchy and the accessibility of services.

Help from some service providers predicts higher satisfaction

Those who received help from crisis teams or a psychologist/psychiatrist were more often satisfied with the help than those who received help from other services. These services were also those that participants missed the most. That help from a psychologist/psychiatrist was influential can be understood by the type of help these professionals provide and whether they have the tools to address and treat forms of complicated grief and posttraumatic stress. The term psychologist is used synonymously with psychotherapist in Norway (Lye, 2008). The academic profession of the therapist seems to be unimportant for the outcome of therapy (Fawcett & Crane, 2013; Simmons & Doherty, 1998). We can reasonably argue that the bereaved want competent professional help focusing on psychological and emotional needs. Thus, services that predict higher satisfaction with help and that participants want more of probably entail early help, flexible help and an emphasis on psychological and emotional needs — which is in line with earlier findings on what kind of help the traumatically bereaved want (Dyregrov, 2002; Dyregrov & Kristensen, 2021).

That higher satisfaction is associated with help from specific services might be related to the finding that participants bereaved a long time ago were more likely to be satisfied with help than recently bereaved participants. As the funding of health and welfare services has increased in recent decades (Norwegian Ministry of Finance, 2021), it is unlikely that the finding is due to decreased access to and the quality of professional help. A more likely explanation is the change in the public discourse, which shows that expectations on health and welfare services have increased (Anvik et al., 2020). Psychosocial crisis teams did not exist 35 years ago (Dyregrov & Dyregrov, 2008), whereas they are now the norm in Norwegian municipalities. In addition, there is an increased awareness of and emphasis on emotional needs and therapeutic help (Madsen, 2017). The increased expectations are reflected in a national guideline from 2016 recommending proactive and flexible psychosocial professional help after crises, accidents and disasters (Norwegian Directorate of Health, 2016). Thus, satisfaction with services is likely influenced by the participants' expectations, which again is influenced by the general public discourse and service organisation.

Special considerations should be paid to young bereaved

The bereaved person's age at the time of death was related to satisfaction with services in that older age predicted higher satisfaction. Help from a psychologist/psychiatrist predicted satisfaction with help better for younger bereaved than older bereaved. A possible explanation for these findings is related to age-specific variables. Older age is generally associated with higher well-being and less emotional reactivity, suggesting that older persons' emotion regulation capacities are generally better than those of younger persons (Charles & Luong, 2013; Urry & Gross, 2010). Rostila et al. (2012) found that the bereaved of younger age (18–39 years) had the highest increase in mortality risk associated with the death of a sibling, and suggested that this could be because of high stress levels, greater grief difficulties or fewer coping strategies among this group of bereaved people (Rostila et al., 2012). They also proposed that the finding could reflect the grief process in the family, where parents could be absorbed in their grief and unable to tend adequately to the bereaved sibling's needs (Rostila et al., 2012). If the younger bereaved are less robust or receive less informal support, they may be more exposed to the adverse impacts of bereavement, which means they could need more or different help than older persons. There may also be cultural and context-bound explanations to lower levels of satisfaction of the younger bereaved, as emphasis on emotional needs and expectations of help from a therapist have become more acknowledged among new generations (Madsen, 2017). That younger persons are less satisfied with the help and that their satisfaction depends more on help from a psychologist/psychiatrist can thus be related to biological/developmental factors, family-related factors and changes in culture and expectations between generations.

Participants reported a low level of received help for children in the family. This can be understood in the broader context of Norwegian health services. Until recently, children as relatives/peers have lacked recognition in policy documents and services (Norwegian Ministry of Health and Care, 2009). A new law intended to ensure that health services recognise and include children as relatives was introduced in 2010 (Norwegian Directorate of Health, 2010), and in 2017 the law was extended to include a focus on children as bereaved people (Health Personnel Act, 1999 § 10b). Thus, the lack of help to children in our sample can at least partly be explained by the lack of recognition in policy documents until recently, which again is related to the general individual-centred focus within health services and the associated professions (Kalsås et al., 2020, p. 14; Ruud et al., 2015). Another explanation is probably professionals' insecurity and lacking competence of helping bereaved children (Dyregrov & Dyregrov, 2013). Ruud et al. (2015) recommend that children and family be one of the main themes in all examinations and treatment within health services and that all services should include a child and family perspective. Dyregrov (2021) also recommends aid to families in creating open and direct communication between adults and children to help them cope and avoid the development of complicated grief reactions. Our findings show that the bereaved are lacking help for children and report low satisfaction, which suggests that an adequate child- and family-based perspective has been absent in the follow-up of the bereaved after a DRD.

Implications for practice and future research

The DRD-bereaved call for help from professional services. Services should routinely and proactively contact the bereaved and offer help if necessary. Based on our findings, we suggest that special considerations should be paid to younger age groups, especially children, and services probably need a family perspective in their follow-up to adequately reach them. The term "bereaved" should be defined broadly, including different family members, children, partners and close friends. Both psychological and biological closeness should be emphasised.

We need more knowledge of the DRD-bereaved who report a high need for help but do not receive it, and how relevant services can reach them. There is also a need for more research on bereaved people's experiences of the helping relationships, where our results only provide a basic frame. In addition, more research is essential on how children can be acknowledged and helped in their own right and as part of help efforts for grief-stricken families. Finally, in these circumstances it is often necessary that different services organise help efforts flexibly but predictably in a situation where help needs vary over time (Norwegian Ministry of Health and Care, 2015). Further central questions concern approaches where different services can successfully include different relations, operate across sectoral boundaries and provide flexible, needs-based and broad-spectrum help over time within an acceptable cost/benefit frame.

Strengths and limitations

As far as we know, this study is the largest of DRD-bereaved family members, partners and friends. It is a strength that a considerable effort was made to recruit the broadest possible sample, both geographically and in sociodemographic terms. Strengthened validity and ethical consciousness have also been achieved by close cooperation with user representatives from the target population in study development and data collection. The survey was made available for those with less digital competence by including manual forms, reducing selection bias.

The cross-sectional design is not well suited for establishing causal relationships. In terms of the findings, we therefore argue for associations, not causality. As a non-probability sample, generalisations must be made cautiously. Selection bias may be present because of geographical over-representation from the south of Norway, skewed sex distribution in favour of females, which is often the case in studies on bereavement (see Boelen et al., 2016; Feigelman et al., 2009), and above average scores on socioeconomic variables (Statistics Norway, 2020). It is documented that low scores on socioeconomic variables are associated with higher risks of opioid-related overdoses (van Draanen et al., 2020), thus suggesting that a representative sample of DRD-bereaved people would also mirror this distribution. Since our sample reported average income and above-average education level compared to the general Norwegian population, the target population must probably cope with less psychosocial resources than our study sample.

There is a likelihood of recall bias because of the 35 years separating the different losses within the sample. This may especially influence the finding that time since loss predicts higher satisfaction with help. It is also important to note that the needs of bereaved children and adolescents are reported by adult family members, which may over- or understate their needs. Some participants were related to the same deceased, but the dataset did not contain sufficient information to identify dependent observations. Finally, it was not possible to fit a complete logistic regression model with all relevant variables because of inadequate data power, which we solved using "purposeful selection" (Hosmer et al., 2013). Confidence intervals in the results of this analysis are wide, primarily due to the low number of participants who had received help from a crisis team ($n = 25$).

Conclusion

This study shows that only a minority of those bereaved through a DRD received adequate help, and help for children was rare and perceived as unsatisfactory. Younger age groups and children need particular recognition, and a family perspective from services is essential for them to be reached adequately. When assessing the help needs of the DRD-bereaved, relations of both psychological and biological closeness should be recognised, including children, siblings, extended family members and close friends. Help efforts should be tailored according to established knowledge of help that bereaved populations deem effective. Every country must establish a foundation through legislation and guidelines that enables services to help and support the bereaved adequately. In Norway, this framework is established through the guideline for psychosocial measures in crises, accidents and disasters (Norwegian Directorate of Health, 2016).

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Supplemental material

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The social health domain of people bereaved by a drug-related death and associations with professional help: A cross-sectional study

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ABSTRACT

People bereaved by traumatic deaths are vulnerable to long-lasting impairments in social health, including the quality of social relationships and the capacity to manage their social lives. In this Norwegian study involving 255 participants bereaved by a drug-related death, we aimed to investigate their social health and associations with professional help. The results of a cross-sectional survey showed that participants on average rated their social health as poor, though with large variations within the group. Participants who reported high satisfaction with professional help reported significantly higher scores on most social health-related variables. More research is needed on professional help focusing on the social health of traumatically bereaved people.

Introduction

Meaningful relationships with others are crucial when grieving; still, bereavement may lead to long-lasting difficulties in social interactions between people (Dyregrov & Dyregrov, 2008; Sajan et al., 2022). People who have been bereaved through traumatic deaths seem to be especially vulnerable to adversity in their social connection with others (Dutta et al., 2019, Dyregrov et al., 2003; McDonnell et al., 2022; Pitman et al., 2014; Sajan et al., 2022). Furthermore, studies exploring the situation of people bereaved by drug-related deaths (DRDs) show that this group also struggles with severe social challenges (Lambert et al., 2022; Titlestad & Dyregrov, 2022; Titlestad, Lindeman, et al., 2021). However, no quantitative study has, to our knowledge, investigated the social health of DRD-bereaved people until now.

According to Huber et al. (2011), social health is the third health domain besides physical and mental health. The empirical data for this study is situated at the micro-level of social health, which refers to the individual's "quality of social relationships, and the capacity to manage social life" (Cho et al., 2020, p. 3). The study investigates three dimensions on this level: adjustment to work- and social activities, perceived and obtained social support, and connecting with or withdrawing from other people.

The first dimension is how bereaved people adjust to work-related and social activities. Bereaved populations often suffer impairment in this dimension, which seems to correlate highly with complicated grief reactions (Mauro et al., 2017; Shear et al., 2016; Tal et al., 2017).

A second dimension is perceived and obtained social support. The current literature finds perceived social support important for mental health outcomes (Wang et al., 2018). Furthermore, studies show that bereaved people experience social network support as essential (Dyregrov & Dyregrov, 2008) and that emotional caring and support are most helpful (Cacciatore et al., 2021). Low perceived social support is consistently reported as a major risk factor for mental distress and complicated grief reactions after bereavement (Lobb et al., 2010; Mason et al., 2020; Scott et al., 2020). Concerning bereavement by DRD, O'Callaghan et al. (2022) reported dialogue and social support as one of three main themes in DRD-bereaved people's pathways to posttraumatic growth.

Third, connecting with or withdrawing from other people are essential social health dimensions. Bereaved people who have withdrawn from others are more

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likely to report high psychosocial distress, andprolonged grief symptoms (Dyregrov et al., 2003; Titlestad, Schmid, et al., 2021), and a recent study found significantly less psychological distress following increased social connection among bereaved people (Smith et al., 2020).

Health-related quality of life, "a multidimensional construct covering physical, emotional, mental, social and behavioral components of wellbeing and functioning" (Andersen et al., 2017, p. 3421), includes social health dimensions. Health-related quality of life often decreases significantly in the first months after bereavement, and some studies find long-term negative impacts (Liu et al., 2019; Song et al., 2010).

DRD-bereavement and social health

Some factors suggest that the social health of those bereaved by DRD may be particularly challenged compared to other traumatically bereaved people. One aspect is a severe strain on family members before the death, often including an ambivalent relationship with the drug-using family member, complex family dynamics, and withdrawal from social relationships outside the family (Lindeman et al., 2022). Another aspect is stigma toward drug using persons, which is more pronounced than stigma toward people with mental illness (Yang et al., 2017) and suicidal persons (Kheibari et al., 2022). This stigma can spill over to close relationships (Dyregrov & Selseng, 2022) and prevail after death. Two recent qualitative studies support these notions. First, an Irish study highlights how DRD-bereaved people experience challenges in family dynamics and relations with surrounding community members due to stigma (Lambert et al., 2022). Second, a Norwegian study found that DRD-bereaved parents struggled with shame, guilt, stigma, self-stigma, and challenging communication with their social network members (Titlestad, Mellingen, et al., 2021).

Still, there are many similarities between DRD-bereavement and other kinds of traumatic bereavement. Studies on those bereaved by suicides (Sajan et al., 2022; Shields et al., 2017) and parents bereaved through a child's chronic illness (Dutta et al., 2019) report that many experience problems in familial communication and social relationships. Furthermore, qualitative studies on bereavement by suicides find that stigma, shame, guilt, and blame are frequently experienced by those bereaved (Sajan et al., 2022; Shields et al., 2017), adding to a socially strenuous bereavement. These experiences seem to parallel those of DRD-bereaved people, although the pre-loss strain and stigma may disfavor DRD-bereaved people even more.

Professional help, satisfaction with help, and social health

Professional help services can influence bereaved people's social health indirectly or directly. The indirect path entails individual help to a bereaved person. The interactions in the helping relationship can then help the bereaved relate with people in their social network (Baddeley & Singer, 2009). The direct path entails including different social network members in the same meeting, for example, in a family or social network meeting (Seikkula, 2012) or bereavement support groups.

Regardless of the pathway, satisfaction with the service (Duggan & Thompson, 2011) and the alliance between helper and help-seeker are crucial in therapeutic relationships (Flückiger et al., 2018). Several studies have documented associations between satisfaction with services and better mental health and quality of life (Bamm et al., 2013; Oetzel et al., 2015; Petkari & Pietschnig, 2015). DRD-bereaved people in Norway who received professional help, reported significant variations in satisfaction with the received help (Kalsås et al., 2022). Services that provided psychotherapeutic help, or early and flexible help, were more often rated as satisfactory (Kalsås et al., 2022).

We have described the knowledge base showing that dimensions of social health often are negatively impacted after bereavement and that there are differences depending on the circumstances and manner of death. DRD-bereaved people's social health is probably vulnerable due to relational strain, stigmatization, and internalization of stigma. Professional help can open paths for connection between bereaved people and their social network members in direct or indirect ways. The alliance and service satisfaction may be one key factor in accomplishing this. Hence, we wanted to map DRD-bereaved people's social health and the relationship between satisfaction with help and social health.

Material and methods

The study is part of the END project, a Norwegian research project investigating DRD-bereaved people's experiences, psychosocial health, experiences with help and support, and professional services' way of relating to them. This study has a cross-sectional design, and

Table 1. Sample characteristics ($N = 255$) presented with (min–max), mean (SD) or *n* (%).

Variable (min–max)	Mean (SD)	*n* (%)
Sociodemographic characteristics		
Age of bereaved at the time of survey (18–80)	48 (14)	
Age of bereaved at the time of loss (5–76)	40 (15)	
Female sex		208 (82)
Educational status		
College/university		125 (49)
Senior high school		97 (38)
Primary school		32 (13)
Employment		
Working (full- or part-time)		155 (61)
Retired		29 (11)
Student		14 (5.5)
Other		58 (23)
Household income (USD)		
≤50,000		85 (34)
50,000–100,000		121 (48)
≥100,000		45 (18)
Relational characteristics		
Years since a family member's or friend's death (0–35)	8.1 (7.4)	
Relation to deceased		
Parent		95 (37)
Sibling		79 (31)
Child		25 (9.8)
Other kin		28 (11)
Close non-kin relation: partner ($n = 13$) or friend ($n = 15$)		28 (11)
Perceived closeness to deceased. Close/very close		222 (88)
Experienced devaluating comments of deceased post-loss		90 (35)
Characteristics of deceased		
Deceased age in years at the time of death (15–68)	31 (9.9)	
Deceased years of drug use before death (0–42)	13 (8.6)	

the reporting is guided by the STROBE Checklist (Von Elm et al., 2007).

Data collection and participants

A survey was administered in March–December 2018 to a heterogeneous convenience sample of 255 DRD-bereaved Norwegian family members, partners, and close friends. The recruitment of 200–300 participants was conceived as feasible and adequate for cautious generalizations of findings to the target population. All participants were over 18 years, with at least three months separating them from the loss. The timeframe of three months was chosen in line with The Regional Committees for Research Ethics policies, as including more recently bereaved participants was considered ethically problematic. The recruitment strategy entailed information letters to all Norwegian municipalities and cooperation with health- and welfare services, hospital services, treatment centers, and non-governmental organizations. In addition, recruitment was promoted through advertising in various media, information at conferences, and snowball recruitment.

Sample characteristics

The time since death ranged from three months to 35 years, with minor statistical differences between the different relationships to the deceased. Almost all participants reported that the deceased had used drugs for several years before the death. Most participants worked, studied, or were on sick leave, but with considerable differences between relations, ranging from 48% (extended family members) to 85% (siblings). A majority of 82–96% of the deceased relatives reported feeling close or very close to the deceased at the time of death, while children stood out from the others, with only 64% reporting the same. More than one-third of the participants had experienced devaluating comments concerning the deceased after the death. At the same time, within the groups of children, close friends, and partners, about half of them reported this experience (Table 1).

Questionnaires and variables

Health-related quality of life

The RAND-12 health survey is the 12-item version of the RAND-36/SF-36, consisting of four nominal variables, two three-point Likert items, and six five-point Likert items regarding the situation for the last four weeks. Examples of questions are "have you felt downhearted and blue," "how much of the time have your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?." The instrument has been validated in several countries (Farivar et al., 2007) and proven cross-culturally reliable in Norway (Gandek et al., 1998). The oblique scoring method and the mental health component score (MCS) were used for this study (Farivar et al., 2007). Seven participants had one or two missing values, which were imputed based on the value of the adjacent variable/variables measuring the same Health-related quality of life dimension. Seven participants with missing values were not included in the analysis.

Perceived and obtained social support

The Crisis Support Scale (CSS) contains seven items measured by seven-point Likert scales (Joseph et al., 1992) and has shown good reliability and validity (Elklit et al., 2001; Joseph et al., 1992). The scale consists of five items tapping positive support, one item tapping negative social experiences, and one item asking about overall satisfaction with social support. The scale gives "a consistent and meaningful picture of both perceived and obtained social support" (Elklit et al., 2001, p. 1300). The first six items were used for the frequency analyses, and the negative experience item was reversed when calculating the sum score. The five first items measuring positive support were used for the subsequent correlation and group comparison analyses. The α of the six-item scale was .706, and for the five-item positive support subscale, it was .779. Five imputations were made on the positive support subscale on participants with one missing item, based on the mean of the participant's other scores.

Work, social adjustment and social connectedness

The Work and Social Adjustment Scale (WSAS) consists of five 0–8 scored items and has shown good reliability and validity (Mundt et al., 2002). A higher sum score interprets as higher levels of impairment due to the bereavement. All five items were used for the descriptive analysis, allowing comparison with other populations. For the ANOVAs, the summary of items three and five that tap social connectedness were used. Three participants had one missing value imputed with the sample's estimated mean. The α of the five-item scale on this sample was .907; for the two-item scale, it was .798 (Pearson's $r = .663$).

Help and social withdrawal

The Assistance Questionnaire (AQ-R) has 22 items, where response alternatives are either nominal or five-point Likert items. The questionnaire is previously used in other studies with traumatized bereaved populations (Dyregrov et al., 2003; Wilson & Clark, 2005) and addresses bereaved people's need for help and received help. We used five items in this study; "Needs for help" (five-point), "Received help" (nominal), "Satisfaction with help" (five-point, collapsed to three-point for analysis), "I have withdrawn from others" (five-point), and "Others have withdrawn from me" (five-point). Further details on the professional help and services involved with the bereaved in this sample can be found in Kalsås et al. (2022).

Ethical considerations

The Norwegian Regional Committee for Medical and Health Research Ethics has approved the END research project (ref. nr. 2017/2486/REK vest). All participants were informed in writing about the project's aim before participating and were made aware of the possibility of contacting the project manager if answering the survey prompted a need to talk to someone. Furthermore, it was explained that the data would be published non-identifiable and stored on the research server at the university.

Statistical analyses

Social health was mapped through frequency analyses of RAND-12 MCS (Health-related quality of life, mental component score), WSAS (Work- and social adjustment), CSS (social support), "Own social withdrawal," and "Others' social withdrawal." For correlations between dimensions of social health and time since death, a bivariate correlation analysis was conducted. For the single five-point Likert scaled items, Spearman's rho was measured.

Concerning differences in received help, satisfaction with help, and social health, the first analysis was conducted with T-tests and Mann–Whitney U-tests, examining group differences in social health dimensions between those who had received help and those who had not received help. The aim was to determine differences in social health dimensions of people who reported needing professional help after the death ($n = 230$). The sample was stratified into those who had received professional help ($n = 124$) and those who had not received professional help ($n = 106$). The second analysis examined group differences in social health dimensions among bereaved who had reported different levels of satisfaction with help. The group that had received help was stratified into three groups based on satisfaction with help: low ($n = 23$), medium ($n = 43$), and high ($n = 55$). The analyses were conducted with one-way

ANOVAs and the Kruskal-Willis H test. All analyses were done using IBM SPSS Statistics Version 27.

Results

Frequency analyses

Mean RAND-12 scores were generally better among extended family (43.1) and siblings (42.4) than among partners/friends (35.6), parents (39.3), and children (38). Relative parallel patterns were also observed for CSS and WSAS, while children seem to have withdrawn from others to a higher degree (3.4), especially compared to extended family members (2.3). A total of 67% of the sample reported having withdrawn from others to some-high degree, and 46% reported that others had withdrawn from them to the same degree. There were only minor differences between groups in the scorings of "Others' withdrawal" (Table 2).

Correlation analysis

"Time since death" showed a small significant correlation only with RAND-12 MCS (r = .205). "I have withdrawn" correlated most with the WSAS subscale measuring social connectedness (r = .533) and showed a medium-high negative correlation with the RAND-12 mental component score (MCS) ($r = -.447$). Furthermore, the full WSAS scale and WSAS subscale correlated highly negatively with RAND-12 MCS ($r = -.722$ and $r = -.657$). "Others have withdrawn" showed small-medium correlations between r = .260 and r = .334 to all other dimensions except "Time since death." CSS, scored as a five-item positive support subscale, correlated on a small-medium level with the other scales, highest at r = .323 with RAND-12 MCS. WSAS sub = WSAS sum score of items three and five (Table 3).

Analyses comparing groups

We planned to use "Time since death" as a covariate to control for possible confounding in all following analyses. However, correlation and linear regression analyses showed no relationship between "Time since death" and dependent variables. Therefore, we decided not to include the variable.

Social health dimensions: help group versus no help group

When comparing positive social support (CSS 5-items), no significant differences in scores between the group

Table 2. Frequency analyses, whole sample and different relations to deceased.

Measure	Tot. sample ($n = 249$) M (SD) range	Parent ($n = 92$) M (SD)	Sibling ($n = 79$) M (SD)	Child ($n = 24$) M (SD)	Ext. fam ($n = 27$) M (SD)	Part/friend ($n = 27$) M (SD)
RAND-12 MCS	40.2 (12.9) 12–65	39.3 (12.9)	42.4 (12.5)	38 (12.1)	43.1 (13)	35.6 (13.3)
CSS (six items)	28 (6.9) 7–42	28.9 (6.8)	28 (6.5)	25 (8.5)	29.6 (7.2)	25.9 (5.9)
WSAS	12.7 (10.9) 0–40	14.4 (10.3)	10.8 (10.7)	12.8 (11.1)	10 (10.2)	15.1 (12.6)
Own withdrawal	2.9 (1.2) 1–5	2.8 (1.1)	3 (1.2)	3.4 (0.8)	2.3 (1.1)	3 (1)
Others' withdrawal	2.4 (1) 1–5	2.4 (1.1)	2.3 (1)	2.5 (0.7)	2.3 (1.1)	2.2 (1)

Table 3. Correlation matrix, social health dimensions and time since death.

	I withdraw	Others withdraw	RAND-12 MCS	CSS pos	WSAS full	WSAS sub	Time^{b}
I withdraw^{a}	1						
Others withdr.^{a}	.334**	1					
RAND-12 MCS	–.447**	–.239**	1				
CSS pos	–.267**	–.244**	.323**	1			
WSAS full	.501**	.298**	–.722**	–.219**	1		
WSAS sub	.533**	.260**	–.657**	–.219**	.918**	1	
Time^{b}	.014	.042	.205**	.046	–.098	–.047	1

*$p < .05$; **$p < .001$ (two-tailed). ^{a}Coefficients on "I have withdrawn" and "Others have withdrawn" calculated as Spearman's rho. ^{b}Time = Time since death.

that had received professional help (M = 24.8, SE = .569) versus the group that had not received professional help (M = 23.5, SE = .648) emerged, homogeneity of variances assumed (Levene's test $p = .517$), $t(227) = 1.53$, $p = .127$. Impairment in social connectedness (WSAS subscale) also showed no significant differences in scores between the help group (M = 5.98, SE = .436) and the no help group (M = 4.89, SE = .442), homogeneity of variances assumed (Levene's test $p = .320$), $t(226) = 1.75$, $p = .082$. Considering "I have withdrawn," the distribution of scores for the help group (M = 2.89) and no help group (M = 2.84) were similar assessed by visual inspection, and there were no significant differences between the two groups' scores, $U = 6621.5$, $z = .344$, $p = .731$. Finally, the test for differences concerning "Others' withdrawal" showed that the distribution of scores for the help group (M = 2.44) and the no help group (M = 2.28) were similar, assessed by visual inspection, and there were no significant differences between the two groups' scores, $U = 7055$, $z = .477$, $p = .262$.

Social health dimensions at low, medium, and high satisfaction with help

All analyses showed a linear relationship where social health dimensions increased with higher-rated satisfaction with help. However, not all relationships were statistically significant at $p < .05$. When comparing positive social support (CSS 5-items) with a one-way ANOVA, the group means were significantly different, $F(2,117) = 7.9$, $p < .001$, $\omega^2 = .103$), homogeneity of variances assumed (Levene's test mean: $p = .947$). Tukey HSD Post hoc analysis showed that the difference between the high satisfaction group (M = 27.2, SD = 6.1) and the medium satisfaction group (M = 23.5, SD = 5.9) was statistically significant (3.70, 95% CI [0.81–6.59], $p = .008$), as well as the difference between the high satisfaction group and low satisfaction group (M = 22, SD = 5.7) (5.19, 95% CI [1.66–8.71], $p = .002$).

Impairment in social connectedness (WSAS subscale) showed significant differences in group means, $F(2,117) = 3.26$, $p = .042$, $\omega^2 = .036$), homogeneity of variances assumed (Levene's test mean: $p = .694$). Tukey HSD Post hoc analysis showed that the difference between the high satisfaction group (M = 5.25, SD = 4.7) and the low satisfaction group (M = 8.22, SD = 5.2) was significantly different (−2.96, 95% CI [−5.76 to −0.17], $p = .035$).

For the item "I have withdrawn," the Kruskal–Wallis H test showed a statistically significant difference between the high satisfaction group (mean rank 52.15) and the low satisfaction group (mean rank 73.76), H(2) = 7.558, $p = .023$. Finally, the Kruskal-Wallis H test for differences concerning others' withdrawal showed no significant differences between groups, although close (mean rank high satisfaction group 54.46, low satisfaction group 72.52), H(2) = 4.873, $p = .087$. The distributions of scores between the different satisfaction groups on both Kruskal-Wallis tests could not be confirmed as similar for all groups based on visual inspections of a boxplot. Pairwise comparisons (Dunn, 1964) and a Bonferroni correction for multiple comparisons were made.

Discussion

The frequency analyses of the different social health dimensions showed a low mean score on the mental health-related quality of life component (RAND-12 MCS). For work- and social adjustment (WSAS), the average score suggests significant impairment (Mundt et al., 2002), and the mean score for social support (CSS) was relatively low compared to other bereaved populations (Arnberg et al., 2012). Two-thirds of respondents reported having withdrawn from other people to some-high degree, and almost half of the sample reported that other people had withdrawn from them in correspondingly degree. All scores were quite evenly distributed across different relations, although extended family scored somewhat better on all measured variables. No social health dimensions correlated positively or negatively with "Time since death," indicating that those bereaved a long time ago did not have better social health than those newly bereaved. This result suggests that social health variables do not improve substantially with time, or that the participants who lost a long time ago, reported low scores for reasons not investigated in this study. The analyses examining the social health dimensions between the groups who rated help satisfaction differently showed a positive linear relationship: higher satisfaction was associated with better scores on all social health dimensions, except "Others have withdrawn from me." These differences in social health dimensions for the groups who rated satisfaction differently might be related to the help-providing.

DRD-bereaved people's results in social health dimensions

The WSAS average score of 12.7 (SD 10.9) indicates that many participants scored at the same level as those seeking treatment for complicated grief and that a large group also had low work- and social impairment. A study including a random sample of bereaved people showed average WSAS scores of 0.8 (SD 2.4) (Mauro et al., 2017), while studies on bereaved people seeking treatment for complicated grief, have shown average WSAS scores from 19.7 to 26.3 (SD 8.3–10.1) (Mauro et al., 2017; Shear et al., 2016; Tal et al., 2017). Our sample of DRD-bereaved people thus scored averagely better than bereaved populations seeking treatment for complicated grief and considerably worse than a random sample of bereaved people (see Mauro et al., 2017; Shear et al., 2016; Tal et al., 2017).

The mean scores on health-related quality of life measured with RAND-12 MCS and social support measured with CSS were poor. Scores on RAND-12 MCS were significantly below the Norwegian norm, 40.2 vs. 51.8 (Statistics Norway, 2012), and a Danish study found higher mean scores in different groups of parentally bereaved youth measured with the SF-36 ($M = 45.4–49.6$) (Appel et al., 2019). The SF-36 MCS is highly correlated with the RAND-12 MCS (Gandek et al., 1998; Lee et al., 2008). The mean score on CSS (six items) was 28 (SD 6.9). In comparison, a large sample of bereaved Swedish people reported a mean of 30.7 (SD 7.6) 14 months after the 2004 tsunami (Arnberg et al., 2012), which is significantly better. The level at which participants reported "I have withdrawn" was considerably higher in our sample compared to people bereaved by suicides, accidents, and sudden infant deaths in another Norwegian study, respectively 67%, 45%, 50%, and 57% (Dyregrov et al., 2003). Though less stated, almost half of participants also reported that others had withdrawn from them to some-large degree, supporting findings from other studies of DRD-bereavement (Feigelman et al., 2020). Traumatically bereaved people are vulnerable to impaired social health (Dutta et al., 2019; Sajan et al., 2022; Shields et al., 2017), and we have shown that DRD-bereaved people score even poorer on many social health dimensions than other bereaved populations. Possible explanations for these results will be discussed.

Strain, stigma, and shame before and after the death

Several studies show that problematic substance use may severely impact close family members, affecting the family structure and increasing the family members' risk for different mental and physical illnesses (Di Sarno et al., 2021; Lindeman et al., 2022; Orford et al., 2010). In addition, the experience of problematic substance use is considered a "family matter" for many families, contributing to feelings of shame and guilt for being closely related to the drug-using person (Lindeman et al., 2022). As a result, many distances themselves from social relationships outside the family, and feelings of isolation and loneliness are recurring themes (Lindeman et al., 2022).

This distancing is probably partly due to processes of stigmatization that drug-using persons are subjected to (Titlestad, Mellingen, et al., 2021) and have a spillover effect on family members (Dyregrov & Selseng, 2022). Experiences of stigmatization are closely connected with feelings of shame (Luoma et al., 2013), which signal threats to social bonds (Scheff, 2006). Approach behaviors toward other people can mend this threat to social bonds and alleviate the feelings of shame (De Hooge et al., 2010). However, the difficulty of shame repair through approach behaviors may be exacerbated by stigma (Cibich et al., 2016) and cultural expectations concerning what one should keep within the family (Lindeman et al., 2022). Thus, withdrawing from others is one way people can cope with stigma and feelings of shame, and try to protect the self from further social harm (De Hooge et al., 2010).

These dynamics show how stigma at a macro level (e.g., norms, public discourse, and jurisdiction) can connect with individual and familiar strain at a micro-level (e.g., shame, withdrawal, avoidance from other people). These dynamics seem to start before the loss and may also prevail after the death

(Dyregrov & Selseng, 2022), likely impacting the social health of DRD-bereaved people negatively.

The circular causality of social health

The finding that many DRD-bereaved people also have experienced that others have withdrawn from them may illustrate how social health, including social support, is an interactional phenomenon (Lakey & Orehek, 2011). Both the interpersonal actions of the individual and other people's way of relating to the bereaved person are essential. Social network members may avoid contacting bereaved people due to their own insecurity, or because they interpret the withdrawal of the one who is bereaved as a wish to be left in peace (Dyregrov & Dyregrov, 2008). The social network members' withdrawal may be interpreted as motivated by prejudice by the bereaved person, possibly leading to a circle of misunderstanding, avoidance, and withdrawal from both parties. Bereaved people have stated that "openness" is vital for alleviating the problem; to tell the social network members their story, inform them, and clarify their needs (Dyregrov & Dyregrov, 2008). Social network members recommended the same for themselves; that is, openness from both parties (Dyregrov, 2006). Depending on the bereaved person's resources and the state and quality of the existing social relationships, some bereaved people will manage to take this responsibility themselves, thus alleviating the interaction with others. The findings from this study may suggest that many DRD-bereaved people with their social network members could need professional help to manage these problems.

Professional help and social health

There were significant differences in the social health dimensions between the group that rated the professional help as highly satisfactory versus those with low satisfaction. This finding supports a hypothesis that the level of satisfaction with professional help might positively affect most social health dimensions, although a causal or directional relationship cannot be inferred from the cross-sectional data. We have stated a hypothesis of strain, stigma, shame, and withdrawal as drivers of the reduction in social health. If a directional relationship exists, a possible explanation might be that professional help has mitigated the impairing potential of these dynamics and facilitated openness between the bereaved and their social network members. If so, this kind of help is not only immediately helpful but also aids bereaved persons in turning to other people for connection and support later.

Furthermore, given that a directional relationship is present, the finding suggests that monitoring the helping alliance and satisfaction should be adopted as an integrated part of the help provisions. This is common in psychotherapy and other therapeutic settings (Kidd et al., 2017). However, the help to DRD-bereaved people does not necessarily include a structured intervention based on a diagnosis. Good outcomes in public mental health settings may differ from a highly structured therapeutic arena (Moltu et al., 2017). For bereaved people, we argue that social health outcomes should be included.

Strengths and limitations

This study has several strengths. To our knowledge, the sample of DRD-bereaved family members and friends is the largest in a cross-sectional study in one country until now. The sampling process ensured a large variety of participants concerning relationship, age, and geography. Furthermore, the study has user involvement in the study design, data collection, and the interpretation of findings. This ensures the study's relevance for the primary stakeholder group, DRD-bereaved people. There are also limitations. Causal associations cannot be inferred from the cross-sectional design. Second, quantitative measuring of social relationships through a cross-sectional survey gives limited information on relationships and social interaction. Third, social withdrawal was reported using single Likert-scale items, and impairment in social connectedness using two items from WSAS. More complex measures would provide more nuances, for example, the newly developed "Oxford Grief Social Disconnection Scale" (Smith et al., 2020). Fourth, the sample may be biased because of self-selection and relations between participants and is skewed concerning gender, geographical representation, and above-average education level. Thus, generalization of the results to the target population must be made with some caution. Finally, the large variations in the time since death increase the possibility of recall bias and confounding variables, which makes it more difficult to assume causality.

Implications for practice and future research

Professional services should emphasize ways of working with the bereaved to improve social health dimensions. We argue that interventions that use the direct pathway, including more than one individual at a time, are likely the most effective for improving social health. Such interventions may include social network meetings and family meetings with or without psychoeducational elements, for example, social network meetings based on the "Open Dialogue" approach (Olson et al., 2014), "Systematic Early Intervention for Bereaved" (Pereira et al., 2016), or bereavement and family support groups (see O'Callaghan et al., 2022).

Since few studies have investigated early helping interventions to improve social health for bereaved people (Andriessen et al., 2019; Wittouck et al., 2011), we argue for both quantitative and qualitative studies on this topic. A longitudinal experimental study can yield important knowledge concerning possible benefits of such therapeutic approaches. A naturalistic study design is probably most feasible, where social health outcomes of bereaved populations in different geographic areas could be compared. An action research design could be beneficial in developing therapeutic approaches adapted to local sociocultural contexts. These study designs could be used independently, or they could be combined.

Conclusion

DRD-bereaved people reported poorer social health than comparable bereaved populations, and social health dimensions did not correlate with time since death. Reduced social health might be mitigated through professional help, and DRD-bereaved who reported high satisfaction with help also reported better social health. Helping measures that include social network members can potentially mitigate mutual social withdrawal and increase social connectedness. There is a need for more research on these types of helping interventions.

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ORIGINAL PAPER

Drug Death-Bereaved Parents' Perspectives on Family Interactions and Help Needs: A Qualitative Study

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Abstract

Family relations are essential for the bereaved in terms of healing and adjusting to life, especially after experiencing a traumatic death. Although 500 000 people die in drug-related deaths each year, few works focus on family interactions and the help needs of those bereaved by such losses. In this qualitative study, we interviewed 14 parents who had lost their child through a drug-related death. Through a reflexive thematic analysis, we generated three themes: *(I) considerable needs in the family become our responsibility*, capturing how parents try to mend the disrupted family system and provide adequate care for those who struggle after death, *(II) conversations that are important for family connections are obstructed*, encompassing how family members sometimes seem afraid of grief emotions and try to protect each other by not talking, and *(III) as parents, we can strengthen family connections*, encapsulating how parents create space to talk and listen to each other in the family and navigate relational challenges in maintaining relationships. The findings are discussed through the Dual Process Model of Coping with Bereavement as well as family resilience theory. Based on the results, we propose that professional family-oriented help efforts for drug death-bereaved families in two main domains should be considered. The first includes those related to the family's need and ability to adapt roles and relationships to the new reality, and the second involves those connected to creating a space and environment for emotional sharing and joint meaning-making processes in the family.

Keywords Grief · Family · Bereavement · Drug-related deaths · Loss · Drug use

Introduction

Most people consider having a family to belong to and sharing mutual care essential for healing and adjusting to life after bereavement (Dyregrov & Dyregrov, 2008). These aspects may be especially significant for those bereaved by sudden, traumatic losses, like drug-related deaths (DRDs), which increase the risk for severe impairments in all health domains (Bottomley et al., 2021; Djelantik et al., 2020; Kalsås et al., 2022; Song et al., 2010; Spillane et al., 2017). Approximately 500,000 individuals die in DRDs every year (World Health Organization, 2022), impacting millions of bereaved people. Quantitative studies have shown that many DRD-bereaved people report severe grief reactions a long time after the death and achieve low scores in relation to social health dimensions (Bottomley et al., 2021; Kalsås et al., 2022; Titlestad & Dyregrov, 2022). Furthermore, qualitative works demonstrate that bereaved parents and family members struggle with a variety of stressors like complex relationships and stigmatization, complicated emotions like anger, shame, guilt, and relief, in addition to social isolation and finding communicating about the loss challenging (Lambert et al., 2021; Titlestad et al., 2021a).

The negative personal and relational impact of a traumatic death may also affect family functioning (Walsh & McGoldrick, 2013). However, the interpersonal and interactive factors in grief have so far been understudied (Delalibera et al., 2015; Stroebe et al., 2013b). Delalibera et al. (2015) reviewed the few publications on grief and family dynamics and concluded that troublesome interactions and

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low cohesiveness were associated with worse grief and psychosocial health. Following bereavement by suicide, social withdrawal between family members is frequently reported (Sajan et al., 2021), and studies have shown that family members` reciprocal efforts to protect each other from suffering have resulted in protective silence and non-communication between parents and siblings (Adams et al., 2019; Dyregrov & Dyregrov, 2005). In terms of couples, a longitudinal study by Stroebe et al. (2013a) showed that one partner's withholding of emotional expressions to protect the other had the opposite effect of their intention, as suppressing their emotions was predictive of higher grief levels in their partner. In another longitudinal work, Buyukcan-Tetik et al. (2017) found that bereaved parents reported lower relationship satisfaction when one partner perceived that they had different levels of grief. Bergstraesser et al. (2015) explored how parents who had lost a child dealt with grief and identified that how they managed as a couple played an essential part. Coping with individual differences in emotions, perspectives, priorities, and actions were central themes, and open and continuous communication was crucial (Bergstraesser et al., 2015). Similar conclusions were drawn in a study by Dyregrov and Dyregrov (2017), who discovered that openly communicating thoughts and feelings was related to a couple's satisfaction with their relationship after losing a child.

Regarding DRDs, an analysis by Titlestad et al. (2020) showed that communication strategies such as openness and talking with others were central themes in how parents adjusted to life after the loss, and O'Callaghan et al. (2022) generated similar themes in an exploration of 17 DRD-bereaved family members focusing on posttraumatic growth. Still, complex familial relationships and challenges in communication about the loss, both within family relationships and between the family members and extended social networks, remain recurring themes in publications on this population (Dyregrov et al., 2022; Lambert et al., 2021; Titlestad et al., 2021b).

Family Resilience and the Dual Process Model of Coping with Bereavement

For this study, we define family as the people living together in a shared household, with an extended circle connected through biological/formal family ties, including those who have lived with biological family members in a relatively stable relationship over time (Koerner & Fitzpatrick, 2012). Walsh (2021) suggests that resilience in families should be assessed in terms of how they approach adverse situations, their immediate response to the situation, and their long-term coping strategies. Hooghe and Neimeyer (2012) emphasize three processes for strengthening family resilience in the wake of loss: (1) family meaning-making, emphasizing shared participation in conversations where both positive and negative feelings can be shared and meaningful shared rituals can take place, (2) open communication or emotional sharing to forge stronger bonds and increase relational intimacy, and (3) fostering relational connectedness and family cohesion.

In addition to the relational, communicational/emotional and meaning-making processes, Walsh and McGoldrick (2013) also emphasize the possible need to reorganize the family system by realigning relationships and redistributing role functions. Olson et al. (2019) use the term family flexibility to define the quality and expression of leadership and organization, as well as role relationships, relationship rules, and negotiations in the family. Family flexibility addresses questions such as who makes decisions, who is responsible for what tasks, and how these responsibilities and decisions are negotiated, expressed and executed. Addressing such topics can ensure that changed responsibilities in the family are distributed in ways that are adequately balanced with individual capacities, the needs of different family members, and the family unit.

Stroebe and Schut (2015) have developed a revised version of the Dual Process Model of Coping with Bereavement that integrates grief processing on a family level (DPM-R). A central loss-oriented family task includes how sharing emotions may reduce the family members' grief and increase family cohesion (Stroebe & Schut, 2015). Restoration-oriented tasks include how the family takes part in shared non-grief-related activities and how they manage to move on with new roles in the family. Stroebe and Schut (2015) assert that family-level stressors such as conflicts or poverty may challenge their acceptance of the changed world. For many DRD-bereaved families, such challenges will probably also include the cultural stigma associated with drug use and drug users (Dyregrov & Selseng, 2021; Titlestad et al., 2021b).

The reviewed studies consistently show that communication on the interpersonal level through sharing and openness is essential for individuals and relationships when grieving a loss. These findings are supported by family resilience theory (see Hooghe and Neimeyer, 2012; Walsh and McGoldrick, 2013) and the DPM-R (see Stroebe and Schut, 2015). However, studies also demonstrate that such interactional processes may become complicated or blocked. Families affected by problematic drug use are often severely strained, and the members frequently struggle with complex emotions, relations and loneliness (Di Sarno et al., 2021; Lindeman et al., 2021). Those bereaved by DRDs often report complicated relationships and social isolation (Dyregrov et al., 2022; Kalsås et al., 2022; Titlestad et al., 2021b). Thus, they face the double risk of a traumatic bereavement combined with difficulties connecting, communicating and receiving support in their family. To our knowledge, no existing studies focus primarily on DRD-bereaved people's interaction and help needs on a family level. Hence, this analysis aims to generate knowledge regarding those help needs based on DRD-bereaved parents' reflections on family interactions.

Method

This study is part of the Norwegian END-project that started in 2017. The project focuses on DRD-bereaved people's psychosocial situation, their help needs, the help and support provided, and health and welfare services' way of relating to them.

Recruitment and Sample

Between March and December 2018, 255 DRD-bereaved family members and close friends/partners from across Norway were asked to complete a survey. Of these, 95 were parents, 75 agreed to be contacted for individual interviews, and 14 were interviewed. Inclusion criteria were that participants spoke fluent Norwegian and that the death had happened at least three months before recruitment. The parents were recruited based on the following variables in order of priority: gender, place of residence (including northern/southern/western/eastern parts of the country and urban/rural areas), a variety of ages above 18 years, a range of durations since the death occurred, and parents of deceased children of both genders and various age. Table 1 presents background data of the participants.

Table 1 Characteristics of participants (N=14)

Variable (min-max)	Mean (SD)	n
Age (45-75)	58 (8)	
Age time of loss	55 (8)	
Years since death (1-16)	4 (4)	
Gender. Female		7
Educational status		
College/university		11
Senior high school		3
Relational status. Married/cohabiting		12
Living with the other parent of deceased		2
Residency. Urban		6
Part of the country. Southern		10
Employment		
Working (full- or part-time)		9
Retired		3
Student/Other		2
Household income. USD		
≤50'		1
50'–100'		9
≥100'		4
Perceived closeness to deceased. Close/very close		13
Characteristics of deceased		
Sex. Male		10
Age time of death	27 (9)	
Years of drug use	12 (9)	
Manner of death		
Unintentional overdose		9
Intentional overdose (suicide)		1
Drug-related disease, accident or violence		2
Manner uncertain		2

All parents reported that the deaths had happened suddenly. One mother had lost two of her children to DRDs, and two parents in the sample had lost the same child but had been divorced for several years before the death. In two cases, the other parent was dead, and in 10 cases, the interviewed parent was no longer a partner to the other parent. In these 10 cases, the break-up occurred before their child's death. At the time of the interviews, 12 parents had grown-up children. Seven parents had grandchildren; in five cases, some or all of these were the children of the deceased. Most of the grandchildren were under the age of 18 years, and only two children of the deceased were adults at the time of the interviews.

Semi-Structured Individual Interviews

The interviews were conducted by three researchers in the END-project between August and December 2018 (clinical social educator Kristine Berg Titlestad, sociologist Kari Dyregrov, and psychologist Sonja Mellingen). The semi-structured interviews followed a guide with five overarching topics based on theory and previous research on traumatically bereaved populations: (1) time before the death, (2) the period after the death and the grief process, (3) stigma and self-stigma, (4) experiences of support and help, and (5) coping and posttraumatic growth. The interview guide was calibrated through a pilot interview with a DRD-bereaved parent conducted by the team's senior grief researcher (K.D.) with all other interviewers present, followed by a discussion with the interviewee and the interviewers.

The interviews took place in private settings selected by the participants. Nine interviews were conducted at the participant's home, four at their work office, and one in a hotel. The form of the interviews was fairly open, first and foremost following the interviewee after the initial question asking who the deceased was and the nature of the interviewee's relationship with them. However, all the interviews included the topics mentioned above. The interviews lasted from 1.5 to three hours, including breaks. The interviews were audio-recorded and transcribed verbatim by a research assistant. Transcripts covered 431 single-spaced pages; each interview ranged from 20 to 39 pages. When half of the interviews had been conducted, the interviewers exchanged experiences and calibrated future interviews based on notes and experiences.

For sample selection and size, we drew on Malterud et al. (2016) proposals of criteria for determining information power, which depends on the study aim, sample specificity, use of established theory, quality of dialogue and analysis strategy. The study aims for the interviews were broad, encompassing all the aims of the END-project. Thus, only a limited part of the interview data was related to the current study. The sample specificity was high, as the parents belonged to the target group and had considerable variations in experiences. The study did not rely on a solid theoretical background, suggesting a need for a larger sample to obtain sufficient information power. We perceived the quality of the dialogues of the interviews as ranging from medium to very high. Finally, the in-depth and primarily experiential-hermeneutical analysis strategy in a reflexive thematic framework requires fewer participants than, for example, a cross-case analysis. After assessing the need for further interviews after 13 were conducted, one last interview was conducted to even the gender distribution in the sample. This final interview contributed only marginally to new knowledge; thus, we decided satisfactory information power was obtained.

Individual interviews were preferred over relational interviews because of their purpose and feasibility. Most topics covered in the interviews were of a personal character, which we found to be best approached in an individual setting. The process of reaching a sample with diverse individual demographic characteristics was demanding, and we prioritized individual over relational diversity (e.g., parents of the deceased that still lived together, relationship between split-up parents that would allow joint interviews etc.). Furthermore, interviews with parents were chosen instead of, for example, siblings, as parents often are in an empowered position vis-à-vis help services due to their position in families and the “grief hierarchy” (cf. Robson and Walter, 2013). In addition, parents often take the initiative for other family members, especially adolescents, to access help services (see Andriessen et al., 2019; Rickwood et al., 2015). Thus, the parents` experiences and views are of special importance when assessing whether family-oriented help efforts might be needed and feasible.

Analysis

The analysis followed the guidelines for reflexive thematic analysis (Braun & Clarke, 2022). An experiential-hermeneutical approach guided the analysis, in which we aimed to understand the help needs of the parents based on an intimate understanding of how they experienced the phenomena of family interactions (Braun & Clarke, 2022). The first, second, and last author read all the interviews. The first author conducted all the coding, shared the codebook with the other authors, and adjusted the codes and themes based on discussions between the researchers.

The research question addressed how the need for family-oriented help could be understood through DRD-bereaved parents’ reflections on family interactions. The analysis was inductive, explorative, and developed from a semantic interpretation to a more latent one as the wholeness of the data and codes provided more context for the data segments (see Braun & Clarke, 2022). Hence, the final codes’ analytic approach is in the middle of the semantic and latent coding range. All the interviews were read in the familiarization phase (Phase 1), with any reflections and questions noted. In the second reading, highly relevant passages that dealt with family life and interactions were highlighted but not coded. Phase 2, involving coding, was conducted through a close third reading of the interviews, emphasizing the previously highlighted segments. The process and evolvement of the codes and labels were carried out by thoroughly undertaking the coding process twice, followed by a light rereading of the code labels and segments and a discussion with the co-authors. The recursive process involved moving back and forth when developing the themes in phases 3-5. Finally, we arrived at three themes that included 50 codes. These were then checked against the suggested theme evaluation questions outlined in Braun and Clarke (2022). All coding was undertaken by the first author using NVivo 1.6. The theme development encompassed both manual labor with paper and the NVivo software.

Ethical Considerations

The Norwegian Regional Committee for Medical and Health Research Ethics has approved the END research project (ref. nr. 2017/2486/REK vest). All participants received written information about the project’s aim before participation and were verbally informed about the study’s purpose and methodology at the start of the interviews. Furthermore, it was explained that the data would be stored on the research server at the university and published in a non-identifiable form. The parents provided written consent for participation and were informed that they could withdraw from the process at any time and demand the deletion of their data. The inclusion limit of three months since loss and the interview procedures followed experiences from co-author and project leader K.D.`s comprehensive research on traumatically bereaved populations (see Dyregrov, 2004; Dyregrov and Dyregrov, 2008). The participants were given information, including the project leader`s phone number and e-mail address, and invited to make contact after the interviews if they needed follow-up. All the parents reported positive experiences related to their participation.

All the interview citations have been anonymized by changing any recognizable elements, including given names. In addition, verbose oral speech and fillers irrelevant to the current themes have been removed from the quotes, taking care not to undermine the authenticity.

Trustworthiness

Lincoln and Guba (1985) propose that credibility, transferability, dependability, and confirmability indicate the trustworthiness of qualitative research. Measures to achieve adequate credibility were the first author's writing of a self-reflexivity note on both personal, functional and disciplinary reflexivity (see Braun and Clarke, 2022; Wilkinson, 1988) in advance of reading the interviews, increasing the awareness of own prejudgments before analyzing the data. Furthermore, the process of reflexivity was ongoing throughout the analysis by continuously writing a reflexive journal, ongoing discussions on analytic choices and coding with the last author (K.B.T.) and two joint discussions with all authors.

The authors have various disciplinary backgrounds that were drawn upon to ensure a breadth of perspectives in discussions: Ø.R.K. and S.K.L. are social workers and family therapists with twenty years of experience within substance use treatment and rehabilitation, L.T.F. is an MD, clinical specialist in family medicine who also has lead research projects in substance use and health, K.D. is a sociologist highly specialized in grief research, and and K.B.T. is a social educator with a PhD on parents` grief after a drug-related death. To illustrate reflexivity, all codes and coded data segments were revised after the first joint meeting, as they did not adequately capture the relational aspects the research question aimed to capture. Furthermore, the development of themes also resulted in discarding the initially developed themes, as Ø.R.K. and K.B.T. evaluated them as too deductively oriented. Another feature of credibility, prolonged engagement (cf. Lincoln and Guba, 1985), was ensured through media appearances by the project leader and project group members and a countrywide conference where members of the study population were invited free of charge. These events early in the research project were crucial for building trust in the study population.

Table 2 The research question, theme titles, and theme descriptions

How can drug death-bereaved families' needs for family-oriented help be understood through bereaved parents' reflections on family interactions post-loss?

Theme	Description
I. Considerable needs in the family become our responsibility	The family and its members often have comprehensive needs. As parents, we must provide adequate care for the children and those who struggle after the death. The scarcity of integrated help for the family and its members exacerbates our responsibility.
II. Conversations that are important for family connections are obstructed	Family members are sometimes afraid of grief and difficult emotions like bitterness and blame, and we try to protect ourselves and each other by not talking. I also see that other family members struggle, but I am unable to reach them.
III. As parents, we can strengthen family connections	Family is the most important element in adjusting to life, and we create space to talk and listen to each other, try to be open in our communication, and navigate challenges like blame and a scattered family structure by maintaining relationships.

Dependability is heightened by an audit trail that has described all research steps. Confirmability was achieved through the discussions and reflection with the other researchers who had read all the interviews (K.B.T. and K.D.), and transferability was achieved through the thick descriptions with context information.

Data Availability Statement

The interview data that support the findings of this study are protected and not available due to ethical obligations and data privacy laws.

Results

We generated three themes as a result of our analysis of the parents' reflections (Table 2):

I. Considerable needs in the family become our responsibility.
II. Conversations that are important for family connections are obstructed.
III. As parents, we can strengthen family connections.

I. Considerable Needs in the Family Become Our Responsibility

This theme captures the parents' expressions concerning the challenges the family and family members faced after the loss and how the parents often took responsibility for attending to different family members' needs. These challenges were often stated when discussing the needs of children in the family, mainly the parents` grandchildren or the sibling(s) of the deceased.

Many parents expressed a need for adjustment in the family structure to ensure adequate care for children, taking great responsibility for such needs, sometimes even becoming their parentally bereaved grandchildren's foster parent. Some parents experienced overwhelming tasks, like this mother who cared for three parentally bereaved grandchildren:

> (…) and then I was a mom for three more with completely different needs. And (…) they had a complicated relationship with their mom, and the boy to the father. He has not seen his father in many years, and it is a process that is always difficult. And then (sigh), I felt I had octopus arms with hands in all directions. And then I was supposed to satisfy all kinds of things, and I was quite overstretched. Both physically and mentally. (Emma, lost daughter).

Many parents clearly stated the needs of different family members and the family unit. In addition to the deceased person's children, the deceased's siblings were highly prioritized in many parents' care focus. The parents recognized that many siblings faced struggles connected to the loss, and although they tried to reach the siblings in various ways, the task was often difficult. Still, the parents shared hardly any examples of family-oriented professional help that aided connections within the family. For example, Clare had a daughter with substance use problems who also struggled with grief after her brother's death. Clare continuously tried to enter a dialogue with her daughter regarding her struggles but did not feel she could reach her. She stated that she had missed that some professional service had involved them both in conversations: "(…) because I think that if it comes from me (…) it is more resistance in her than if someone had contacted us and said that they can offer conversations for each of us, and one joint conversation, or something like that".

Some parents noted that other family members did not receive help from health and social services in their own right either, illustrated with Reese's experiences with her general practitioner:

> No, he is concerned with me, yes, he is. But no one else, so my husband (the step-father) has no one, really. (…). Marion (the child of the deceased) has no one either, it's just me, and we talk, but not so often, because her grief is something completely different. (Reese, lost son).

The health and social services' lack of focus on the family system and other family members left the parents responsible for trying to meet their family members' needs. Several parents seemed very used to taking such responsibility through a role as one who watches out and cares for others. For some parents, a tendency to protect other family members from their own grief seemed to accompany this role. This phenomenon was sometimes expressed in a somewhat contradictory way, where parents missed support in the family but also were afraid to enter a situation where others might feel that they had to care for them:

> I actually miss someone who can meet me and let me unload, but I haven't got that, my husband cannot do that. Right, he would not have known what to do with it (…), and if I had collapsed in his arms, I think he would have become terrified as a matter of fact, and I cannot do that to him. (Reese, lost son).

Overall, many parents considered the family's and family members' needs to be comprehensive, and several took great responsibility for fulfilling those needs. Few had received integrated help for the family, which increased the workload on the parents. In addition, several parents seemed to assume the role of one who should care for others, protecting other family members from their own grief and needs.

II. Conversations that are Important for Family Connections are Obstructed

This theme captures how interactional processes that might be essential for maintaining or deepening connections within the family were obstructed by difficulties in talking about the loss, grief, and deceased's life with family members. Approximately half of the parents reflected on how conversations regarding their child and ensuing grief were impeded. Several parents said family members avoided the topic and sometimes failed to respond when they expressed feelings of grief or talked about the deceased. In a few cases, they could not talk about the death and the hard feelings at all:

> And I think many of them, my siblings and sisters in law and others I know, and my mother doesn't talk, she doesn't ask anything. (…) I must say that I have missed it, of course it is hard to talk about, but at the same time, when people actually do not comment that you have lost a son or a situation like this, don't comment it at all, that also becomes very strange. (Vera, lost son).

Fear of grief and "hard feelings" were most frequently mentioned as possible reasons why the parents did not find space to talk about the loss with family members, as well as difficulties in finding the words to talk about it together.

Some parents felt left in the dark concerning other family members' stances, so they assumed their intentions and reasons without them being voiced. Many assumptions about the family members' reasons for avoiding the topic were positively connotated, like wanting to protect the parent from hard feelings. In addition to assuming protection as the rationale for family members' avoidance of bringing up the person who died and the grief, some parents also noted that they used the same reasoning for avoiding the topic themselves.

Sometimes, bitterness and blame were represented as dangerous elements in conversations and family connections. In most cases, this was somewhat vaguely mentioned as an underlying fear inhibiting conversations, but there were also cases where this was explicitly noted. For example, one father said that his ex-wife's blaming of him was the triggering cause for their failure to talk to each other about their remaining child after the death: "(…) You understand why, when the mother started a meeting by stating that I am one out of two people who have killed our son (…)". (Christian, lost son).

Many parents also talked about family members who struggled with their own grief and/or psychosocial difficulties. Sometimes, the parents had been unaware of these struggles, and at other times they felt powerless to help their family member. The former was especially linked to the role of step-parents, where some parents were not aware of how they struggled although they had been deeply integrated with the family for a long time: "Then I just see that the tears (of my partner) flow, I sat here, and he sat here: 'I am not fucking allowed even to grieve'". (Emma, lost daughter). The feeling of powerlessness in helping other family members was especially stated concerning the deceased's children and siblings. The parents expressed awareness of their struggles but did not manage to reach them: "She (step-daughter) sits with a feeling of guilt in one way or another. I've said that you must not do that, but it sits deep in her, so she struggles really hard". (Patrick, lost daughter).

Overall, the parents talked about how obstructions to important conversations about the deceased, the loss, and the bereavement were assumed to be rooted in a fear of eliciting grief reactions and hard feelings like bitterness and blame. Several parents discussed how they avoided speaking about their grief and showing their vulnerability to other family members. Finally, some parents shared experiences of problems in reaching those family members who struggled after the death, and sometimes a lack of awareness of these struggles.

III. As Parents, We Can Strengthen Family Connections

The last theme expresses how parents try to navigate family life to maintain or deepen family connections, often successfully. Experiences of togetherness as family members and growing closer as a family, as well as bonds with grandchildren, all had major contributions to the parents' experiences of purpose and their quality of life. Several parents highlighted the importance of creating space to talk and listen to each other, and create open dialogue about the situation and the loss, like Ralph who had lost his son: "I think, no matter what, I do mean it is important to talk about it, the worst you can do is not talk about it. No matter what".

Some parents shared experiences of family members expressing an ambivalent or strained relationship with the deceased, such as shamefulness regarding their drug use and lifestyle. As family members consequently had vastly different grief reactions, creating space to talk and listen was associated with acknowledging such differences in feelings about and relations to the deceased.

Some parents described a somewhat fragmented family structure. Most parents were divorced from the other parent of the deceased. In the cases where the deceased had children of their own, the deceased son or daughter was most often not committed to the main care of those children before their death. Sometimes the parents assumed the role of foster parents temporarily or permanently, which challenged the family structure and cohesion. In another case, the parent did not know she had a grandchild until after her own child's death. Still, many parents managed to navigate these structural challenges and create or maintain good connections.

Several parents also described how they tried to navigate the threat of blame distribution in the family, trying to keep it from creating conflicts or distance from each other. This motivation was clearly stated by Jeremy, reflecting on the communication with family members and relating it to the son`s diary notes:

> (…) You could very well enter a state of bitterness, it is clear that there were a whole lot of questions and critical questions at times. (…) I am actually the only one who has read these (diary notes). I have just told them that I have them, and you can read them if you want, no problem. But the catch is that suddenly you might start with some distribution of blame, and then it is a bit like… I say that nothing good comes from it. (Jeremy, lost son).

In addition to reflecting on different ways of adjusting interaction in the family to navigate dilemmas and threats to the family connections, approximately half of the parents had experiences of not needing much help from other sources when they felt that relations in the family and social network functioned well. Margaret, who lost her son, illustrated this experience when describing her relationship with her grown-up children and their families: "(…) we really are quite close, so we haven`t needed so much else than that.".

Overall, the parents reflected on their efforts to maintain and strengthen family connections by creating space to talk and listen to each other and being open in family communication. Some parents also talked about how they navigated challenges like blame and bitterness in family interactions by being conscious of how they talked about the loss and the grief within the family. Finally, approximately half of the parents interviewed experienced a low need for outside help from health and social services when they perceived family relations as safe and supportive.

Discussion

The generated themes, (I) Considerable needs in the family become our responsibility, (II) Conversations that are important for family connections are obstructed, and (III) As parents, we can strengthen family connections, reflect both barriers to family connection and flexibility and the agency of the DRD-bereaved parents in positively impacting the family environment.

Theme I, Considerable needs in the family become our responsibility, is a finding that seldom is reported in other studies on traumatically bereaved parents, although role changes within the family often are a consequence when losing a family member (see Walsh and McGoldrick, 2013). The finding might be related to the time before death, as many parents had lived with problematic drug use in the family for years. Experiences of overwhelming stress and responsibilities have been reported in many studies on parents affected by substance use (cf. Di Sarno et al., 2021; Lindeman et al., 2023; Lindeman et al., 2021; Orford, 2017; Titlestad et al., 2021b). Furthermore, many parents in the current sample have previously reported being in constant preparedness for a long time before the death, "prepared to step in if their child needed help, while putting their own life on hold" (Titlestad et al., 2021b, p. 5). Similar experiences have been described in a metaetnography comprising several studies on substance use and family life, reporting that parents often "expressed guilt caused by a sense of never-ending responsibility for the adult child" (Lindeman et al., 2021, p. 8). Concerning other family members, a study focusing on DRD-bereaved siblings' experiences before the loss, reported that the siblings often tried to balance the family environment and functioning by not taking significant space in the family (Løberg et al., 2022). Thus, the pre-loss stress imposed on the family members and the consequent family adjustments probably affect the family flexibility and parents' experienced responsibilities also after death. The post-loss needs within the family might underscore these responsibilities even further.

Theme II, Conversations that are important for family connections are obstructed, resonates with findings from a recent study on DRD-bereaved siblings, who reported that the siblings often relied on themselves post-loss, not sharing difficult emotions and experiences with family members due to challenging family relations (Dyregrov et al., 2022). The theme also echoes findings from studies on bereavement by suicide, where obstructions to family conversations concerning the loss are frequently reported (see Sajan et al., 2021). For example, Chapple et al. (2015) discussed how sharing emotions concerning self-inflicted deaths seems especially challenging. Furthermore, parents in the current study described mutual avoidance of conversations on loss-oriented topics to protect the other family member from pain, which resonate with findings of protective silence reported in many studies on suicidal deaths (Adams et al., 2019; Sajan et al., 2021).

Still, "why"-questions are especially stated after deaths where the deceased are perceived to bear responsibility for the death (see Dransart, 2013; Pritchard & Buckle, 2018), including DRDs (cf. Titlestad et al., 2020, 2021a). Such questions prompt meaning-making processes, which are highly interpersonal (Neimeyer et al., 2014), and make social sharing especially important after these kinds of bereavements. The absence of emotionally oriented conversations is most likely a driver for social withdrawal (see Rimé, 2009; Rimé et al., 2020), frequently reported after both suicidal deaths (Azorina et al., 2019; Sajan et al., 2021) and DRDs (Kalsås et al., 2022). Thus, the theme Conversations that are important for family connections are obstructed, has important implications for the DRD-bereaved families` potential help needs.

Theme III, As parents, we can strengthen family connections, align with studies concerning social processes that people in bereaved families find helpful. The theme includes creating space to talk and listen to eachother, being open in communication, and navigating relational and emotional challenges while maintaining relationships. Openly communicating emotions and feelings regarding the loss and the deceased, as well as own needs, are rated as an important self-help strategy for many bereaved people (Dyregrov, 2004). This way of communicating is also consistently associated with better individual and relational adjustment to loss (see Bergstraesser et al., 2015; Dyregrov and Dyregrov, 2017; Stroebe et al., 2013a). Thus, this theme captures the parents' agency in impacting their own psychosocial situation and the family cohesion after the death.

Clinical Implications

Based on these findings, we suggest approaching the family-oriented help needs of such families through two main frameworks (Table 2). The first is the Dual Process Model of Coping with Bereavement - Revised (DPM-R), which includes family-level coping (Stroebe & Schut, 2015). The other framework is based on family resilience, understood as the family's capacity, as a functional system, to withstand and rebound from disruptive life challenges (Walsh, 2021, p. 256). In this section, we use the term "family-oriented help" denoting help from professionals formally trained in facilitating multi-actor dialogues and understanding family interaction and structure. Family-oriented help could, for example, be provided by professionals trained in systemic family therapy (Wampler et al., 2020) or Open Dialogue (Seikkula, 2005).

The model suggests two paths for assessing and approaching family-oriented help needs based on theory and findings in this study. The white boxes are derived from theory based on the DPM-R (see Stroebe and Schut, 2015) and family resilience (see Hooghe and Neimeyer, 2012; Olson et al., 2019; Walsh and McGoldrick, 2013). The row of dark gray boxes are the themes from the current study.

The theme "Considerable needs in the family become our responsibility" denotes processes that might indicate or lead to "Unbalanced family flexibility". In parallel, "Conversations that are important for family connections are obstructed" denotes processes that might indicate or lead to "Decreased family connections". "As parents, we can strengthen family connections" denotes the bereaved parents` efforts to strengthen family connections and flexibility. The double arrows between the outcomes of family flexibility and family connections, illustrate the likely interaction between these processes. Finally, "In need of family-oriented help" follows from "Unbalanced family flexibility" and "Decreased family connections", illustrating that the family might need family-oriented help if they struggle in one or both of these domains.

Restoration-Oriented Tasks: Assessing Family Needs and Renegotiating Family Interactions and Roles

The right path of the model concerns matters of family structure, roles, and flexibility; matters vital for moving on as a family after the loss, i.e. restoration-oriented tasks (see Stroebe and Schut, 2015). The DRD has disrupted the

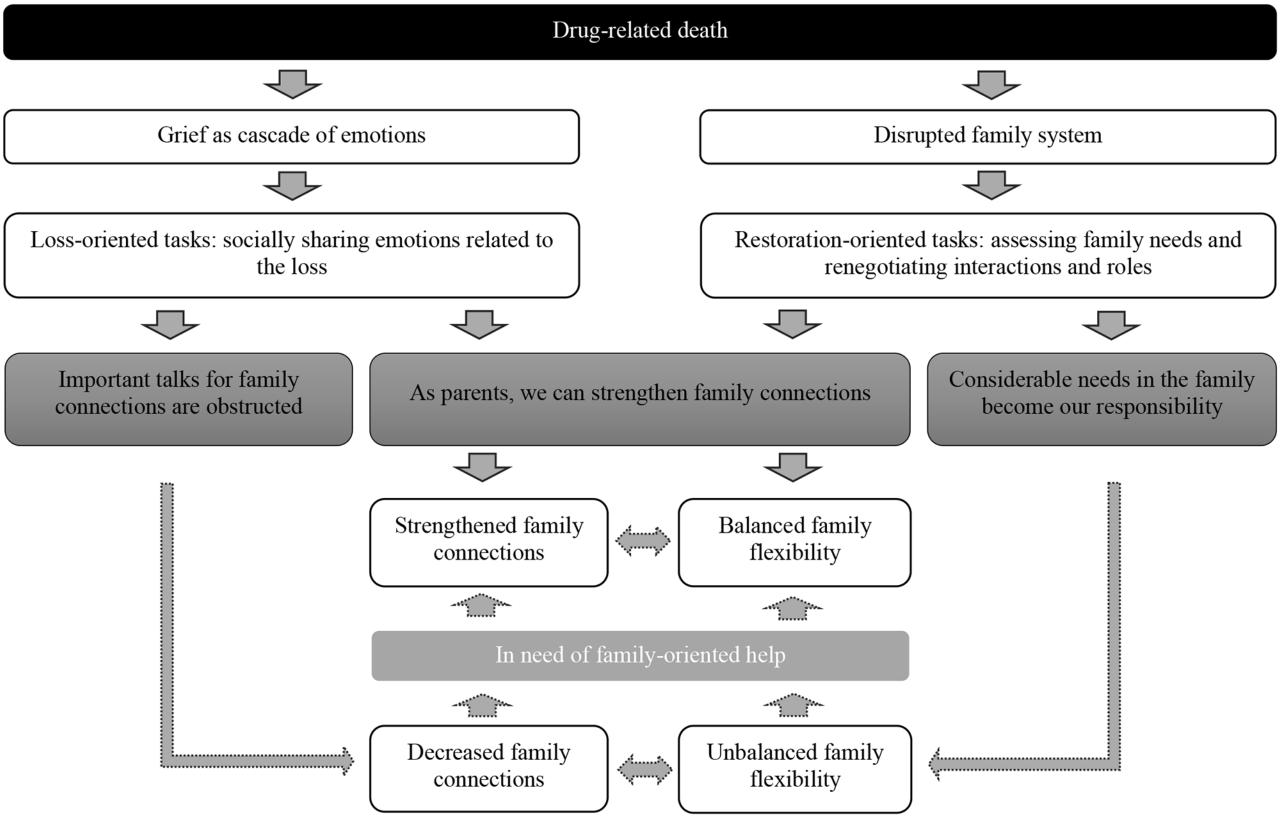

Fig. 1 The family-level processes following DRD and potential help needs

family system, and the considerable needs of the family and family members must be met. If the adjustments to balance the individual family members' needs and caretaking capacities are made appropriately, balanced family flexibility will probably be achieved (see Olson et al., 2019; Walsh and McGoldrick, 2013). The considerable needs within the family and the parents` experienced responsibility can be a barrier to adequate adjustment.

Our findings indicate some central questions in making such adjustments: who should have daily care of the children of the deceased? Who should provide adequate support to the ones who take on these responsibilities? How can the remaining sibling(s) get the support they need? Should I be the one to whom others in the family come with their needs, or is there more room for reciprocity? What are the barriers to reciprocity and how could we find a balance in our family? To whom can I turn to with my grief and need to share emotions and experiences? Could I show (more) vulnerability to any of my family members, and might that possibly open up new ways of being together in the family? How can we facilitate safe spaces for such sharing? How much should the children be shielded or "see" my grief, and how should I approach and support their grief?

Loss-Oriented Tasks: Socially Sharing Emotions Related to the Loss

The social sharing of emotions between family members following a loss is a vital part of meaning-making and can help maintain or increase family connection and cohesion (see Hooghe and Neimeyer, 2012; Rimé et al., 2020). Based on our findings, obstructions to social sharing seemed linked with family members' fear of raising hard emotions, their insecurity in expressing them, and how to deal with them. When family members experienced these obstructions to emotional sharing, some families seemed unable to create the space to talk and listen to each other.

Family-oriented help efforts could aid family members in addressing necessary topics and endure, relate, and respond to the emotional expressions that arise when doing so (see Seikkula and Trimble, 2005). When helping with the social sharing of emotions and meaning-making processes, therapists should be reflective on the family members` different need to share and their ability to listen (Hooghe et al., 2018), and accommodate for different family environments and cultural norms (cf. Li et al., 2023). If conducted competently, facilitating such processes could widen the family members' tolerance of complex emotions and increase connectedness between family members, increasing the family members` ability to address and explore such topics without professionals at a later stage.

Taken together, we suggest that family-oriented help might aid DRD-bereaved families in addressing family flexibility (restoration-oriented task) or the social sharing of emotions (loss-oriented task) if they struggle to do so independently. Furthermore, we suggest that such help is provided within a family resilience framework, viewing family members as "valued partners and essential in addressing their problems" (Walsh, 2016, p. 136) and advocating a non-pathologizing perspective with corresponding demands for non-stigmatizing language (Walsh, 2016). A family resilience framework can challenge the implicit or explicit notion that there is something "wrong" with the family when suggesting family-oriented help interventions (see Haley, 1997; Walsh, 2016). Given the already present threats of stigma, guilt/blame, and shame in many DRD-bereaved families (Titlestad et al., 2021a, b), such sensitivity may be crucial.

Limitations and Future Directions

Strengths of this study include a purposefully recruited heterogeneous sample of DRD-bereaved parents who were interviewed in safe settings with an interview structure co-designed with a participant from the target population. However, some limitations must be considered. The interviews explored several aspects of the parents` experiences in addition to family-oriented topics, as the knowledge of experiences with drug-related bereavement has been very scarce. Interviews focusing solely on family themes would have provided richer data for answering our research question. The research question has only been answered by interpreting the parents' reflections. Including other family members would have generated more nuanced and possibly different answers (cf. Dyregrov et al., 2022).

We did not have the opportunity to include the participants in the analysis and writing of the report through member checking, which would have enhanced the study`s trustworthiness. It should also be noted that most parents were divorced from the other parent. Some parents expressed a close relationship, while others noted a conflictual relationship with their ex-partner. Thus, the divorce`s impact on the information shared in the interviews is probably multidirectional. Finally, although the sample was heterogeneous in some aspects, it was homogeneous regarding ethnicity, sexual orientation and the parents' household income and education, which were somewhat above the Norwegian norm. This homogeneity means that the transferability of the findings has limitations.

As both this and a previous study from Norway show that family-oriented help is scarcely available for this population (Kalsås et al., 2023), we recommend that future investigations focus on family-oriented needs and help interventions. Such works could include the feasibility of screening for family functioning and coping in bereaved families, for example, using the circumplex model (Olson et al., 2019) or the Walsh Family Resilience Questionnaire (Duncan et al., 2021). Furthermore, analyses of help interventions at the dyadic, parental, or family levels are lacking for all bereaved populations (Baumann et al., 2022; Dias et al., 2019). Considering the complex ethical and practical domain of bereavement, families, and help-providing, a variant of a participatory action research design could be the most ethically sound and flexible method for developing family-oriented therapeutic help practices that meet the population's needs.

Conclusion

The current study has identified processes showing DRD-bereaved parents` agency in strengthening family connections and barriers to family connections and flexibility in the bereaved families. The barriers were related to the parents` experiences of (a) responsibility for highly demanding needs in the family and (b) obstructions to loss-oriented conversations where emotions are shared. We have argued that these barriers might relate to the impact of problematic drug use on the family unit before death and the parents` adjustment to this situation. Furthermore, the findings are discussed from the theoretical perspective of The Dual Process Model of Coping with Bereavement and family resilience theory. Based on the findings of this study and the risk of severe psychological and relational difficulties after traumatic deaths, we recommend considering family-oriented help for DRD-bereaved families in two domains. These include, first, the family's need and ability to adapt roles and relationships to new tasks, such as, for example, the caretaking of children. The second relates to creating a space and environment for emotional sharing and joint meaning-making processes between family members.

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Data Availability The interview data that support the findings of this study are protected and not available due to ethical obligations and data privacy laws.

Declarations

Competing interests The authors have no competing interests to declare that are relevant to the content of this article.

Compliance with Ethical Standards The Norwegian Regional Committee for Medical and Health Research Ethics has approved the END research project (ref. nr. 2017/2486/REK vest). All participants received written information about the project's aim before participation and were verbally informed about the study's purpose and methodology at the start of the interviews. Furthermore, it was explained that the data would be stored on the research server at the university and published in a non-identifiable form. The parents provided written consent for participation and were informed that they could withdraw from the process at any time and demand the deletion of their data. The interview procedures followed recommendations on research participation developed from work with traumatically bereaved parents (Dyregrov, 2004). The participants were given information including the project leader's phone number and e-mail address and invited to make contact after the interviews if they needed follow-up. All the parents reported positive experiences related to their participation.

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Appendices

Appendix 1: Information and consent form for participation END project

Appendix 2: The END survey

Appendix 3: Flyer with information for recruitment of participants

Appendix 4: Detailed steps in logistic regression analysis, Article I

Appendix 5: Interview guide

Appendix 6: Regional Committee for Medical and Health Research Ethics (REK) approval for the END project

Appendix 7: REK approval of extended storage and usage of research data

Appendix 8: REK approval of doctorate project with names of PhD students.

Appendix 9: Information letter to the END project`s participants concerning the extension of data usage and storage

Appendix 1

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET
ETTERLATTE VED NARKOTIKARELATERT DØD
- SPØRRESKJEMA

Dette er en henvendelse til deg som har mistet noen i narkotikarelatert død om å delta i et forskningsprosjekt. Vi spør deg om å delta fordi du er et nært familiemedlem, venn eller kjæreste til avdøde. Du har selv gitt oss navnet ditt, og samtykket til at vi kan ta kontakt, da du deltok på END-konferansen i november 2017 *eller* du har tatt kontakt med oss etter å ha lest/hørt om prosjektet i media, sosiale medier, konferanser eller via prosjektets informasjonsbrosjyre (flyer).

Bakgrunnen for forskningsprosjektet er at det i dag finnes svært lite dokumentasjon på verdensbasis om hvordan det går med de som blir tilbake når noen dør i overdoser eller andre narkotikarelaterte dødsfall. Slike dødsfall omtales ofte som unaturlige dødsfall, med potensielt økte belastninger for etterlatte. Målet for studien er derfor å fremskaffe kunnskap for å belyse etterlattes situasjon før og etter dødsfallet og foreslå tiltak for å bedre etterlattes livskvalitet og fungering. Prosjektet er i regi av Høgskulen på Vestlandet (HVL), Fakultet for helse- og sosialfag og ledes av professor Kari Dyregrov.

HVA INNEBÆRER DELTAGELSE I PROSJEKTET?

Du deltar i forskningsprosjektet ved å svare på et spørreskjema. Spørsmålene kartlegger din opplevelse av hvordan det er å ha mistet nærstående ved narkotikarelatert død. Noen spørsmål vil innhente og registrere bakgrunnsopplysninger om deg og avdøde; som alder, kjønn og bosted. I tillegg stiller vi spørsmål om hvordan livet har vært før og etter dødsfallet og hvordan dette har påvirke din livskvalitet og fungering i hverdagen. Vi vil ikke samle inn direkte personidentifiserende opplysninger, som for eksempel navn og personnummer.

Det tar ca. 40 minutter å fylle ut spørreskjemaet. Skjemaet kan du enten fylle ut digitalt via linken i denne mailen, skrive ut og fylle ut spørreskjemaet fra vedlagte fil, eller du kan få tilsendt en papirversjon direkte fra oss. Et papir utfylt skjema sender du i retur til Høgskulen på Vestlandet, Kari Dyregrov, Møllendalsveien 6, Postboks 7030, 5020 Bergen.

Et lite utvalg som besvarer spørreskjemaet og som samtykker til intervju vil bli trukket ut til intervju i etterkant av spørreundersøkelsen. Etterlatte familiemedlemmer vil intervjues enkeltvis, mens nære venner av avdøde vil intervjues i grupper med ca. 4-5 personer. De som blir trukket ut, blir kontaktet.

MULIGE FORDELER OG ULEMPER

Ny fagkunnskap om å være etterlatt ved narkotikarelatert død vil kunne bidra til bedre fysisk, psykisk og sosial fungering og forbedre støtte- og hjelpetiltak til etterlatte. Prosjektets mestringsfokus vil dessuten gi lærdom om gunstige mestringsstrategier for å leve videre etter narkotikarelatert død. Prosjektet skal også gi kunnskap til politikere og myndigheter i forhold til hva nære etterlatte sliter med, hva problemer og utfordringer er knyttet til, og hvordan dette henger sammen med hvilken hjelp etterlatte får.

For noen kan også det å svare på spørsmål i et spørreskjema om vanskelige livserfaringer skape et behov for å samtale med noen i etterkant. Dersom et slikt behov oppstår hos deg kan du kontakte prosjektleder Kari Dyregrov, tlf. 977 35 584 eller mail kdy@hvl.no

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i forskning. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke om deltakelse i denne studien, uten at det vil få konsekvenser for deg. Dersom du trekker deg fra studien etter at den er påbegynt, kan du også kreve å få slettet opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

På slutten av dette brevet finner du en samtykkeerklæring, der du kan samtykke til å delta i en spørreskjemaundersøkelse og til å bli kontaktet for å delta på intervju. Hvis du ønsker å delta, undertegner du samtykkeerklæringen og fyller ut kontaktinformasjonen. Samtykkeskjemaet sendes i retur til Høgskulen på Vestlandet sammen med spørreskjemaet dersom du velger å fylle ut skjemaet på papir.

Dersom vi i prosjektgruppen ikke hører fra deg innen ca. 14 dager etter at du har fått tilsendt spørreskjemaet, tar vi kontakt med deg pr. mail eller SMS. Vi tar kontakt for å forsikre oss om at du har mottatt spørreskjemaet og for å svare på spørsmål som du kan ha. Dersom årsaken til manglende respons er at du ikke ønsker å delta vil vi med en gang akseptere dette.

HVA SKJER MED INFORMASJONEN OM DEG?

Opplysninger og data fra spørreskjema, vil bli oppbevart i henhold til HVL sine forskningsetiske retningslinjer. Dette innebærer at utfylte spørreskjema vil ha en kodenøkkel som forbinder disse til en navneliste. Alle navne- og adresselister vil ligge på HVL sin forskningsserver, og ikke på en lokal PC. Alle data fra spørreskjema vil således bli behandlet uten navn og personnummer eller andre direkte personidentifiserende opplysninger knyttet til seg.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet konfidensielt. Alle personopplysninger vil bli slettet ved forskningsperiodens slutt, 31.12.21. Øvrige forskningsdata vil bli slettet eller anonymisert ved prosjektslutt. Anonymiserte data vil oppbevares sikkert på HVL sin forskningsserver med mulighet for fremtidig forskning i 15 år, og deretter slettet.

All formidling av resultater fra studien vil beskrive erfaringer hos grupper av mennesker, og på en slik måte at ingen enkeltpersoner vil kunne kjennes igjen.

GODKJENNING

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk, saksnr. hos REK 2017/2486/REK vest.

Dersom du ønsker mer informasjon om forskningsprosjektet, er du velkommen til å ta kontakt med prosjektleder Kari Dyregrov på telefon 977 35 584.

Bergen, ____.____-____(dato)

____

Professor Kari Dyregrov
Prosjektleder

Høgskulen på Vestlandet

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET VED Å BESVARE ET SPØRRESKJEMA

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

JEG ER OGSÅ VILLIG TIL Å BLI KONTAKTET FOR Å DELTA PÅ INTERVJU

For å delta i intervju, må du også samtykke til å besvare spørreskjemaet.

Jeg kan kontaktes for å gjøre avtale om intervju på mail:______________________ eller SMS: ___________

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

Appendix 2

Høgskulen på Vestlandet

ID nr.:						
Dato:						

SPØRRESKJEMA –
ETTERLATT NARKOTIKARELATERT DØD

Takk for at du har sagt deg villig til å være med i denne undersøkelsen!

Spørreundersøkelsen inneholder spørsmål om hvordan du har det og opplever din situasjon.

Det tar ca. 30-40 minutter å fylle ut disse spørsmålene. Det er viktig at du leser instruksjonene underveis nøye og følger disse.

Mange av spørsmålene krever at du besvarer dem ved bruk av en vurderingsskala. Noen ganger kan det sikkert være vanskelig å vite hvor du skal sette kryss (kanskje ligger svaret ditt midt mellom), men vi ber deg svare det alternativet som ligger NÆRMEST.

Det er viktig at du svarer på ALLE spørsmålene så godt du kan.

Vi ber deg fylle ut spørreskjemaet så snart du har fått det og returnerer det ferdig utfylte skjemaet og samtykkeskjemaet i vedlagte returkonvolutt.

Har du spørsmål tilknyttet spørreskjemaet kan du kontakte:
prosjektleder Kari Dyregrov tlf. 97 73 55 84 eller mail: kdy@hvl.no

Lykke til med utfyllingen!

BAKGRUNNSOPPLYSNINGER OM DEG

1. Alder: _____ år

2. Kjønn: ☐ Kvinne ☐ Mann

3. Høyeste utdanning:

☐ Grunnskole
☐ Videregående skole
☐ Høgskole/universitet
☐ Annet, spesifiser _______________

4. Sivilstatus:

☐ Gift/samboer
☐ Kjæreste, men bor ikke sammen
☐ Enke/enkemann
☐ Skilt/separert
☐ Singel
☐ Annet _______________

5. Bosted: ☐ Bygd ☐ By

6. Bor i Norge: ☐ Nord ☐ Midt ☐ Vest ☐ Øst ☐ Sør

7. Arbeid:

☐ Heltidsarbeidende
☐ Deltidsarbeidende
☐ Sykemeldt
☐ Pensjonist
☐ Student
☐ Annet, spesifiser _______________

8. Husstandens totale brutto årlige inntekt:

☐ Under 250.000
☐ 250.000-499.999
☐ 500.000-749.999
☐ 750.000-999.999
☐ 1.000.000-1.250.000
☐ Over 1.250.000

9. I løpet av livet ditt, hvor mange krevende livsbelastninger (f.eks. skilsmisse, sterke krenkelser som vold og seksuelle overgrep, dødsfall, ulykker) har du opplevd, og som gikk sterkt inn på deg? ____

10. I løpet av livet ditt, hvor mange har du mistet på grunn av narkotikarelatert død som stod deg nær (se ulike årsaker i spørsmål 16)? _____

Hvis du har mistet mer enn én person, velg han/hun som stod deg nærmest når du svarer på resten av spørreskjemaet.

11. Hva var din relasjon til han/henne? _______________

(f.eks. barn/forelder/søsken/ektefelle/besteforelder/kjæreste/nær venn?)

---

12. Personen som døde var: ☐ Kvinne ☐ Mann

---

13. Hvor gammel var personen når han/hun døde? _____ år

---

14. Hvor lenge er det siden personen døde? _____ år _____ måneder

---

15. På en skala fra 1-5, sett ring rundt tallet som beskriver hvor nært du følte deg til personen ved dødstidspunktet:

Svært nær		Nokså nær		Lite nær
1	2	3	4	5

---

16. Hvordan døde han/hun?

☐ Forgiftning uten intensjon (overdose)

☐ Forgiftning med intensjon (selvmord)

☐ Sykdom, ulykke eller vold som var relatert til inntak av narkotika

☐ Usikker årsak

---

17. Personen døde:

☐ Etter fengselsopphold

☐ Etter avgiftning/behandlingsopplegg

☐ I aktiv rus

☐ Etter tilbakefall

☐ Uavklart

☐ Annet _______________

---

18. Var rusbruken kjent for deg? ☐ Ja ☐ Nei

---

19. Hvor mange år før dødsfallet startet rusbruken? _____

20. Har han/hennes livsførsel preget din økonomi negativt?

I liten grad		I noen grad		I stor grad
☐	☐	☐	☐	☐

21. Var du sykemeldt under rusmisbruket til avdøde?

☐ Nei ☐ Ja Hvis Ja, hvor lenge? ______ år ______ måneder

22. Var du sykemeldt i tiden etter dødsfallet?

☐ Nei ☐ Ja

Hvis Ja, kan du beskrive hvordan din arbeidsevne har vært preget av dødsfallet frem til i dag?

____

____

DEN SPESIELLE SORGEN

Spørsmålene under handler om i hvilken grad sorgen du opplever over han/hun som døde er blandet med lettelse, skyld, (selv)bebreidelse, osv. Sett ring rundt det svaralternativet som best passer for deg for hvert spørsmål.

På en skala fra 1-5, sett ring rundt tallet som best beskriver det du tenker om de ulike spørsmålene	**I stor grad**		**I noen grad**		**I liten grad**
23. Jeg var engstelig for at han/hun kom til å dø i tiden før det skjedde	1	2	3	4	5
24. Frykten for at han/hun ville ruse seg til døde forstyrret nattesøvnen min	1	2	3	4	5
25. Jeg føler lettelse over at han/hun slapp fri fra et vanskelige liv	1	2	3	4	5
26. Jeg føler skyld for å føle lettelse over dødsfallet	1	2	3	4	5
27. Andre bebreider meg for dødsfallet	1	2	3	4	5
28. Jeg bebreider meg selv for dødsfallet	1	2	3	4	5
29. Jeg gjorde alt som sto i min makt for å forhindre dødsfallet	1	2	3	4	5
30. Jeg føler meg skamfull over å snakke åpent om han/henne fordi han/hun døde av rusbruk	1	2	3	4	5
31. Jeg opplever at (andre forventer at) jeg bør skamme meg over dødsfallet og hans/hennes livsførsel	1	2	3	4	5
32. Jeg tenker at vi som har mistet noen etter rusbruk har en forpliktelse til å slåss mot stigmaet og stillheten som følger	1	2	3	4	5
33. Andre snakker negativt om meg bak ryggen min på grunn av han/henne	1	2	3	4	5

På en skala fra 1-5, sett ring rundt tallet som best beskriver det du tenker om de ulike spørsmålene	**I stor grad**		**I noen grad**		**I liten grad**
34. Jeg har opplevd stigmatiserende bemerkninger rundt dødsfallet på sosiale medier	1	2	3	4	5
35. Jeg holder dødsårsaken til hans/hennes død skjult for de fleste	1	2	3	4	5
36. Jeg opplever at andre tenker at jeg ikke har rett til å sørge	1	2	3	4	5
37. Jeg opplever at andre synes synd på meg	1	2	3	4	5
38. Jeg ønsker å snakke om han/henne i samtaler med andre når det kjennes naturlig å gjøre det	1	2	3	4	5

39. Jeg har opplevd at andre har kommet med nedsettende bemerkninger om han/henne: Ja☐ Nei☐

Hvis Ja, hvem har kommet med nedsettende bemerkninger? (spesifiser)

____

Hva er det verste andre har sagt om han/henne? (beskriv)

____

____

DIN HELSE

Spørsmålene under handler om hvordan du oppfatter helsen din. Disse opplysningene vil hjelpe oss til å forstå hvordan du føler deg og hvor godt du er i stand til å utføre dine vanlige aktiviteter. Hvert spørsmål skal besvares ved å sette et kryss (X) i den boksen som passer best for deg.

40. Stort sett, vil du si at helsen din er:

Utmerket	Veldig god	God	Nokså god	Dårlig
☐	☐	☐	☐	☐

41. De neste spørsmålene handler om aktiviteter som du kanskje utfører i løpet av en vanlig dag. Er helsen din slik at den begrenser deg i utførelsen av disse aktivitetene nå?

Hvis Ja, hvor mye? [Kryss (X) en boks på hver linje]

	Ja, begrenser meg mye	**Ja, begrenser meg litt**	**Nei, begrenser meg ikke i det hele tatt**
a. **Moderate aktiviteter** som å flytte et bord, støvsuge, gå en spasertur eller drive med hagearbeid	☐	☐	☐
b. Gå opp trappen **flere** etasjer	☐	☐	☐

42. I løpet av de siste fire ukene, har du hatt noen av de følgende problemene i arbeidet ditt eller i andre daglige aktiviteter på grunn av din fysiske helse?

	Ja	**Nei**
a. **Fått gjort mindre** enn du ønsket	☐	☐
b. Vært begrenset i type **arbeidsoppgaver** eller andre aktiviteter	☐	☐

43. I løpet av de siste fire ukene, har du hatt noen av de følgende problemene i arbeidet ditt eller i andre daglige aktiviteter på grunn av følelsesmessige problemer (som å føle seg engstelig eller deprimert)?

	Ja	**Nei**
a. **Fått gjort mindre** enn du ønsket	☐	☐
b. Utført arbeid eller andre aktiviteter **mindre grundig** enn vanlig	☐	☐

44. I løpet av de siste fire ukene, hvor mye har smerter påvirket det vanlige arbeidet ditt (gjelder både arbeid utenfor hjemmet og husarbeid)?

Ikke i det hele tatt	Litt	Moderat	Ganske mye	Ekstremt mye
☐	☐	☐	☐	☐

45. De neste spørsmålene handler om hvordan du føler deg og hvordan du har hatt det i løpet av de siste fire ukene. For hvert spørsmål, ber vi deg velge det svaret som best beskriver hvordan du har følt deg. Hvor ofte i løpet av de siste fire ukene:

	Hele tiden	**Meste-parten av tiden**	**En god del av tiden**	**Noe av tiden**	**Litt av tiden**	**Aldri**
a. Har du følt deg rolig og avslappet?	☐	☐	☐	☐	☐	☐
b. Har du hatt mye overskudd?	☐	☐	☐	☐	☐	☐
c. Har du følt deg nedfor og deprimert?	☐	☐	☐	☐	☐	☐

46. I løpet av de siste fire ukene, hvor mye av tiden har den fysiske helsen din eller følelsesmessige problemer påvirket dine sosiale aktiviteter (som å besøke venner, slektninger osv.)?

Hele tiden	Mesteparten av tiden	En del av tiden	Litt av tiden	Aldri
☐	☐	☐	☐	☐

ARBEID OG FRITID

Å miste noen som har stått en nær på en traumatisk måte kan påvirke en rekke områder i livet. Bedøm i hvilken grad det du opplevde i forbindelse med å miste en nær har svekket deg i løpet av de siste 4 ukene, i forhold til de fem områdene som er nevnt under. For hvert av de følgende punktene angir du din bedømmelse på en skala fra 0 til 8, hvor 0 betyr at du ikke anser deg svekket i det hele tatt, og hvor 8 betyr at du anser deg svært alvorlig svekket.

Sett ring rundt alternativet som passer best	**Ikke svekket i det hele tatt**								**Svært alvorlig svekket**
47. Min evne til å arbeide eller studere	0	1	2	3	4	5	6	7	8
48. Mitt hjemmearbeid (slik som å vaske, rydde, handle, lage mat, betale regninger, passe hjemmet)	0	1	2	3	4	5	6	7	8
49. Mine sosiale fritidsaktiviteter (som jeg gjør sammen med andre, f.eks. gå på bar/kafe, selskaper/fester, utflukter, besøk, hjemmehygge)	0	1	2	3	4	5	6	7	8
50. Mine private fritidsaktiviteter (som jeg gjør alene, f.eks. som å lese, male, gå turer alene, trene, hagearbeid)	0	1	2	3	4	5	6	7	8
51. Min evne til å etablere og opprettholde nære forhold til andre (inkludert de jeg bor sammen med)	0	1	2	3	4	5	6	7	8

MESTRING

Spørsmålene under handler om hvordan du oppfatter egne forventninger til mestring. Forventning av mestring handler om troen en person har på at en kan utføre nye eller vanskelige oppgaver i livet, eller takle motgang. Hvert spørsmål skal besvares ved å sette et kryss (X) i den boksen som passer best for deg.

Vennligst sett kryss ved de svarene som passer best for deg	**Helt riktig**	**Nokså riktig**	**Nokså galt**	**Helt galt**
52. Jeg klarer alltid å løse vanskelige problemer hvis jeg prøver hardt nok.	☐	☐	☐	☐
53. Hvis noen motarbeider meg, så kan jeg finne måter og veier for å få det som jeg vil.	☐	☐	☐	☐
54. Takket være ressursene mine så vet jeg hvordan jeg skal takle uventede situasjoner.	☐	☐	☐	☐
55. Jeg beholder roen når jeg møter vanskeligheter fordi jeg stoler på mestringsevnen min.	☐	☐	☐	☐
56. Hvis jeg er i knipe, så finner jeg vanligvis en vei ut.	☐	☐	☐	☐

57. Har du selv misbrukt, eller misbruker du, rusmidler (alkohol, narkotika)?

☐ Nei

☐ Ja, før dødsfallet

☐ Ja, etter dødsfallet

☐ Ja, både før og etter dødsfallet

58. Hvis Ja: hvor ofte har du misbrukt rusmidler for å dempe sorg og savn i løpet av de siste 4 ukene?

☐ Ikke brukt de siste 4 ukene

☐ Sjeldnere enn hver uke

☐ Hver uke, men ikke daglig

☐ Daglig

	Bestemt, nei	Jeg tror ikke det	Av og til	Ja, ofte
59. Har du tenkt på muligheten av å gjøre slutt på livet de siste par ukene?	☐	☐	☐	☐

SOSIAL STØTTE

Her ber vi deg vurdere den sosiale støtten du har nå. Nedenfor følger noen ulike former for sosial støtte. Hvordan vurderer du disse i forhold til din egen situasjon nå? Bruk vurderingsskalaen fra 1 til 7.

Sett ring rundt alternativet som passer best	**Aldri**						**Alltid**
60. Når du har behov for å snakke, hvor ofte er noen villig til å lytte til deg?	1	2	3	4	5	6	7
61. Har du kontakt med andre i samme situasjon, eller mennesker med liknende opplevelser?	1	2	3	4	5	6	7
62. Kan du snakke om dine tanker og følelser?	1	2	3	4	5	6	7
63. Viser andre mennesker deg sympati og støtte?	1	2	3	4	5	6	7
64. Er det noen som kan gi deg praktisk hjelp?	1	2	3	4	5	6	7
65. Har du noen gang følt deg sviktet av mennesker som du regnet med ville støtte deg?	1	2	3	4	5	6	7
66. Alt i alt, er du tilfreds med den sosiale støtten du har mottatt etter dødsfallet?	1	2	3	4	5	6	7

SORGREAKSJONER

I denne delen av spørreskjemaet ønsker vi å kartlegge hvor du befinner deg i sorgen over dødsfallet.

DEL I: Sett et kryss i det alternativet som passer best for deg.

	Flere ganger daglig	**Minst én gang om dagen**	**Minst én gang i uken**	**Minst én gang**	**Ikke i det hele tatt**
67. I løpet av den siste måneden, hvor ofte har du lengtet etter den du har mistet?	☐	☐	☐	☐	☐
68. I løpet av den siste måneden, hvor ofte har du opplevd intens følelsesmessig smerte, tristhet, eller «bølger av sorg» knyttet til tapet?	☐	☐	☐	☐	☐

69. Vedrørende spørsmål 67 og 68; har du opplevd ett eller begge symptomene minst daglig og i minst 6 måneder?

Nei ☐ Ja ☐

	Flere ganger daglig	**Minst én gang om dagen**	**Minst én gang i uken**	**Minst én gang**	**Ikke i det hele tatt**
70. I løpet av den siste måneden, hvor ofte har du forsøkt å unngå ting som minner deg om at den du har mistet er borte?	☐	☐	☐	☐	☐
71. I løpet av den siste måneden, hvor ofte har du følt deg nummen, lamslått eller sjokkert av tapet?	☐	☐	☐	☐	☐

DEL II: For hvert spørsmål, vennligst sett kryss i det svaralternativet som passer best for hvordan du har det nå for tiden.

	Ikke i det hele tatt	**I liten grad**	**Til en viss grad**	**I ganske stor grad**	**I svært stor grad**
72. Føler du deg forvirret i forhold til hvilken rolle du har i livet eller at du ikke helt vet hvem du er (f.eks. føler at en del av deg er død)?	☐	☐	☐	☐	☐
73. Har du vanskelig for å akseptere tapet?	☐	☐	☐	☐	☐
74. Er det vanskelig for deg å stole på andre mennesker etter tapet?	☐	☐	☐	☐	☐
75. Føler du deg bitter over tapet?	☐	☐	☐	☐	☐
76. Opplever du at det å gå videre i livet (f.eks. få nye venner, eller nye interesser) er vanskelig for deg?	☐	☐	☐	☐	☐
77. Føler du deg nummen (bedøvet, uten følelser) etter tapet?	☐	☐	☐	☐	☐
78. Føler du at livet er tomt eller meningsløst etter tapet?	☐	☐	☐	☐	☐

79. Opplever du at du fungerer betydelig dårligere sosialt, yrkesmessig, eller på andre viktige områder (f.eks. i forhold til ansvarsoppgaver i hjemmet) som en følge av tapet?

Ja ☐ Nei ☐

PERSONLIGE LIVSENDRINGER

Det hender at folk rapporterer personlige endringer etter større traumatiske opplevelser. Vi ønsker å undersøke i hvilken grad dødsfallet har bidratt til personlige endringer i livet ditt. For hvert av de følgende punktene angir du din bedømmelse på en skala fra 1 til 6, hvor 1 betyr at dødsfallet ikke i det hele tatt har bidratt til personlige endringer i livet ditt, og hvor 6 betyr i svært stor grad.

Sett ring rundt alternativet som passer best	**Ikke i det hele tatt**					**I svært stor grad**
80. Jeg har endret mine prioriteringer av hva som er viktig i livet	1	2	3	4	5	6
81. Jeg setter mer pris på livet	1	2	3	4	5	6
82. Jeg har funnet en ny kurs i livet	1	2	3	4	5	6
83. Jeg føler mer nærhet til andre mennesker	1	2	3	4	5	6
84. Jeg har blitt tryggere på at jeg kan takle vanskeligheter	1	2	3	4	5	6
85. Jeg får mer ut av livet	1	2	3	4	5	6
86. Jeg har oppdaget at jeg er sterkere enn jeg trodde	1	2	3	4	5	6
87. Jeg har lært mye om hvor flotte mennesker kan være	1	2	3	4	5	6

HJELPSKJEMA

I denne delen av undersøkelsen vil vi spørre om ditt behov for hjelp og støtte etter dødsfallet. Vi spør om hvilke erfaringer du har hatt i møte med ulike fagpersoner og hjelpere – hvilken type hjelp du har fått og hva som kan bli bedre.

88. Har du mottatt hjelp fra fagfolk/hjelpeapparat ette dødsfallet?

Ja, tidligere	Ja, fremdeles	Nei (Hvis Nei, gå til spørsmål 94)
☐	☐	☐

89. Dersom du har mottatt hjelp – hvilke instanser/personer har du fått hjelp fra? *(Sett evt. flere kryss)*

☐ Fastlege
☐ (Psykiatrisk) sykepleier
☐ NAV
☐ Frivillige organisasjon
☐ Politi
☐ Kriseteam
☐ AMK/sykehus
☐ Psykolog/psykiater
☐ Begravelsesbyrå
☐ Prest/menighetsarbeider
☐ Familierådgivningskontor
☐ Annet, spesifiser

____

90. Har noen av fagfolkene nevnt over kommet på hjemmebesøk?

☐ Nei ☐ Ja Hvis Ja, hvem? ________________

91. Hvordan ble kontakten med hjelpeapparatet etablert?

Jeg ble kontaktet	Jeg tok selv kontakt	Andre tok kontakt for meg
☐	☐	☐

92. Er du fornøyd med hjelpen fra hjelpeapparatet?

I stor grad	I nokså stor grad	Til en viss grad	I liten grad	Ikke i hele tatt
☐	☐	☐	☐	☐

93. Har kontakten med noen av fagfolkene blitt opplevd som en belastning?

☐ Nei ☐ Ja Hvis Ja, kan du kort beskrive hvem som var en belastning og hvorfor?

____

____

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94. Opplevde du behov for hjelp fra fagfolk/hjelpeapparat like etter dødsfallet?

I stor grad	I nokså stor grad	Til en viss grad	I liten grad	Ikke i hele tatt
☐	☐	☐	☐	☐

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95. Har du følt behov for hjelp fra fagfolk/hjelpeapparat de siste fire ukene?

I stor grad	I nokså stor grad	Til en viss grad	I liten grad	Ikke i hele tatt
☐	☐	☐	☐	☐

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96. Er det noen instanser/personer du har savnet kontakt med? (Sett evt. flere kryss)

☐ Nei, ingen

☐ Fastlege

☐ (Psykiatrisk) sykepleier

☐ NAV

☐ Frivillige organisasjon

☐ Politi

☐ Kriseteam

☐ AMK/sykehus

☐ Psykolog/psykiater

☐ Begravelsesbyrå

☐ Prest/menighetsarbeider

☐ Familierådgivningskontor

☐ Annet, spesifiser

____

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97. Hvor lenge ville du ideelt sett ha ønsket hjelp fra hjelpeapparatet?

Minst 1 måned	Minst 2 måneder	Minst 3 måneder	Minst 6 måneder	Minst 12 måneder	Annet (hvor lenge?
☐	☐	☐	☐	☐	__________

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98. Mottar du hjelp og støtte fra familie, venner eller nærmiljø nå?

Ikke i det hele tatt	I liten grad	Til en viss grad	I nokså stor grad	I stor grad
☐	☐	☐	☐	☐

99. Er du fornøyd med hjelpen du får fra familie, venner og nærmiljø nå?

Ikke i det hele tatt	I liten grad	Til en viss grad	I nokså stor grad	I stor grad
☐	☐	☐	☐	☐

100. Hvordan har kontakten med andre mennesker vært i tiden etter dødsfallet?

	Ikke i det hele tatt	I liten grad	Til en viss grad	I nokså stor grad	I stor grad
a. Jeg har opplevd at andre har trukket seg unna	☐	☐	☐	☐	☐
b. Jeg har trukket meg mer unna andre	☐	☐	☐	☐	☐
c. Jeg har opplevd å komme nærmere andre	☐	☐	☐	☐	☐
d. Vi i familien har kommet lengre fra hverandre	☐	☐	☐	☐	☐
e. Vi i familien har kommet nærmere hverandre	☐	☐	☐	☐	☐

101. Har du en person som virkelig forstår situasjonen du er i, og som du kan fortelle alt til? ☐ Ja ☐ Nei

102. Hvis ja, i hvilken grad benytter du deg av denne personens støtte?

I stor grad	I nokså stor grad	Til en viss grad	I liten grad	Ikke i hele tatt
☐	☐	☐	☐	☐

103. Hjelper noe av det følgende deg nå?

	Ikke i det hele tatt	I liten grad	Til en viss grad	I nokså stor grad	I stor grad
a. Religiøse aktiviteter	☐	☐	☐	☐	☐
b. Sorg- og samtalegrupper	☐	☐	☐	☐	☐
c. Hobbyer	☐	☐	☐	☐	☐
d. Fysisk aktivitet	☐	☐	☐	☐	☐
e. Yrkesaktivitet	☐	☐	☐	☐	☐
f. Snakke med noen	☐	☐	☐	☐	☐
g. Internett/sosiale medier	☐	☐	☐	☐	☐
h. Gråte	☐	☐	☐	☐	☐
i. Ta ut sinne	☐	☐	☐	☐	☐
j. Være for meg selv	☐	☐	☐	☐	☐
k. Annet, spesifiser ________________	☐	☐	☐	☐	☐

104. Har eventuelle barn i familien fått egen hjelp fra hjelpeapparatet?

☐ Nei ☐ Ja ☐ Ikke relevant

105. Dersom barnet/barna har fått egen hjelp, er du fornøyd med denne hjelpen?

I stor grad	I nokså stor grad	Til en viss grad	I liten grad	Ikke i hele tatt
☐	☐	☐	☐	☐

106. Har du savnet hjelp til barnet/barna fra hjelpeapparatet?

I stor grad	I nokså stor grad	Til en viss grad	I liten grad	Ikke i hele tatt
☐	☐	☐	☐	☐

107. Hva har vært viktigste støtte og/eller hjelp for deg etter dødsfallet?

108. Er det noe som hindrer deg i å ta imot støtte eller hjelp fra hjelpeapparatet og/eller andre nå?

☐ Nei ☐ Ja Hvis Ja, beskriv

109. Er det noen råd du vil gi til politikere?

☐ Nei ☐ Ja Hvis Ja, beskriv

Tusen takk for din deltakelse!

Invitasjon til forskningsdeltakelse

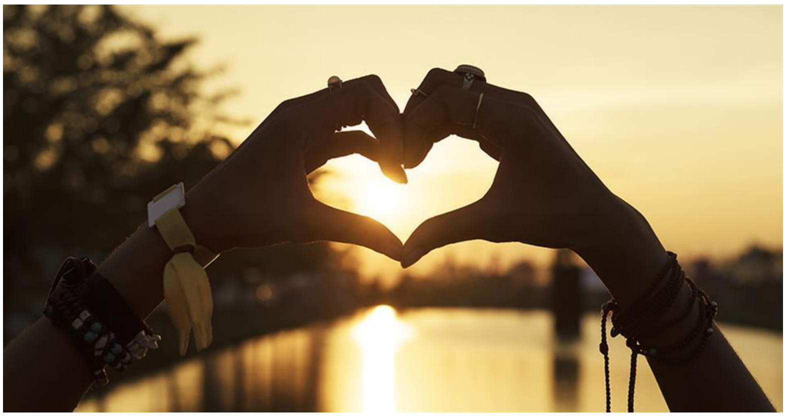

Foto: Pexels photos

Har du mistet familiemedlem eller nær venn ved narkotikarelatert død?

Hvert år dør 250-300 personer i Norge på grunn av narkotikabruk. Rusrelaterte dødsfall, rusavhengige og de pårørende sin situasjon er et alvorlig folkehelseproblem. Mange etterlatte sitter tilbake i stillhet når den rusavhengige dør. Forskingsprosjektet «Etterlatte ved narkotikarelatert død» (END) startet opp i november 2017 ved Høgskolen på Vestlandet, Fakultet for helse- og sosialvitskap, Institutt for velferd og deltaking. Prosjektgruppen arbeider i nært samarbeid med Bergen kommune og en stor gruppe nasjonale og internasjonale fageksperter på rus, stigma, traume, sorg, helse- og velferdstjenesten og helsepolitikk.

Vi rekrutterer etterlatte familiemedlemmer og nære venner til en stor nasjonal spørreundersøkelse. Gjennom å dokumentere etterlattes situasjon både før og etter dødsfallet, og hva de trenger av hjelp og støtte, er prosjektets hovedmål å forbedre deres livskvalitet og daglige fungering.

Dersom du har mistet noen og ønsker å delta i studien, og/eller at du vil delta ved å rekruttere etterlatte til studien, så ønsker vi i prosjektgruppen å komme i kontakt med deg. **Vi rekrutterer ut året 2018.** Deltakere må være over 18 år, det må være minst 3 måneder siden tapet, men det er ingen maksimum grense for når dødsfallet har skjedd.

Kontakt prosjektleder professor Kari Dyregrov på
e-mail kdy@hvl.no **eller sms/telefon** 977 35 584
Post: Høgskulen på Vestlandet, v/Kari Dyregrov, Pb 7030, 5020 Bergen.

BERGEN
KOMMUNE

Høgskulen
på Vestlandet

Supplementary file I: steps in logistic regression analysis

The logistic regression analysis was conducted using the "purposeful selection" method based on Hosmer and Lemeshow (2013) since there were too many independent variables (24) compared to observations (n=115–129) for a standard analysis. The independent variables were divided into three different sources on a theoretical assumption for variables that possibly could affect satisfaction with help: the characteristics of the participants (nine), strain before or surrounding the death (seven), and variables concerning the service provider and providing (eight). All nominal or Likert scale variables were collapsed into dichotomous variables, "relations to deceased" was collapsed into "parents" and "other" relations, based on the number of observations and findings from the chi-square analyses. Two continuous variables, number of adverse life events (min-max: 1–100) and the number of drug-related losses (min-max: 1–25), were dichotomized at the median level to keep outliers in the analyses. The remaining continuous variables were converted into Z-scores, making it easier to compare effect sizes. The correlation matrix showed a collinearity issue between relations to deceased and age at bereaved at time of death (*r*=.787). We conducted two separate preliminary analyses with the two different variables. We chose to continue with age at bereaved at time of death since this variable showed a significant association with the dependent variable.

Based on Hosmer and Lemeshow (2013, p. 90), we started with standard contingency table analyses for all dichotomous variables and selected variables significant at p<.25 for further analysis. For the first multivariate regression model, seven independent variables were included.

In step 2, the multivariate model was fitted with these variables and those that did not contribute at p<.05 was removed in continuing analysis (Hosmer et al., 2013, p. 90). Four variables were significant at p<.05 (n=124). These four variables were fitted to a new model, and this model was compared to the model with all seven variables, computed with a log-likelihood test (p=.11), i.e., this model was as good as the former. We cycled through stages two and three, including and excluding variables to assess significance levels and calculate coefficient changes, as recommended by Hosmer and Lemeshow (2013, p. 92), and obtained a preliminary main effects model with five independent variables. The logit of the continuous independent variables was checked for linear increase/decrease as a function of the covariate. Finally, the natural log transformations of the continuous variables were added as an interaction term in a model that included the independent variables in the preliminary main effects model. This resulted in a non-significant result for all interaction terms (p=.542, p=.462, p=.497), i.e., all continuous independent variables were found to be linearly related to the logit of the dependent variable (see Box & Tidwell, 1962). The main effects model obtained was then checked with all theoretically plausible interactions (eight). The different models -2 log-likelihood were compared to find the models with a better fit than the preliminary effect model. Two interactions terms gave models with a significantly better fit (p <.10), and a model with these interaction terms were set up. One of the interaction terms in this model yielded a clearly insignificant result (p=.852), while the other was close to a significance level of p<.05 (p=.076). We removed the clearly insignificant interaction term from the model and decided to keep the interaction term now at p=.073 in the final model because this interaction may be clinically meaningful. The final model consisted of five independent predictor variables at p<.05, and one interaction term at p=.073. All analyses were undertaken using IBM SPSS Statistics Version 27.

References

Box, G. E., & Tidwell, P. W. (1962). Transformation of the independent variables. *Technometrics*, *4*(4), 531-550.

Hosmer, D. W., Lemeshow, S., & Sturdivant, R. X. (2013). *Applied Logistic Regression*. John Wiley & Sons, Incorporated.

TEMAGUIDE FOR INTERVJU (FAMILIE) REVIDERT 3.10.18

TEMA 0: TIDEN FØR DØDSFALLET

- Kan du si litt om hvem NN var?
- Kan du beskrive forholdet ditt til avdøde før dødsfallet (opp/ned, konfliktfylt, voldelig, etc.)?
- Kan du beskrive avdødes rusbruk, og innsatsen for å forhindre dødsfallet (innvirkning på eget/familiens liv, arbeidssituasjon, håp-skuffelse-svik, oppturer-nederlag, ventesorg, etc.)?
- Hva visste du om avdødes levevaner (bolig, nettverk)?

HOVED-SPØRSMÅL 1: KAN DU SI LITT OM HVORDAN DU HAR OPPLEVD Å MISTE DIN…….?

TEMA 1: TIDEN ETTER DØDSFALLET

- Hvordan var omstendighetene rundt dødsfallet (informert om dødsfallet? tilstede/ikke tilstede? fant avdøde? sett avdøde? hvem informerte? hvordan døde h*n?, etc.)
- Hvordan har dine sorgreaksjoner vært over tid? Endret seg? (skyldfølelse over at dødsfallet skjedde, sinne, skuffelse, lettelse, skyld for å føle lettelse, bebreidelse/selvbebreidelse, skam, sorg og savn, ikke-anerkjent sorg)
- Hvordan har familiemedlemmenes sorgreaksjoner og forløp vært? (likheter/ forskjeller, beskyttelse, bebreidelse, endring i familiesamspill og konfliktnivå, nærmere/fjernere hverandre, etc.)

- Hvordan vil andre som kjenner deg beskrive din sorgprosess?
- Hva tenker du at kan påvirke hvordan du opplever og uttrykker din sorg overfor andre/utad? (konflikt/nærhet før dødsfallet; andre prøver å forstå men vet ikke hva de skal si; stigma; holdninger)
- Hvordan vil du beskrive din egen helse, arbeidssituasjon, fritid?

TEMA 2: STIGMA FRA OMGIVELSENE, OG SELVSTIGMA

- Hvilke typer holdninger opplever du å møte fra omgivelsene?
- Har du behov for å snakke om dødsfallet?
- Hvordan snakker du om dødsfallet? (til hvem/hvem ikke, etc.)
- Opplever du vonde utsagn, bemerkninger, handlinger fra andre?

HOVED-SPØRSMÅL 2: HVILKEN HJELP FIKK DU OG DIN FAMILIE ETTER DØDSFALLET?

TEMA 3: Støtte og hjelp

- Hvilke erfaringer har du med støtte fra familie, venner, arbeidskolleger, sosiale nettverk og likepersoner, sorggrupper?
    - Hvilken omsorgskultur har du møtt (ingen?; prøver de – evt. hvordan?)
    - Viktigste støtte? Barrierer for støtte? Savnet støtte?
- Hvilke erfaringer har du med hjelp fra hjelpeapparatet (helse-sosial, politi, ambulanse, prest, kriseteam, etc.)?

  - Hvilken omsorgskultur har du møtt (ingen, instrumentell, empatisk, familiefokus, etc.)?
  - Hvilken hjelp har familien fått samlet/som system?
  - Viktigste hjelp? Barrierer for hjelp? Savnet hjelp?

TEMA 4: EGENMESTRING OG PERSONLIG VEKST

- Hva er det viktigste du selv har kunnet gjøre for å leve videre etter dødsfallet?
- Hva har fremmet eller hemmet egen mestring?
- Har du opplevd at du har endret deg som person på noen måter etter dødsfallet – og kan du i så fall beskrive hvordan?

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Camilla Gjerstad	55978499	01.02.2018	2017/2486/REK vest
			Deres dato:	**Deres referanse:**
			31.01.2018	

Vår referanse må oppgis ved alle henvendelser

Kari Dyregrov
Avdeling for helse og sosialfag

2017/2486 Etterlatte ved narkotikarelatert død i et recoveryperspektiv

Forskningsansvarlig: Høgskulen på Vestlandet
Prosjektleder: Kari Dyregrov

Vi viser til din tilbakemelding om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Tilbakemeldingen ble behandlet av leder av Regional komité for medisinsk og helsefaglig forskningsetikk (REK vest) på fullmakt. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10.

Prosjektleders prosjektomtale

Norge ligger på verdenstoppen i antall overdoser pr. innbygger. På verdensbasis fins det nesten ikke forskning om etterlatte som mister sine ved narkotikarelatert død (NRdød). Vi vil gjennomføre et nasjonalt prosjekt med fire studier (vedlegg 6). Det søkes her om studie 1 og 2 – se protokoll (vedlegg 1). Studiene har som mål å studere hva det innebærer for nære familiemedlemmer og venner å miste ved NRdød. Konsekvensene studeres i sammenheng med belastninger og innsats før dødsfallet, og behov for hjelp og hvilke hjelpetiltak som tilbys fra helse- og sosialtjenestene etter dødsfallet. Hva som hindrer eller fremmer livskvalitet, mestring og fungering (eks. stigma, slitenhet, egne ressurser) er sentralt. HVL samarbeider tett med Bergen kommune i prosjektet. Gjennom ny kunnskap til politikere, befolkningen og helse-sosialtjenestene i kommunene, vil ny kunnskap bidra til å redusere stigma, og forbedre livskvalitet og fungering for en stor gruppe mennesker.

REK vest ba om tilbakemelding:

- Revidert informasjonsskriv sendes til REK vest.
- Et eget informasjonsskriv om individuelt intervju sendes til REK vest.
- Et eget informasjonsskriv om fokusgruppeintervju sendes til REK vest.
- Rekrutteringen endres slik at purring på telefon utgår.
- Det gis tilbakemelding på om det er utarbeidet databehandleravtale for bruk av SurveyMonkey ogom den forskingsansvarlige har forsikret seg om at SurveyMonkey har et tilstrekkeligsikkerhetsnivå.

Tilbakemelding fra prosjektleder

- Protollen er nå revidert.
- Forsvarlighetsvurdering: Forskerne som skal gjennomføre intervjuene er Kari Dyregrov, Kristine Berg Titlestad, SariKaarina Lindeman, Birthe Møgster og Sonja Mellingen. De fem intervjuerne vil fordele de individuelle- og fokusgruppeintervjuene omtrent likt mellom seg. For å standardisere fremgangsmåte for kommende intervju, vil prosjektleder i forkant av intervjurunden, gjennomføre

Besøksadresse:
Armauer Hansens Hus (AHH), Tverrfløy Nord, 2 etasje. Rom 281. Haukelandsveien 28

Telefon: 55975000
E-post: post@helseforskning.etikkom.no
Web: http://helseforskning.etikkom.no/

All post og e-post som inngår i saksbehandlingen, bes adressert til REK vest og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK vest, not to individual staff

et prøveintervju (med en av medforskerne) der intervjuerne er tilskuere og alle diskuterer intervjutema og fremgangsmåte i etterkant. Ved starten av både individuelle- og gruppeintervju vil intervjuer gjennomgå en oppstartsprosedyre for deltakerne.

- Rekruttering: Informasjonsbrevet er nå endret til at kontakt etter 14 dager skjer via epost eller SMS.
- Informasjonsskriv: Formuleringen er endret og forklarer nå i informasjonsbrevet hvor forskergruppen har fått kontaktinformasjon fra.
- Nytt informasjonsskriv i forhold til dybdeintervju er vedlagt.
- Nytt informasjonsskriv i forhold til fokusgruppeintervju er vedlagt.
- Databehandling:HVL har databehandleravtale med Questback. Studien har nå endret digital innsamlingsmetode fra SurveyMonkey til Questback. Man har også tilføyd i informasjonsskrivene at forskningsdata vil bli slettet eller anonymisert ved prosjektslutt.

Vurdering av tilbakemeldingen
Tilbakemelding er utfyllende og besvarer komiteen spørsmål på en god måte. REK vest har ingen ytterligere merknader.

Vedtak
REK vest godkjenner prosjektet i samsvar med forelagt søknad og tilbakemelding.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK vest på eget skjema senest 30.06.2022, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK vest dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Marit Grønning
dr.med. professor
komitéleder

Camilla Gjerstad
rådgiver

Kopi til:post@hvl.no

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Appendix 7

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Camilla Gjerstad		17.11.2020	11121
			Deres referanse:	

Kari Madeleine Stabell Dyregrov

11121 Etterlatte ved narkotikarelatert død i et recoveryperspektiv

Forskningsansvarlig: Høgskulen på Vestlandet

Søker: Kari Madeleine Stabell Dyregrov

REKs vurdering

Vi viser til søknad om prosjektendring mottatt 21.10.20 for ovennevnte forskningsprosjekt. Søknaden er behandlet av komiteleder for REK vest på delegert fullmakt fra komiteen, med hjemmel i forskningsetikkforskriften § 7, første ledd, tredje punktum. Søknaden er vurdert med hjemmel i helseforskningsloven § 11.

REK vest ba om tilbakemelding (brev 23.09.20)

REK vest ba om tilbakemelding på en endringsmelding innsendt 04.09.20.
I brev av 23.09.20 uttalte REK vest:

REK vest oppfatter søknaden slik at man vil legge til nye prosjektmedarbeidere (fem nye stipendiater og flere forskere) for å utnytte de innsamlede data i større grad. Det opplyses i endringsmeldingen at problemstilling og protokoll er som tidligere. REK vest gjør oppmerksom på at selv om den overordnete problemstillingen i studien er uendret, må en forskningsprotokoll til enhvert tid oppdateres og beskrive alle konkrete endringer, f.eks. endringer i tidsplan, medarbeidere, nye eller endrete dataanalyser, nye forskningsspørsmål, nye delmål mm. Det må videre gis tilbakemelding til REK hvem de nye medarbeiderne er (navn, grad, institusjon, rolle) og hva de skal bidra med i prosjektet. REK vest ber om en utfyllende tilbakemelding og en oppdatert forskningsprotokoll der alle nye endringer som ikke tidligere er vurdert av REK må markeres. Protokollen må merkes med dato og versjonsnummer. REK vest vil så ta stilling til tilbakemeldingen og vurdere om endringene vil kreve en eller flere nye prosjektsøknader eller om dette er tilstrekkelig å beskrive dette i en endringsmelding. Deltakerne i studien har samtykket til at "Alle personopplysninger vil bli slettet ved forskningsperiodens slutt, 31.12.21. Øvrige forskningsdata vil bli slettet eller anonymisert ved prosjektslutt". REK vest ber om tilbakemelding på om det nå søkes om å utvide lagringstiden for koblingsnøkkel og personidentifiserende data til 2023, og om det evt. vil bli gitt ny oppdatert informasjon om dette til studiedeltakerne.

Prosjektendring/ Tilbakemelding innsendt 21.10.20

Prosjektleder har sendt en endringsmelding, som REK vest oppfatter er en tilbakemelding på våre merknader i brev 23.09.20.

Det søkes om å få å utvide lagringstiden for koblingsnøkkel og personidentifiserende data. Ny prosjektslutt vil være 31.12.2026. Søker begrunner endringen med at man nå har fått flere stipendiatstillinger som vil bidra til å utnytte data i de problemstillingene man opprinnelig har søkt og fått godkjenning for av REK. Det legges opp til at deltakerne i studien vil få et informasjonsskriv om forlengelsen av studien og ny prosjektslutt. Informasjonsskrivet og den reviderte forskningsprotokollen er innsendt sammen med endringsmeldingen.

Det søkes om å legge til fire nye stipendiater. Tre av disse er nå tilsatt og informasjon om de nye medarbeiderne er gitt i eget vedlegg. Når det gjelder dataanalyser, forskningsspørsmål, og delmål er de knyttet til de fire delstudiene som tidligere er godkjent av REK. Man tar sikte på å undersøke de opprinnelige problemstillingene mer inngående. Forskningsspørsmålene til stipendiatene p.t. er omtalt i eget vedlegg.

Vurdering
REK vest ved komitéleder har vurdert endringsmeldingen. REK vest oppfatter at det ikke vil bli innhentet nye data, men at man vil undersøke de opprinnelige problemstillingene mer inngående ved bruk av allerede innsamlete data. REK vest vektlegger at informasjon om utvidet lagring vil bli sendt til deltakerne i studien.

Forskningsspørsmålene som de nye stipendiatene vil arbeide med, er beskrevet i et eget vedlegg. Søker peker på at arbeidet med operasjonaliseringer av forskningsspørsmålene til stipendiatene og øvrige prosjektmedarbeidere er et kontinuerlig pågående arbeid ettersom formulering av forskningsspørsmål bl.a. blir utarbeidet underveis i studien når nye resultater etter hvert foreligger. REK vest aksepterer dette, men ber om at det jevnlig sendes inn nye endringsmeldinger etter hvert når studien vil inkludere nye/endrete forskningsspørsmål, nye delmål, nye medarbeidere mm.

Vedtak

Godkjent med vilkår

REK vest godkjenner prosjektendringen på betingelse av ovennevnte vilkår, med hjemmel i helseforskningsloven § 11.

Med vennlig hilsen

Marit Grønning
Professor dr.med.
komiteleder REK vest

Camilla Gjerstad
rådgiver

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK

vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag (NEM) for endelig vurdering.

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Appendix 8

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Camilla Gjerstad		15.12.2020	11121
			Deres referanse:	

Kari Madeleine Stabell Dyregrov

11121 Etterlatte ved narkotikarelatert død i et recoveryperspektiv

Forskningsansvarlig: Høgskulen på Vestlandet

Søker: Kari Madeleine Stabell Dyregrov

REKs vurdering

Vi viser til søknad om prosjektendring mottatt 12.12.20 for ovennevnte forskningsprosjekt. Søknaden er behandlet av komiteleder for REK vest på delegert fullmakt fra komiteen, med hjemmel i forskningsetikkforskriften § 7, første ledd, tredje punktum. Søknaden er vurdert med hjemmel i helseforskningsloven § 11.

Prosjektendring
Det søkes om å legge til nye prosjektmedarbeidere:

- Gunhild Meen, PhD stipendiat, Høgskulen på Vestlandet, prosjektrolle: PhD stipendiat og medlem av prosjektgruppen.
- Øivind Reehorst Kalsaas, PhD stipendiat, Høgskulen på Vestlandet, prosjektrolle: PhD stipendiat og medlem av prosjektgruppen.
- Camilla Johnsen, Masterstudent ved IVD, Høgskulen på Vestlandet, prosjektrolle: skriver masteroppgave på kvant END data.

Søkers begrunnelse for endringen:
Opprinnelig REK-godkjente END protokoll har inkludert muligheter for at HVLs BA oig MA studenter skal kunne skrive på avgrensede og anonymiserte data i END (jfr. merket nmed gult s. 7 i vedlagte protokoll). Denne endringsmeldingen gjelder derfor at END ønsker å la Masterstudent Camilla Johnsen skrive en avgrenset problemstilling på anonymiserte kvantitative data (jfr. s. 4 i protokollen). Johnsen er fysioterapeut og Masterstudent på HVLs masterutdanning. Hun er håndplukket av prosjektleder Kari Dyregrov og godt egnet til oppgaven på en betryggende måte. Hun vil selvsagt følge alle etiske retningslinjer og krav som ligger i END sin REK-godkjenning og til HVLs krav til forskningsprosjekt. Hun vil veiledes av prof. Kari Dyregrov og 1. amanuensis Marit Schmid (PHD), HVL

Vurdering
REK vest ved komitéleder har vurdert endringsmeldingen og har ingen merknader.

Vedtak

Godkjent

REK vest godkjenner prosjektendringen, med hjemmel i helseforskningsloven § 11.

Med vennlig hilsen

Marit Grønning
Professor dr.med.
komiteleder REK vest

Camilla Gjerstad
rådgiver

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag (NEM) for endelig vurdering.

Forskingsprosjektet «Etterlatte etter narkotikarelatert død (END-prosjektet)»

Kjære du som har deltatt i END-prosjektet

Med dette skrivet vil vi **informere om forlengelse av END-prosjektet** samt gi informasjon om status for prosjektet og hva videre oppbevaring av data vil innebære for de av dere som har vært deltakere i dette forskingsprosjektet.

Bakgrunn

«Etterlatte ved narkotikarelatert død - i et recoveryperspektiv» (END) er et stort nasjonalt forskingsprosjekt. Det startet opp våren 2017 ved Høgskulen på Vestlandet, Institutt for velferd og deltaking, Fakultet for helse- og sosialvitskap, under ledelse av professor Kari Dyregrov.

END-prosjektet forsker på hva konsekvenser og belastninger narkotikadødsfall har for nære etterlatte, hvordan de mestrer hverdagen og hvilken støtte de får. Hva hjelpeapparatet gjør og ønsker å forbedre er også et viktig forskningstema.

I løpet av 2018 og 2019 har END-prosjektet fått samlet inn viktige data. 255 etterlatte familiemedlemmer og nære venner har svart på et omfattende spørreskjema. 14 etterlatte foreldre, 12 søsken og 18 nære venner har deltatt i individuelle intervju og 105 representanter fra ulike deler av hjelpeapparatet har deltatt i fokusgruppeintervjuer og svart på spørreskjema. Dette gir oss et meget godt grunnlag til å kunne utvikle viktig kunnskap.

Det er svært gledelig at END-prosjektet har fått økt støtten til forskingsaktiviteten gjennom å få tildelt midler fra Norges Forskingsråd, Helsedirektoratet, stiftelsen DAM, Bergen kommune og Høgskulen på Vestlandet. Det har blant annet bidradd til at fire nye stipendiater er tilsatt, som gjennom sine doktorgradsarbeider kan fremskaffe mer kunnskap om hvordan etterlatte etter narkotikarelatert død har det. Sammen med andre forskere i prosjektet vil de også bidra til økt fokus på hvordan hjelpeapparatet kan bedre sin hjelp til denne gruppen etterlatte.

Som følge av de økte mulighetene til å analysere datamaterialet ønsker vi å forlenge tiden vi oppbevarer og bruker det innsamlede datamaterialet fra 31.12.21 til 31.12.26.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger

Opplysninger og data fra spørreskjema og intervju er oppbevart i henhold til HVL sine forskningsetiske retningslinjer, slik vi tidligere har informert om. Dette innebærer at utfylte spørreskjema, lydfiler fra intervju og utskrevne intervju vil ha en kodenøkkel som forbinder disse til en navneliste. Alle navne- og adresselister og alt datamateriale lagres på HVL sin sikre forskningsserver. Navn og kontaktinformasjon lagres også atskilt fra lydopptak og spørreskjema. Alle data vil således bli behandlet uten navn eller andre direkte personidentifiserende opplysninger knyttet til seg.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet strengt konfidensielt. Alle personopplysninger vil bli slettet ved forskningsperiodens slutt, 31.12.26. Øvrige forskningsdata vil bli slettet eller anonymisert ved prosjektslutt. Anonymiserte data vil oppbevares sikkert på HVL sin forskningsserver med mulighet for fremtidig forskning i 15 år, og deretter slettet.

Formidling av resultater fra studien vil beskrive erfaringer hos grupper av mennesker, og på en slik måte at ingen enkeltpersoner vil kunne kjennes igjen.

Frivillighet og rettigheter

Det er frivillig å delta i forskning. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke om deltakelse i denne studien, uten at det vil få konsekvenser for deg. Dersom du trekker deg fra studien etter at den er påbegynt, kan du også kreve å få slettet dine opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Ønsker du å vite mer om forskingsprosjektet?

Dersom du har deltatt i END-prosjektet og har spørsmål til prosjektet som helhet eller hvordan informasjon du har gitt blir behandler kan du gjerne kontakte prosjektleder Kari Dyregrov på tlf. 97735584 eller e-postKari.Dyregrov@hvl.no. Det samme gjelder hvis du ønsker å benytte deg av dine rettigheter som er gjengitt over.

Ønsker du informasjon om aktivitet og kunnskap som kommer ut av prosjektet, så følg oss gjerne på vår nettside **hvl.no/end**

Tusen takk for ditt bidrag!

Med vennlig hilsen

Kari Dyregrov

Prosjektleder

Oktober 2020