Western Norway
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Applied Sciences

The “special grief” of parents bereaved by drug-related death

Mixed methods research - a qualitative driven concurrent design

Kristine Berg Titlestad

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

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Disputation: 16.08.2021

DEDICATION

To my dad.

“Grief is the price we pay for love”.

Dr. Colin Murray Parkes

Year:	2021
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Scientific environment

This doctoral project was carried out between 2018 and 2021 at the Department of Welfare and Participation, Western Norway University of Applied Sciences (HVL).

The project is part of "*The Drug-death Related Bereavement and Recovery Study*" (The END-study). The initiators of the END-study were the main supervisor, Professor Kari Dyregrov (HVL) and co-supervisor, Dr Svanaug Fjær (Head of Department of Welfare and Participation, HVL). In addition, within the scientific environment which has contributed to the widening of my perspectives, are co-supervisor, Dr Pål Kristensen (Centre for Crisis Psychology, University of Bergen (UiB)), co-authors Professor Hans Lund, PhD colleague Sari Lindeman, Dr Sonja Mellingen, Dr Marit Therese Schmid, Professor Margaret Stroebe and Professor Kari Dyregrov, as well as my colleagues in the END-study.

I began my doctoral training at the Research School of Municipal Healthcare Services (MUNI-HEALTH-CARE). The Research School is partnered with the University of Oslo, UiB, HVL, the Arctic University of Norway, OsloMet, NTNU (Gjoevik division) and Nord University. In September 2019, I was also accepted on the newly established PhD programme in Health, Function and Participation at HVL. In the spring of 2020, I was a visiting postgraduate scholar at the University of Bath, Department of Psychology, for six weeks. I have also been a student on a part-time bereavement course study, over a two year period, at UiB.

HVL funded the research. At HVL, I am part of the mental health and drug use research group and am affiliated to the Social Educator education programme.

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I have always been extremely grateful that I am part of a large, well-functioning research project group. The END group, made up of the bereaved, as well as interprofessional, interdisciplinary co-workers, all willingly share their experiences, in order that we can reach our common goal: to improve the life situation of the bereaved following drug-related deaths and to provide public services with the necessary knowledge, needed to help such individuals.

Many thanks to MUNI-HEALTH-CARE for making financial support available to my visiting scholar at the University of Bath. A warm thank you to Professor Paula Smith at the University of Bath for welcoming me, and who made it possible for me to become a visiting research scholar. To the teachers and my fellow PhD-students, both at MUNI-HEALTH-CARE and HVL, thank you for sharing your expertise and reflections with me. A special thanks to my fellow students, Susanne Grødem Johnson, Karolina Mæland and Ragnhild Alice Bjerk Steinsland for continuing to motivate me. Spending one hour every other week over this last year with Trine-Lise Dræge Steinskog and Ann Britt Sandvin Olsson on Zoom to discuss one other's work, has been both inspiring and enlightening. Thank you also, to Mauricio Pavez at Media Lab for making amendments to the "special grief" figure each time I had a new suggestion!

Most importantly, thank you to my extended family in the South and West for cheering me on. My most heartfelt thanks go to my parents for believing in me and for always supporting my family and I. This project would not have been possible without my husband, Rune's blessing. To dearest Rune – thank you for your support and patience, and for engaging in my research throughout these years. A special thanks to our children, Sander Loke and Andrine, who remind me of the most important things in life. Finally, thank you to all my friends who have been patiently waiting for me "to be done with it", yet who acknowledge that I will probably never choose to stop educating myself.

Thank you!

Abstract

Introduction: This doctoral project was carried out between 2018 and 2021 at the Department of Welfare and Participation, Western Norway University of Applied Sciences. A sociological perspective is incorporated when exploring, analysing and interpreting grief and bereavement, while the psychological perspective forms an important backdrop. The research is situated within the fields of grief, bereavement, welfare and drug research.

Background: Despite extensive preventive actions, reducing drug-related deaths (DRDs) remains an international major health challenge. How bereaved parents experience DRDs has scarcely been studied. Losing a child can be more intense and prolonged than other losses, and bereaved parents who experience unnatural deaths, such as DRDs, are at risk of developing grief complications. Clearly, there is a need to pay attention to the situation of parents, left behind following a DRD.

Aim: The main aim was to explore how bereaved parents experience DRDs, what the consequences are for bereaved parents and how they cope with everyday life.

Several research questions have been explored and investigated in four articles:

Article I. A systematic review of the qualitative and quantitative literature regarding how family members experience drug-death bereavement, to understand: (1) the experience of family members before and after losing a next of kin and (2) how they perceive help and support and its influence on their bereavement processes.

Article II. How do parents experience drug-death bereavement and what different kinds of help and support do they receive?

Article III. How do drug-death bereaved parents adjust to life without the deceased and what seems to inhibit or promote adaptation during their grieving process?

Article IV. Do Norwegian parents bereaved from DRDs suffer from prolonged grief symptoms as measured by PG-13, and if so, which predictors are key to explaining their high levels of prolonged grief symptoms?

Method: The design was a qualitative driven, concurrent design, as qualitative results were used to investigate quantitative findings. This article-based thesis consists of a synopsis and four research articles: a systematic review (Article I); qualitative studies using semi-structured in-depth interviews (n=14 parents) and reflexive thematic analysis (Article II, III), and a quantitative study with a cross-sectional correlational design, using survey data (n=93 parents) (Article IV). The synopsis gives an overview of the theoretical background, the applied methodology, research design, data collection methods and data analysis. The discussion integrates the findings from Articles II-IV, followed by methodological and ethical discussion. Finally, the implications for practice, policy and research are discussed.

Results: The "special grief" was characterised by the processing of the overload of stress, due to extended parenthood, grief-related emotions and reactions, and perceived societal and self-stigma. How parents cope with the loss was influenced by processes on an intrapersonal (e.g., level of self-efficacy, using proactive coping strategies) and an interpersonal level (e.g., attitudes and norms). How the parents coped was an individual experience, affected by the context. The intensity of processing the overload decreased in the case of most of the bereaved as time went by. The parents who struggled the most, reported low self-efficacy, withdrawal and long-lasting grief.

The findings in the "special grief" of parents bereaved by drug-related deaths was discussed with regard to (1) the complexity of the "special grief"; (2) the complications of spill-over stigma; (3) the challenges of providing and receiving support and (4) the oscillation between coping styles.

Conclusion: On an individual level there is a need for immediate, proactive crises help post-loss, broad spectrum and need-related help and help over time. On a group level there is a need for support groups for those bereaved by DRD and support from social networks. Finally, there is a need to take action to reduce stigma related to drug use, enhance public recognition of those bereaved by DRD and to coordinate services on a societal level. The knowledge generated is of national and international relevance for practice, policy and for further research purposes, and may be transferable to other forms of unnatural death.

Abstrakt

Introduksjon: Dette doktorgradsprosjektet ble utført i perioden 2018 til 2021 ved Institutt for velferd og deltaking, Høgskulen på Vestlandet. Prosjektet studerer sorg og sorgbearbeiding. Et sosiologisk perspektiv ligger til grunn for utforskning, analysering og tolkning, mens et psykologiske perspektiv danner et viktig bakteppe. Forskningen plasserer seg innenfor feltene sorg-, velferds- og narkotikaforskning.

Bakgrunn: Til tross for betydelige tiltak for å redusere narkotikarelaterte dødsfall (NRdød) så er NRdød fortsatt et omfattende internasjonalt folkehelseproblem. Vi har lite kunnskap om hvordan det oppleves å miste et barn ved NRdød. Likevel vet vi at tap av et barn gir økt sjanse for sorgkomplikasjoner, og at foreldre etter unaturlige dødsfall (som NRdød), har større risiko for å utvikle forlenget sorglidelse. Det er derfor behov for fokus på og kunnskap om situasjonen til etterlatte foreldre ved NRdød.

Mål: Hovedproblemstillingen var å utforske hvordan etterlatte foreldre opplever konsekvenser og belastninger etter NRdød og hvordan de håndterer hverdagen.

Flere forskningsspørsmål er utforsket og undersøkt gjennom fire artikler:

Artikkel I. En systematisk oversikt over kvalitativ og kvantitativ forskning om familiemedlemmers opplevelse av NRdød. Fokuset var på: (1) familiemedlemmers opplevelse av tiden før og etter tap av en nærstående, og (2) hvordan de opplever hjelp og støtte, og hvordan dette påvirker sorgprosessen.

Artikkel II. Hvordan opplever foreldre NRdød og hvilken type hjelp og støtte mottar de?

Artikkel III. Hvordan tilpasser foreldre ved NRdød seg livet uten den avdøde, og hva fremmer eller hemmer deres håndtering av tapet?

Artikkel IV. Opplever etterlatte foreldre ved NRdød symptomer på forlenget sorg som målt ved PG-13, og i så fall, hvilke prediktorer er sentrale for å forklare høye nivåer av symptomer på forlenget sorg?

Metode: Et eksplorerende mixed metode design ble anvendt, der kvalitative funn var utgangspunktet for å undersøke kvantitative forskningsspørsmål. Denne artikkelbaserte avhandlingen består av en kappe og fire artikler: en systematisk oversikt (Artikkel I); to kvalitative artikler som analyserer semistrukturerte dybdeintervju (n=14 foreldre) med refleksiv tematisk analyse (Artikkel II, III); og en kvantitativ artikkel som baserer seg på en tverrsnittstudie med data fra en spørreskjemaundersøkelse (n=93 foreldre) (Artikkel IV). Kappen gir en oversikt over prosjektets teoretiske bakgrunn, metodologi, forskningsdesign, og metoder for datainnsamling og analyser. I diskusjonen integreres en drøfting av resultatene fra Artikkel II, III, og IV. Deretter følger metodologiske og etiske diskusjoner og resultatenes implikasjoner for praksis, politiske føringer og videre forskning.

Resultater: Den "spesielle sorgen" hos foreldrene ved NRdød var karakterisert av opplevelse av forlenget foreldreskap, sterke sorgrelaterte emosjoner og reaksjoner, og opplevelse av sosial stigmatisering og selvstigmatisering. Hvordan foreldrene håndterte tapet var påvirket av intrapersonlige (f.eks. mestringstro og proaktive mestringsstrategier) og interpersonlige (f.eks. holdninger og normer) forhold og prosesser. Intensiteten i de sterke sorgrelaterte emosjonene og reaksjonene avtok gradvis med tid siden død. De foreldrene som slet mest rapporterte lav mestringstro, at de isolerte seg og vedvarende/forlenget sorg.

Funnene fra de ulike artiklene ble drøftet i forhold til (1) kompleksiteten i den "spesielle sorgen"; (2) komplikasjonene ved "spill-over stigma"; (3) utfordringene med å gi og motta støtte og (4) pendling mellom ulike måter å håndtere tapet på.

Konklusjon: På individnivå er det behov for proaktiv krisehjelp umiddelbart etter tapet, samt bredspektret og behovsrelatert hjelp, og hjelp over tid. På gruppenivå er det behov for egne støttegrupper for etterlatte ved NRdød og bedre støtte fra sosiale nettverk. Videre er det behov for å iverksette tiltak for å redusere stigma relatert til narkotikabruk, styrke offentlig anerkjennelse av de som er etterlatt av NRdød, og å koordinere tjenester til etterlatte på et samfunnsnivå. Kunnskapen fra prosjektet har nasjonal og internasjonal relevans for praksis, og for politiske føringer og videre forskning. Trolig er også kunnskap overførbar til andre former for unaturlig og stigmatisert død.

List of publications

I. Titlestad, K. B., Lindeman, S. K., Lund, H. & Dyregrov, K. (2019). How do family members experience drug death bereavement? A systematic review of the literature. *Death Studies*, 1-14. https://doi.org/10.1080/07481187.2019.1649085

II. Titlestad, K. B., Mellingen, S., Stroebe, M. & Dyregrov, K. (2020). Sounds of silence. The "special grief" of drug-death bereaved parents: a qualitative study. *Addiction Research & Theory*. https://doi.org/https://doi.org/10.1080/16066359.2020.1751827

III. Titlestad, K. B., Stroebe, M. & Dyregrov, K. (2020). How Do Drug-death Bereaved Parents Adjust to Life without the Deceased? A Qualitative study. *OMEGA - Journal of Death and Dying,* 82(1), 141-164. https://doi.org/https://doi.org/10.1177/0030222820923168

IV. Titlestad, K. B., Schmid, M. T. & Dyregrov, K. (2021). Prevalence and predictors of prolonged grief symptoms among those bereaved from a drug-related death in a convenience sample of Norwegian parents: A cross-sectional study. *Death Studies*, 1-10. https://doi.org/10.1080/07481187.2020.1867255

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List of abbreviations

Table 1 List of abbreviations in the synopsis.

AB	Advisory Board in the END-study
AQ	Assistance Questionnaire
CGT	Complicated Grief Treatment
CSS	Crisis Support Scale
DPM	The Dual Process Model of coping with bereavement
DRD	Drug-Related Death
END-study	Drug-death related bereavement and recovery study
GSE-SF	General Self-Efficacy scale, Short-Form
HL	Hans Lund
HVL	Western Norway University of Applied Sciences
ICF	WHO's framework for health and disability
KBT	Kristine Berg Titlestad
KD	Kari Dyregrov
LO	Loss-Orientation
M	Means
MS	Margaret Stroebe
MTS	Marit Therese Schmid
PG	Project Group in the END-study
PGD	Prolonged Grief Disorder
PGS	Prolonged Grief Symptoms
PG-13	Prolonged Grief Disorder-13
PIOS	Population (P), Intervention(s), exposure or phenomena of Interest (I), Outcome (O), and Study design (S)
PRISMA	The Preferred Reporting Items for Systematic review and Meta-Analyses
RO	Restoration-Orientation
SD	Standard Deviations
SGQ	"Special Grief" Questions
SKL	Sari Kaarina Lindeman
SM	Sonja Mellingen
SPSS	IBM SPSS Statistics version 26
SR	Systematic Review
UK	United Kingdom
US	United States
WHO	The World Health Organization

Note on terminology

Table 2 Note on the terminology in the synopsis.

Anticipatory grief	Living with a feeling of loss and grief before the loss (Rando, 1986, p. 24)
Bereavement	Denotes the objective situation of a person who has experienced the death of someone significant (Boerner et al., 2015).
Complicated grief	See Prolonged Grief Disorder. Prolonged grief and complicated grief are used as synonyms in this synopsis.
Coping	"The changing thoughts and acts that an individual uses to manage the external or internal demands of stressful situations" (Folkman, 2001, p. 565).
Disenfranchised grief	Grief that is not acknowledged, either by one's own network or by society in general (Doka, 1999).
Drug-related death (DRD)	Deaths caused by the intake of substances, classed as narcotics and deaths among people who use narcotics where the cause of death is violence, an accident, infectious disease or other health disorders, which may be linked to drug use in various ways (Norwegian Directorate of Health, 2014, p. 14).
Dual Process Model of coping with bereavement (DPM)	This model illustrates that to cope effectively, a bereaved person must oscillate between LO and RO (Stroebe & Schut, 1999). Two additional features of the DPM, elaborated on more recently, (a) overload, "the bereaved person's perception of having more than s/he feels able to deal with," can affect the ability to oscillate (Stroebe & Schut, 2016) and (b) family dynamics are understood to affect personal grief and vice versa (Stroebe & Schut, 2015).
Extended parenthood	Reflects the consequences of children who need extended emotional, economical and practical support after having reached the age of majority (Tysnes & Kiik, 2019).
Grief	Refers to the emotional experience of the psychological, behavioral, social, and physical reactions the bereaved person might experience (Boerner et al., 2015)
Helpers	Public services as health and welfare services, police, ambulance personnel, priests, crisis teams
Interpersonal level	The bereaved and their surroundings, e.g., complex relations, attitudes and norms
Intrapersonal level	Deals with the bereaved, e.g., self-efficacy and self-stigma
Loss- Orientation (LO)	Coping processes that focus directly on the stress of the loss itself, including symptoms of grief, loss, and sadness (Stroebe & Schut, 1999).
Meaning- making	Is the process of how people "make sense of the loss or find some compensatory "benefits" or life lessons in it… they commonly integrate the event, adapt, and perhaps even grow through the experience" (Neimeyer, 2019).
Mixed methods research	"The class of research studies in which a researcher mixes or combines quantitative and qualitative research ideas, approaches, and techniques in a single research study" (Johnson & Christensen, 2016, p. 468).
Proactive coping	"Processes through which people anticipate or detect potential stressors and act in advance to prevent them or to mute their impact (proactive coping)" (Aspinwall & Taylor, 1997, p. 417).

Prolonged Grief Disorder (PGD)	Bereaved who experience grief, characterised by yearning and longing, persistent preoccupations, symptoms of intense emotional pain and significant psychosocial impairment for a minimum of six months beyond the expected sociocultural norms, meet the criteria of PGD (WHO, 2020).
Regulatory flexibility	Sensitivity toward demands and opportunities in the situational context; an available repertoire of regulatory strategies; and the ability to monitor and modify feedback (adjusting, maintaining, or ceasing strategy) (Bonanno & Burton, 2013).
Resilience	"A stable trajectory of healthy functioning after a highly adverse event" (George Bonanno in Southwick et al., 2014).
Restoration-Orientation (RO)	The processes one uses to cope with the secondary stressors that accompany one's new status as a bereaved person (Stroebe & Schut, 1999).
Special death	A death characterised by a high level of trauma, that can be socially stigmatising or existentially problematic, with the attendant grief being frequently disenfranchised (Doka & Martin, 2002).
Stigma	Exist when a stigmatised group or individual is labelled as different from others, the differences are by society perceived as negative, include a separation as an "us" from "them" mentality, discrimination and power must be exercised (Link & Phelan, 2001).
Social networks	Family, friends, colleagues i.e., support from informal network members
Unnatural deaths	Sudden unexpected and potentially traumatic death (include accidents, suicides, homicides and deaths connected with natural disasters, terror and war) (Kristensen et al., 2012).

PART I: SYNOPSIS

1. Background

> *And at the funeral the friends could come in first...I sat out of sight. I couldn't bear their grief. But there is something about adolescents that differ from the adults who are more enclosed and (sigh) afraid of saying something wrong. These youths, they were crying, they were asking questions, they were talking, and they were hugging each other and hugging me and they wanted me to sit with them (voice cracking with emotions). So we were kind of together, and I remember it like that...(crying).*
>
> (A mother in Titlestad, Stroebe, et al., 2020)

There is no right or wrong way to grieve the loss of someone who has died. People grieve in various ways, and how a person grieves, is largely influenced by interactions with other people and the context in which the loss occurred (Thompson & Cox, 2017, pp. 1-2). Most of those bereaved find a way to live on and to adjust to a life without the deceased (Bonanno et al., 2002; Galatzer-Levy et al., 2018; Stroebe, Stroebe, et al., 2017). Though bereavement is a natural path for most bereaved individuals, some find it harder than others to cope with the loss. Thus, bereavement may also be associated with distress, impairment and at times, negative health outcomes (Stroebe et al., 2007). Certain modes of death may, for different reasons, contribute to such outcomes.

Unnatural deaths are sudden unexpected deaths (Li et al., 2003). These are potentially traumatic for the bereaved and include accidents, suicides, homicides and deaths connected with disasters, terror and war (Kristensen et al., 2012). Unnatural deaths may cause grief symptoms that significantly affect the bereaved (Bonanno et al., 2002; Galatzer-Levy et al., 2018; Stroebe, Stroebe, et al., 2017). Grief-related reactions like rumination (i.e., repetitive thinking) regarding the causes and consequences of the loss, and grief-related emotional reactions (e.g., yearning, guilt, anger, loneliness or anxiety) can negatively impact the recovery process following a loss (Eisma & Stroebe, 2017; Shear et al., 2007). Thus, bereavement after an unnatural death is associated with severe psychological and physical health difficulties (Dyregrov et al., 2003; Keyes et al., 2014; Li et al., 2005; Stroebe, Stroebe, et al., 2017), a poor health-related quality of life (Song et al., 2010) and disruptions in family and marital life (Bolton et al., 2014). In addition, unnatural deaths can even increase the risk of an early death on the part of bereaved parents (Christiansen et al., 2020; Li et al., 2003). An enduring bond to the deceased and the inability to find a further meaning in life, increase the risk of a complicated grief process (Boelen et al., 2006). Following a potentially traumatic death, the lack of a meaningful life can often be experienced and can lead to suicidal thoughts (Stroebe et al., 2005). To counteract such an experience after an unnatural death, bereaved parents can benefit from support from their social network and from individualized help, provided by public services, enabling them to avoid major health problems (Dias et al., 2019; Stevenson et al., 2017).

DRDs are recognized as a major public health challenge (European Monitoring Centre for Drugs and Drug Addiction, 2018, p. 78). When this project started in January 2018, DRDs had reached epidemic proportions in the United States (US) as 21.7 per 100,000 of the population had died as a result of DRDs in 2017 (an increase of 9.6% from 2016) (Centers for Disease Control and Prevention, 2018). In Europe, the mortality rate due to overdoses, had increased to 22.6 deaths per one million of the population in 2016 (European Monitoring Centre for Drugs and Drug Addiction, 2019, p. 80) and in Norway, where this project was conducted, one of the highest numbers of overdoses were reported in 2016, totalling 81 deaths per million of the population (European Monitoring Centre for Drugs and Drug Addiction, 2018, p. 77). Since then, there has been a slight decrease in the DRD rate, e.g., in the US, a 4.1% decrease from 2017 to 2018 was recorded. However, new figures, published in the US in December 2020, are alarming. The number of overdose deaths increased by 18.2% from June 2019 to May 2020. The largest increase recorded from March to May 2020 coincided with measures implemented as a result of the COVID-19 pandemic (CDC Health Alert Network, 2020).

The definition of DRD varies, and there is a need to clarify the terms regarding DRDs (Robertson et al., 2019). Considering the Norwegian Directorate of Health (2014, p. 14), DRDs are defined as deaths caused by the intake of substances, classed as narcotics and deaths of people linked to drug use in various ways (e.g., violence, suicide, infectious disease or other health disorders). DRDs are unnatural deaths. Due to the negative effects, associated with unnatural deaths and their related consequences for the bereaved, DRDs constitute a challenging, public health problem; there is certainly a need to focus on those bereaved by DRDs.

1.1 Clarification of concepts and terms

It is challenging to draw categorical lines between the concepts of bereavement and grief (Stroebe et al., 2001, p. 6). Thus, there is a need to clarify how the terms are used and understood in this synopsis:

> The term *bereavement* denotes the objective situation of a person who has experienced the death of someone significant. *Grief* then refers to the emotional experience of the psychological, behavioral, social and physical reactions the bereaved person might experience, as a result of this death. (Boerner et al., 2015)

Thus, bereavement is the experience, and grief is the response to the experience (Shear, 2015). A distinction was also made between acute grief and grief that is persistent. Whereas acute grief is an adaptive response to loss that occurs immediately after the event (see Iglewicz et al., 2019), persistent grief denotes severe and prolonged grief, that includes severe loss of function. The latter may meet the criteria for Prolonged Grief Disorder (PGD). PGD is a diagnosis characterized by yearning and longing, persistent preoccupations with the deceased, symptoms of intense emotional pain and significant psychosocial impairment for a minimum of six months beyond the expected sociocultural norms (WHO, 2020). PGD was recently formally included in the 11th edition of the International Classification of Diseases (ICD-11). PGD is also known as complicated grief (Shear, 2015). Hence, prolonged grief and complicated grief are used as synonyms in this synopsis.

A clear distinction was made between DRDs and alcohol-related deaths, as the two types of deaths are likely to have different consequences for the bereaved. Since using drugs is an illegal activity, the addiction stigma is likely to be worsened by criminalization (Corrigan et al., 2017). Furthermore, people who die from an overdose are often younger males, who suffer a death that occurs early in the course of the dependency (Templeton et al., 2017). In contrast, the term, substances, includes drugs and alcohol and refers to research in which a categorical distinction was not made.

The terms support and help are used in relation to the resources available in the bereaved's surroundings. To clarify, the term support and supporters imply family members, friends and colleagues in the social network of those bereaved. Help and helpers refer to helpers from public services (e.g., health and welfare services, police, ambulance personnel, priests, crisis teams) and other professionals relevant for follow-up, such as undertakers.

1.2 Bereavement and grief

The literature on death as a social issue stems from sociologist, Emile Durkheim (1858-1917). Durkheim introduced the necessity of a sociological and contextual perspective to the field. He expressed that the phenomenon of death must always be studied and explained in light of its relationship with other social facts, never biological and psychological factors alone (Brennan, 2017, p. 16). Thus, Durkheim contributed significantly to our understanding of the social implications of death and death as a social problem; his thoughts that the causes of suicide were social rather than psychological, were ground-breaking (Brennan, 2017, pp. 15, 28).

The concepts of grief, bereavement and coping with loss, have developed over the decades and will continue to develop and mature in step with time (Parkes, 2001; Stroebe et al., 2001, p. 4). In 1917, Sigmund Freud (1856-1939), affected by World War I, published the influential paper, "*Mourning and Melancholia*" (Parkes, 2001, p. 27; 2002). Freud described grief as a normal, yet painful experience that the bereaved had to "work through" to accept the loss, the so-called grief work (Freud, 1955, p. 245). Since Freud's first theory, the concept of grief work has been in constant development (Stroebe & Schut, 2018). Kübler-Ross's (1969) five-stage model is one of the theories that has been widely acknowledged among the general public (Corr, 2019). The five stages (i.e., denial, anger, bargaining, depression and acceptance) are described as phases, through which a bereaved individual needs to pass to cope with the loss (Kübler-Ross, 1969). In recent decades, attachment theory (i.e., Bowlby (1982)) and cognitive stress-coping theory, (e.g., Lazarus and Folkman (1984)) have become influential frameworks (Boerner et al., 2015; Stroebe et al., 2001, p. 12). The focus has also shifted from adaptive coping to include theories relating to maladaptive coping with bereavement. Empirical and theoretical researchers have, to a greater extent, tried to understand when and why grief work is effective, in addition to different mechanisms and strategies that could influence and account for its efficacy (Stroebe & Schut, 2018).

Today, grief is considered to be a highly individualized process, without distinct stages or phases (Corr, 2019). Consequently, the five-stage model does not measure up to the standards of today's theories relating to grief and bereavement (see Corr, 2019). Corr (2019) highlights theories that are more dynamic and contextual, e.g., the Dual Process Model (DPM) of coping with bereavement by Stroebe and Schut (2010, 2015, 2016). Theories considered relevant for this doctoral project, are elaborated upon in the chapter, "Theoretical framework".

1.3 Review of the literature

The main aim of this section is to contextualize the doctoral project through a review of the literature. Article I provides a systematic review (SR) of bereaved family members' experiences of DRDs, and the perceived help and support provided. Due to a lack of research in relation to DRDs, this section offers more detailed research into family members' experiences of bereavement, having lost a loved one as a result of a DRD, and the support and help available to those bereaved, following an unnatural death (see 1.1 for a clarification of the concepts drugs versus substances).

1.3.1 Living with a person who uses substances

The summary by Orford et al. (2010) of two decades of qualitative research, shows that family life with a person who uses substances, can be highly stressful. Living with a relative with a history of substance dependency, is characterized by uncertainty, worry, constant conflicts and threats. Although there is a common core in relation to the pain experienced by affected family members, this experience varies depending on social and cultural factors. The difficulties experienced, are likely to be affected by the total burden that the family member has to bear, the closeness to the deceased and the quality of social support available (Orford, 2017).

A meta-ethnography by Lindeman et al. (submitted 2021) as to how substance use influences family life, showed that families were constantly having to adapt to the needs of their family member, that new strategies brought hope at first, which soon turned to despair when it became clear that the strategies were insufficient. Lindeman et al. (submitted 2021) argue that the situation could be viewed as an intrusion, that overshadows all aspects of life, rather than describing the consequences for the family members as a "problem" or a "difficulty".

Most of the literature that describes life with a person who is drug- or alcohol-dependent, group those who use narcotics and alcohol into the same category, without further clarification. Among the limited studies which have only examined living with a person who uses narcotics, the consequences on family life are described as totally overwhelming (Fotopoulou & Parkes, 2017; Maltman et al., 2019). In a study by Fotopoulou and Parkes (2017) in Greece, certain cultural factors that might be different from other contexts were highlighted: the affected families described the importance of family solidarity, as coping with the "problem" was regarded as a family affair, as was the issue of who to ask for support (i.e., extended family members). Both the parents and the child who had drug issues, struggled to manage the demanding life situation and the impact that the use of narcotics had on all aspects of their family life (e.g., finances, family integrity and professional lives) (Fotopoulou & Parkes, 2017). Maltman and colleagues concluded that coping alongside a family member who uses narcotics can be an oscillation between sacrificing one's own interests, versus withdrawing from him or her (Maltman et al., 2019). Thus, parental grief due to loss of identity, control and future aspirations were reported while the child was still alive (Maltman et al., 2019).

1.3.2 Those bereaved as a result of a drug-related death

On a global scale, the experiences of family members, bereaved as a result of a DRD, have hardly been investigated (Titlestad et al., 2019). The earliest empirical article of good methodological quality identified is a pilot study from Brazil. In this case, three family members were aware, and three were unaware of the decent’s drug use (da Silva et al., 2007). They reported that the secrecy surrounding death following an overdose, aroused anger, guilt and helplessness among the bereaved, who felt deprived of information that could have allowed them to take action. Families aware of the drug use seemed prepared for a potential death due to an overdose, bringing about ambivalent feelings of grief and relief, post-loss. The pilot study stressed how disturbing it was to lose a family member as a result of an overdose, and pointed to the need for psychological support for such families.

When this doctoral project was enrolled, Valentine and colleagues had conducted the first large scale research project concerning the experiences of adults, bereaved following a drug- or alcohol-related death in the United Kingdom (UK), (Valentine, 2018). The study included interviews with 106 bereaved adults in focus groups, attended by 40 practitioners (Templeton et al., 2016; Valentine et al., 2017). In the results published, drug- and alcohol-related deaths were not differentiated, with the exception of a study by Templeton et al. (2017) who studied 32 individuals, bereaved following a drugs overdose. As Templeton et al. (2017) reported, those who died of a drugs overdose differed from those who died from alcohol use. Therefore, there is an argument for studying different types of bereavement separately. Those who died as a result of a DRD were likely to be male, young and had lost their lives at an early stage of dependency, sometimes on the very first occasion that the drug was taken (Templeton et al., 2017).

Article I (Titlestad et al., 2019) in this thesis identified just seven qualitative studies from Norway, Denmark, Brazil, the US, England and Scotland (Biong et al., 2015; Biong & Thylstrup, 2016; da Silva et al., 2007; Feigelman et al., 2018; Grace, 2012; Nowak, 2015; Templeton et al., 2017) and one quantitative study from the US (Feigelman et al., 2011) of good methodological quality. This SR suggested that family members, aware of the drug use, experienced years of uncertainty, despair, stigma, hopelessness and powerlessness before their loss. The results indicated that those bereaved due to a DRD, perceived that they were dealing with a heavier emotional burden, and lacked more support from their social environment than those bereaved by other types of natural or unnatural deaths. Two of these studies were small scale studies from Scandinavia (Biong et al., 2015; Biong & Thylstrup, 2016). The findings of these two studies did not differ significantly in terms of the effect of contextual factors. The three studies that included only parents (Feigelman et al., 2018; Feigelman et al., 2011; Nowak, 2015) differed from the other studies, reporting challenges with regard to making sense of the loss and a loss of identity.

As reported in the case of parents bereaved following other unnatural deaths (Li et al., 2003), a recent registry study from Norway concurred that there is an increased risk of mortality for parents bereaved by DRDs, compared with non-bereaved parents or parents bereaved by other causes of death (Christiansen et al., 2020). This study also indicated that bereavement as a result of a DRD is associated with adverse negative health outcomes, that may be more severe than general bereavement, due to the cause of death.

Researchers have spoken about a DRD being a "special death" (Guy & Holloway, 2007; Templeton et al., 2016). Doka and Martin (2002) describe a “special death” as a death characterized by a high level of trauma, that can be socially stigmatizing or existentially problematic, with the attendant grief being frequently disenfranchised. Templeton et al. (2017) argue that DRDs are “special deaths”, highlighting the difficult circumstances surrounding the death, the stigma associated with DRDs, the challenging interactions with public services and the unworthiness associated with grieving. Templeton et al. (2017) also argued that since many of those bereaved by a DRD described living with a feeling of loss and grief before the death, they also experienced so-called “anticipatory grief” (as defined by Rando (1986, p. 24)).

1.3.3 Support and help provided to those bereaved by unnatural deaths

A general assumption is that social support is a protective factor for the bereaved, following both a natural and an unnatural death (Dyregrov & Dyregrov, 2008). In general, the bereaved ask for support from their social network of family and friends, from others who have been bereaved (i.e., peer-support) or they may seek professional help; the support and help from these various sources address different types of needs (Dyregrov & Dyregrov, 2008, p. 50).

Network supporters are commonly essential for a good grieving process, as the support they provide can help the bereaved deal with the overload of stressors they are experiencing (Stroebe & Schut, 2016). Openness, an assertion of personal needs, involves educating others as to how to support them (Dyregrov & Dyregrov, 2008, p. 118). Openness, implying that the bereaved inform their network about their support needs, can help the bereaved confront and work with their grief. However, this assumes that the network and the bereaved can give and receive support and that the supporters, to a certain extent, understand the nature of the loss (Dyregrov & Dyregrov, 2008). In studies of those bereaved by a DRD (Feigelman et al., 2011) and after suicide (Feigelman et al., 2008), parents reported that family and friends' responses were often not beneficial, rather the opposite. Feigelman et al. (2011) discussed that societal stigma due to the cause of death may have led to a lack of communication regarding the deceased, as well as dysfunctional communication, as the supporters blamed the parents.

A SR that summed up qualitative and quantitative peer support studies relating to those bereaved by unnatural deaths, showed that peer support was helpful. Overall, the results indicated that peer support reduces grief symptoms and increases personal growth and well-being. It also showed that the experience of peer supporters who provided support, was considerable beneficial (Bartone et al., 2019). As few help measures were found to be available for those bereaved by substance-related deaths, similarly, studies focusing on support for the bereaved were limited (Valentine et al., 2016). Standing et al. (2018) argued in favour of facilitating peer support for those bereaved by substance use. They argued that the impact of a substance-related death differs from other types of bereavement, that the former in particular, requires the support of a peer, due to feelings of guilt, loneliness, stigma and mixed responses from society. Peer support can offer a space where no one feels judged, and the bereaved receive support from an individual who understands, however, it is important that peer supporters are skilled (Standing et al., 2018).

The effects of bereavement groups, organized by helpers, are marginally more effective than control groups, post-treatment, but not at follow-up, a SR by Maass et al. (2020) showed. They implied that the evidence for bereavement groups is weak, though they problematized that the considerable heterogeneity of concepts for intervention and control groups, limits the generalizability. The importance of studies with more homogeneous populations in the intervention group, might be illustrated by the study of the intervention, "*The 5-Step Method for adults bereaved by substance use*" by Templeton (2020). Considering the small sample size of six bereaved, the findings of new strategies regarding how to respond to the loss and getting support from others, were encouraging. Following Feigelman et al. (2018) findings after interviews with parents bereaved by DRDs, and Templeton (2020) research into the bereaved, highlighted the benefits of talking openly about the type of death and bereavement.

The UK-study showed that those bereaved by DRDs struggled in accessing support from both formal and informal circles (Templeton et al., 2017). The bereaved reported that they were poorly understood, neglected and stigmatized by helpers, and that it was challenging to manoeuvre between fragmented services to gain an overview of procedures and relevant services (Valentine et al., 2017). A guideline with five key messages was developed for helpers, as a result of the UK-study (Cartwright, 2015). The guidelines aim to increase awareness of bereavement after substance-related deaths and adherence to the guidelines that describe how to implement relief measures. One of the key messages related to the importance of showing kindness and compassion when encountering the bereaved. A forensic pathologist and his colleagues demonstrated the importance of this message in a case study that described how a forensic pathologist established a relationship with those bereaved from a DRD (Abiragi et al., 2020). Interviews between the forensic pathologist and the bereaved revealed that it was crucial to determine an accurate cause of death. This insight was described as essential to the bereaved in coping with their loss.

The Norwegian white paper "*The Psychosocial Interventions in the Event of Crisis, Accidents and Disasters*" recommends action plans be followed up in the municipalities after unnatural deaths (Norwegian Directorate of Health (Norwegian Directorate of Health, 2016, pp. 31-35). The white paper's main features state that community helpers should provide early and active outreach, cover a broad spectrum and adapt the help available for all family members, with regular follow ups over time. This white paper highlights that health and welfare services need to initiate preventive work to avoid intense grief reactions and to promote adaptive coping strategies. Considering that this is a relatively new regulation, a study carried out by Biong et al. (2015) into eight Norwegian individuals, bereaved by a DRD, points out that spontaneous support and out-reach help is deficient.

In addition to the literature which advocates help for those bereaved as a result of an unnatural death, a new model which is gaining support, is that of internet support groups (Wagner et al., 2020). All web-based interventions published, are based on cognitive-behavioural therapy, and the numbers of studies are, to date, too scarce to draw any conclusions. Still, the results are promising, as the interventions indicated a moderate to large effect in reducing symptoms of grief and post-traumatic stress disorder and also had a minor beneficial effect on depression (Wagner et al., 2020).

In summary, while the scientific investigation has recently increased our understanding of grief following DRDs, there is still much to learn about this particular type of grief. Research is needed to inform affected families, first responders, professionals in health and welfare services and decision-makers. The literature review shows the complexity of the situation of those bereaved by DRDs. They experience an overload from living with a person with a drug dependency that affects their life before and after the loss and that tailored measures for them are absent. The SR (Article I) showed that DRD studies had essentially merged participants with different relationships to the deceased, e.g., parents, siblings, friends (Titlestad et al., 2019). As there is a need for more precise research questions that define the participant's relationship to the deceased, this doctoral project focuses exclusively on parents.

1.4 The END-study - context for the doctoral project

To fill in the knowledge gap on the topic of bereavement following a DRD, a large Norwegian study known as "*The Drug-death Related Bereavement and Recovery Study*" (Norwegian acronym: "The END-study") was launched in the spring of 2017 at Western Norway University of Applied Sciences (HVL). The purpose of the END-study was to acquire knowledge relating to the bereavement process of family members and close friends following a DRD, ascertain the way in which helpers encountered this group of bereaved individuals and enhance quality and competence in the health and welfare services. The study is funded until October 2023. The doctoral project is part of the END-study. To clearly distinguish between the content that relates to the doctoral thesis and the text referring to the END-study, the term study is used in relation to the END-study and the term project refers to the doctoral project.

The END-study's main aim is to improve the life situation of those bereaved by DRDs. The study also aims to motivate and direct politicians, policymakers and public authorities to improve the competency and efficiency of health and welfare services. The END-study will contribute to developing more effective services by documenting and exploring the situations of family members, coping with drug dependency before and after death, and how health and welfare services function and can be optimized. By generating knowledge relating to preventive and health-promoting factors, tailored interventions will be suggested. This new knowledge will be conveyed to personnel in the health and welfare services and to students in health and welfare education, both nationally and internationally.

The END-study constitutes mixed methods research, collecting quantitative data by means of a survey and qualitative data through in-depth and focus group interviews (ResearchGate, 2020). Figure 1 illustrates the participants included in the END-study and the four sub-studies: 1. situations of bereaved family members and close friends, 2. perspectives of the bereaved in relation to what prevents/facilitates the recovery process, 3. bereaved siblings' experiences before death and 4. the provision of health and welfare services. This doctoral project is based on sub-study 1. and sub-study 2.

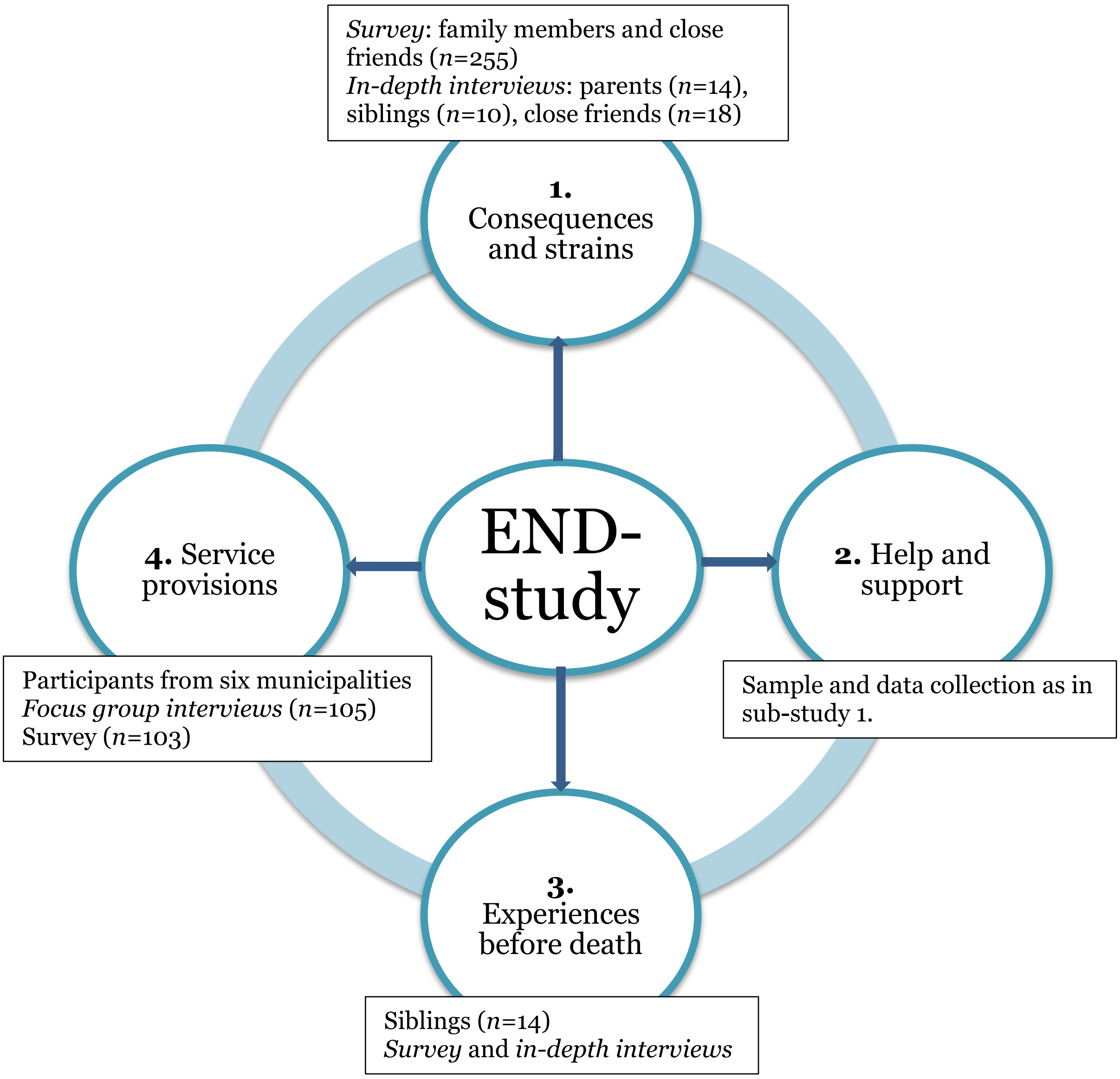

Figure 1 Overview of the aims of the END sub-studies, methods and participants.

A project group (PG) and an advisory board (AB) are involved in the END-study. The PG comprises an interdisciplinary group of 17 researchers, user representatives and teachers at HVL (expertise in substance abuse, family therapy, crisis psychology, bereavement, community crisis assistance). The AB consists of 13 researchers and professionals from the US, England, the Netherlands, Denmark and Norway (research bereavement, substance use, stigma, recovery, health service) from non-governmental organizations, municipalities, university hospitals and universities. The four bereaved user representatives have been working closely with the researchers throughout the research processes. In addition, knowledge translation measures are being formulated by a research circle, consisting of the bereaved, helpers in the municipalities, non-governmental organizations, researchers and students from HVL.

1.5 Study rationale

The END-study took place in Norway. Internationally, the Norwegian welfare state is viewed as service intensive. Health and social services are based on the classic Scandinavian welfare model, in which the state finances and provides universally accessible services to everyone. The Norwegian citizens receive free healthcare or are provided services following a small co-payment (Vabø, 2014, p. 11). The Scandinavian welfare model is characterized by a high degree of equality and is funded by a high level of taxation, with the public spending a large amount of money on welfare (Greve, 2007).

The "Health and Care Services Act" regulates the municipality's duty to offer and provide necessary health and care services to all residents in the municipality (Health and Care Services Act, 2011, ACT 24/06/2011 no.30). The act's objectives are to promote social security, improve living conditions for the disadvantaged, contribute to equal worth and gender equality, and prevent social problems. The act aims to coordinate and ensure the quality and equality of the services offered, and to guarantee that these services are available and are adapted to individual patients' or clients' needs.

This principle of equality is also stated in The Norwegian white paper, "*Principles for priority setting in health care.*" In this paper, the government points out that the citizens of Norway should receive equal services as needed, "regardless of gender, religion, socioeconomic status, level of functionality, relationship status, place of residence or ethnic background" (Norwegian Ministry of Health and Care Services, 2016, p. 12).

In 2016, when planning the END-study, the number of DRDs in Norway was 282, placing Norway among the countries with the highest number of such deaths recorded in Europe (European Monitoring Centre for Drugs and Drug Addiction, 2018, p. 77). DRDs, those who use drugs and the situation faced by their loved ones are acknowledged by the authorities as being serious public health issues. The national guidelines, “*Next of Kin in Health and Social Care*” (Norwegian Directorate of Health, 2018) and “*The Psychosocial Interventions in the Event of Crisis, Accidents and Disasters*” (Norwegian Directorate of Health, 2016) describe the actions required for those bereaved by potentially traumatizing, unnatural deaths. Both the “*National Overdose Strategy 2014-2017*” (Norwegian Directorate of Health, 2014) and the “*Plan to strengthen efforts in drug prevention and rehabilitation*” (2016-2020) (Norwegian Ministry of Health and Care Services, 2015) emphasize the goal of improving assistance for the bereaved, who require help following the death of a loved one from an overdose. These white papers outline the need for measures to improve public services for those bereaved by a DRD, and the importance of user involvement in designing services for these target groups, both on an individual and a systemic level. Despite these governing documents, those bereaved following a DRD in Norway, reported a lack of tailored interventions for individuals bereaved in this way (e.g., through the media).

1.6 Aim and research questions

Since there has scarcely been any empirical investigation into bereaved parents’ grief and the help and support they need, this doctoral project aims to contribute to the understanding, awareness and acceptance of parents’ grief after a DRD. In the doctoral project, an overarching research question is addressed:

> *“How do bereaved parents experience DRD, what are the consequences for bereaved parents, and how do they cope with everyday life?"*

Due to the complexity of the phenomena studied, the implications of drug-death bereavement and the broader range of research questions, a mixed methods research design which prioritized the project’s qualitative components, was chosen. The method is initially exploratory and inductive, i.e., focuses on theoretical discoveries, generation and construction (Johnson & Christensen, 2016, p. 18).

The focus has been on describing parental grief, and the consequences and burdens of a DRD for the parents under study. Moreover, the project explored the parents’ own experience of what inhibited and prompted the adjustment to life. In the synopsis (Part I), the qualitative and the quantitative findings are integrated into the discussion chapter. In addition to the synopsis, a SR, two qualitative articles and one quantitative article are embedded in the thesis (Part II). Several research questions have been explored and investigated in four articles:

Article I – a SR of the qualitative and quantitative literature regarding how family members experience drug-death bereavement, in order to understand: (1) the experience of family members before and after losing a next of kin, and (2) how they perceive help and support and its influence on their bereavement processes.

Article II - in-depth interviews: How do parents experience drug-death bereavement and what different kinds of help and support do they receive?

Article III - in-depth interviews: How do drug-death bereaved parents adjust to life without the deceased and what seems to inhibit or promote adaptation during their grieving process?

Article IV – survey data: Do Norwegian parents bereaved from DRDs suffer from prolonged grief symptoms as measured by PG-13, and if so, which predictors are key to explaining their high levels of prolonged grief symptoms?

1.7 Structure of the synopsis

This synopsis consists of six chapters, and each chapter starts with an outline that clarifies its content. Chapter 1 provides an overview of the project's background and describes its context, leading to the doctoral dissertation's research questions. Presented in more detail are the theoretical frameworks of the projects (chapter 2), although the philosophy of science is presented under methodology, to show how ontology and epistemology govern the choice of methods of data collection (chapter 3). Chapter 4 describes the results of the four published articles. As each article's result is discussed in the articles, the discussion of the results consists of an integrated and extended discussion of the findings in Articles II, III and IV, followed by a discussion of methodological and ethical considerations (chapter 5). Finally, the conclusion and future perspective for practice, policy and research, are presented in chapter 6.

2. Theoretical frameworks

A sociological perspective is incorporated when exploring, analysing and interpreting grief and bereavement, while the psychological perspective forms an important backdrop. Stroebe, Stroebe, et al. (2017) represent a large group of grief theorists when they state that although bereavement merits medical awareness, it is not a disease. I position myself in line with the latter, and also with the theorists and researchers, who state that death, grief and coping with bereavement, do not occur in a social vacuum (Doka & Martin, 2002; Dyregrov et al., 2016; Parkes, 2002; Stroebe et al., 2013; Thompson et al., 2016). It is important to acknowledge individual differences in relation to how a bereaved person copes with a loss, and therefore, it is essential to complement a psychological perspective. Studying the phenomena of grief and bereavement, a psychological approach alone can "produce an incomplete and distorted understanding of the human experience of illness and loss" (Thompson et al., 2016). Therefore, this project was set in a social science tradition, as it is a study of society and how people behave and are influenced by the world around them (see Economic and Social Science Research Council, 2020).

When conducting social science studies, Joas and Knöbl (2009, pp. 17-19) recommend engaging with different theories, and point out that it is essential to be aware of the impossibility of making a clear division between empirical and theoretical knowledge. Hence, different theoretical models within social science theories and grief theories, constitute this project's theoretical lenses. These sections elaborate on theories relevant to this project. With regard to certain theories, epic findings are described to highlight the relevance of the theory.

2.1 The sociology of death, grief and bereavement

Two sociologists, Peter Berger and Thomas Luckmann, are credited for ground-breaking work in the field of sociology. By founding a sociological theory on phenomenology and philosophical anthropology, they establish a bridge between the work of Durkheim and other earlier theorists (e.g., Max Weber). Berger and Luckmann established a sociological theory that filled the gap between subjectivism and objectivism, leading to a paradigm shift in understanding knowledge (Dreher, 2016). Berger and Luckmann stated that “the sociology of knowledge is concerned with the analysis of the social construction of reality.” (Berger & Luckmann, 1991, p. 15) and that “the analysis of the role of knowledge in the dialectic of individual and society, of personal identity and social structure, provides a crucial complementary perspective for all areas of sociology.” (Berger & Luckmann, 1991, p. 208).

A sociological approach offers the opportunity to examine and understand death, grief and bereavement, considering behaviour, attitudes and values in a society. The impact of social network support, professionals’ practice and a society’s policy may have on the bereaved, can contribute to understanding why certain people can go on with their lives after their loss, while others struggle (Thompson & Cox, 2017, pp. 1-2). In terms of a sociological approach, the bereaved are acknowledged as unique individuals, and at the same time, as being a product of a social context and affected by society (Thompson & Cox, 2017, p. 4). Berger and Luckmann’s dual focus on how “society” is situated within human beings through socialization in a given society, and how human beings act on social values which influences them on a societal level, is vital. The external, objective world becomes part of the internal, subjective world, and as social actors, we internalize norms and values, accepting them as a given, and making them our reality (Berger & Luckmann, 1991, p. 84). From this perspective, the social norm of stigmatization may be changed by people reacting to such norms, protesting against them and changing them to a new norm of de-stigmatizing attitudes (e.g., attitudes towards DRDs).

Thus, in line with Berger and Luckmann, the experiences of individuals and groups in relation to drug-death bereavement, are largely influenced by the social context in which they occur. Across a small scale of studies, published on drug-death bereavement, family members have reported that a child’s use of narcotics leads to an overload of consequences, which negatively affect those family members. In society’s social context, they described stigmatization as a lack of understanding on the part of the social world, consequently leading to a lack of help and support after their loss (Titlestad et al., 2019). Hence, parental drug-death bereavement should be studied from an individual perspective and in relation to contextual processes. This understanding of the consequences of context and social implications is also essential in understanding other phenomena and concepts, such as health.

2.2 A socio-historical and contextual understanding of health

As clearly stated, bereavement following an unnatural death has consequences on a bereaved individual's physical and psychological health. When studying the consequences of parental drug-death bereavement, losing a child is likely to affect the health of those bereaved by a DRD, in a similar way to those bereaved by other unnatural deaths. Research from social sciences enables us to clarify how health and well-being have been defined and re-defined through the centuries. To study the well-being of others, health needs to be understood as something more than the absence of disease. This shift in the understanding of health can open up opportunities for more marginalized voices to be heard and to be understood more clearly (Hinchliffe et al., 2018).

The World Health Organization (WHO) defines health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO, 1946). The WHO's definition is generally accepted, although some argue that it is no longer fit for purpose (Huber et al., 2011). Huber and colleagues (2011) propose a change from a static formulation towards a more dynamic understanding of the concept, replacing the definition of health with a conceptual framework of health. Within this framework, health is described as "the ability to adapt and to self-manage", and the concept of health is operationalized in three domains, physical, psychological and social health (Huber et al., 2011). A dynamic understanding of health in which all three domains represent the concept and are understood in a socio-historical context, in relation to one another and as a whole, forms the basis for this doctoral project's research approach.

According to the WHO's framework for health and disability, namely ICF, functioning is conceptualized as a "dynamic interaction between a person's health condition, environmental factors and personal factors." (WHO, 2013, p. 5). ICF describes participation as involvement in a life situation, and participation restrictions as the problems an individual may experience in relation to involvement in life (WHO, 2013, p. 8). Social participation can be described as social interaction with persons other than a spouse (e.g., organizational affiliations, friendship and social networks) (Utz et al., 2002). Lilja and Josephsson (2017) elaborate that participation phenomena take various meanings among different groups and across different cultures. Once again, context plays an important role. Health, functioning and participating are interdependent concepts, influenced by the context and equally have an influence on the context (see Berger & Luckmann, 1991). Hence, the applied holistic approach is assumed to study the consequences of bereavement after a DRD and considers that losing a child affects one's health, functioning and social participation.

2.3 The concept of stigma and its consequences for health

Stigma has negative effects on personal health (Sheehan & Corrigan, 2020). Erving Goffman first presented the fundamentals of stigma as a social theory. Goffman stated that stigma exists in the relationship between an attribute, a person/group and certain individuals who view that attribute as abnormal (Goffman, 1963, p. 3). In recent times, Link and Phelan (2001) have maintained that stigma exists when a stigmatized group or individual is labelled as different by comparison with others; these differences are often perceived by society as negative and include a separation of "us" from "them" mentality, demonstrating clear discrimination. Perceiving stigma can be stressful and can affect a person's psychological well-being (e.g., increased risk of depression and anxiety). In addition, avoidance from seeking help, withdrawal from one's network and experiencing complex relationships with one's surroundings, are consequences of different stigma types and are all moderators for different physical, psychological and social health challenges (Sheehan & Corrigan, 2020).

Sheehan and Corrigan (2020) describe six types of stigma that have the potential to impact health. One is public stigma, namely, the negative attitudes of the general public towards individuals who possess an undesirable characteristic, such as drug use. Experienced stigma, conversely, occurs when a person is treated unreasonably, such as being denied access to public places. Another example of stigma is self-stigma or the internalization of public perceptions, leading an individual to believe that he/she is as incompetent as society believes him/her to be. Anticipated stigma relates to a person's fear of reactions from others (e.g., a father fearing the reaction of colleagues, knowing that his child has died from using narcotics). The last two stigmas are associative stigma and structural stigma, which are stigmas relating to one's surroundings. Structural stigma refers to laws and politics that restrict opportunities for a person (Sheehan & Corrigan, 2020). Goffman (1963) writes about associative stigma as a spill-over, i.e., the tainting of an individual in such a way that social discredit affects them to the same degree. Such discrediting leads the stigmatized person to feel shame.

Stigma in relation to individuals who use drugs, is well known (Corrigan, Kuwabara, et al., 2009). Considering Goffman's descriptions, a stigma directed towards people who use drugs constitutes the stigmatization of a character defect. The "defected" person's family is, to a certain degree, forced to share the discredit because those who are related to or connected to the stigmatized person, have experienced the fact that society treats them as a unit (Goffman, 1963). In this way, the family members themselves become stigmatized through their association with those who have been discredited. It is also relevant to study whether, or to what extent, parents bereaved by a DRD, experience the other five types of stigma.

Results from another part of the END-study indicate that the bereaved risk severe stigmatization from being associated with illegal and criminal activity, as a result of their children's drug use (Dyregrov & Selseng, 2021). In the UK-study, Walter et al. (2017) reported that when the child was alive, parents were ignored over the course of treatment programmes, pathologized as a part of the dependency or regarded as a dysfunctional element, rather than a potential contributor to the solution of the child's problem. The families also encountered stigma in support services in terms of the insensitive language used or the disapproval shown, and perceived that others regard them as bad parents (Templeton et al., 2017). This stigma may be related to attitudes within the support services, that the family has contributed to the drug problem (Valentine et al., 2017). The fact that a person is drug dependent, is regarded negatively by many. The reactions and expectations from others that the bereaved should "get over it", or should move on quickly, results in many bereaved individuals feeling stigmatized (Biong et al., 2015). Therefore, the loss may not be acknowledged by others, due to the stigma. Disenfranchised grief is defined as grief that is not acknowledged, either by one's network or by society in general (Doka, 1999). Disenfranchised grief can also be self-imposed, with the bereaved adopting the social and cultural norms and attitudes of those around them, in relation to what "deserves to be grieved over".

2.4 Prolonged grief disorder

Although most of the bereaved adjust to their loss, a minority continue to struggle with their grief beyond expectations (Stroebe, Stroebe, et al., 2017). The bereaved, who experience grief that causes a severe functional disability for a minimum of six months, meet the criteria for PGD (see 1.1 for PGD characteristics) (WHO, 2020). A SR by Lundorff et al. (2017) suggested that one out of 10 bereaved adults are at risk of PGD. Another SR which investigated the prevalence of PGD showed an increased risk among those bereaved following an unnatural death; as many as five out of 10 met the criteria (Djelantik et al., 2020). A greater prevalence of PGD was associated with the death of an only child, violent killings and a non-western study location. Morris et al. (2019) summarized studies examining the prevalence of PGD among parents, and highlighted that the cause of death affect the likelihood of experiencing PGD. He identified instances of PGD of 10% when a child died of a known disease, (i.e., cancer) versus a rate of 94% following a ferry accident in South Korea. The younger the age of the deceased and the traumatic/sudden cause of death were clear risk factors (Morris et al., 2019).

Several limitations are discussed regarding the PGD prevalence studies, such as the response bias (e.g., the self-reported questionnaire data, collected via a clinical tool), the different criteria for PGD between tools and the sampling/selection bias, due to small sample sizes and random recruitment procedures (Djelantik et al., 2020). Prigerson and Maciejewski (n.d.) developed the Prolonged Grief Disorder-13 (PG-13) to assess PGD symptom levels (Prigerson et al., 2009). This tool has been widely used and has been validated (Işıklı et al., 2020; Pohlkamp et al., 2018); PG-13 is, therefore, included in this doctoral project's survey. The prolonged grief symptom (PGS) level is the main focus of this project, not the prevalence of a PGD diagnosis.

This is due to a lack of consensus regarding a cut-off score in relation to PG-13 (see Pohlkamp et al., 2018) and the fact that a clinical assessment is needed to determine a PGD diagnosis.

Responses as to whether grief is a disease vary (Granek, 2017, p. 264). There are concerns about whether the PGD diagnosis pathologizes grief, which can lead to the "medicalization" of normal grief (Granek, 2017, pp. 266-267). Kari Dyregrov, through her research, voices the experiences of numerous individuals, bereaved by unnatural deaths. She warns against disregarding the reality of prolonged and disabling grief, while theorists are debating the medicalization of grief (Dyregrov, 2004b). Thus, I position myself in line with the latter, and acknowledge the reality that certain bereaved persons experience prolonged and disabling grief. Various measures must be offered in relation to PGD and depression, which should also be mapped by different instruments (Kristensen et al., 2017). From my perspective, a critical advantage of establishing criteria for PGD, is the possibility of distinguishing PGD from depression, two conditions that share certain similarities. The need for tailored measures for bereaved individuals suffering from PGD, is supported by studies comparing therapy for complicated grief with "ordinary" interpersonal psychotherapy (Shear et al., 2005; Shear et al., 2014). Other advances regarding the diagnosis of grief ensure that the bereaved are given access to public benefits, such as therapy and sick leave (i.e., benefits provided in Norway) (Kristensen et al., 2017).

Different therapies for the treatment of PGD are identified. A SR by Johannsen et al. (2019) showed that individually-based therapy for the bereaved might be associated with larger effects than group-based interventions at the post-intervention stage. The SR identified different grief-specific, individual therapies, developed to treat PGD, such as Complicated Grief Treatment (CGT) (Shear & Bloom, 2017) and Integrative Cognitive Behaviour Therapy for Prolonged Grief (Rosner et al., 2015). These therapies aim to resolve grief complications and facilitate the bereaved person's natural adaptive process (Shear & Bloom, 2017).

In accordance with the sociological perspective of the project the PGD experiences of parents, bereaved by a DRD, should be understood as an individual experience, influenced by the social context in which they occur. From such a perspective, help measures for the bereaved must be individually adapted. Whether individual therapy, peer-support or medication should be offered, must be assessed on the basis of the individual's needs and wishes. In addition, helpers need to know more about the context in order to be able to provide the bereaved with the help they need. Thus, we need to understand more about the "special grief" related to a DRD.

2.5 The "special grief" experienced by those bereaved from a drug-related death

From the general literature on grief and bereavement, particularly resulting from sudden, unexpected and potentially traumatizing deaths, it is possible to make certain assumptions in relation to the phenomenon of drug-death bereavement. Grief researcher, Dyregrov, has developed a theoretical model to explore the phenomenon (Figure 2) (Dyregrov et al., 2019). While the first two boxes (serious drug use and anticipatory grief) refer to the period before death, the last three boxes (ambivalence, complicated grief and disenfranchised grief) describe critical aspects after death.

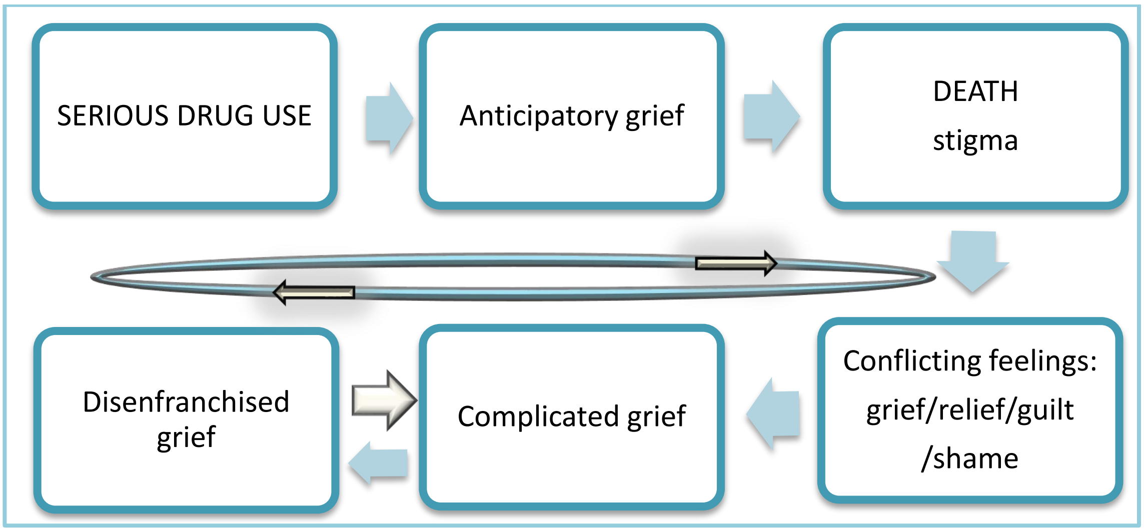

Figure 2 The "special grief"-model. A theoretical model by Dyregrov et al. (2019).

The box, “serious drug use” refers to the way in which individuals, close to the person who uses narcotics, are faced with a strenuous and challenging situation while the person using drugs is still alive. Dyregrov et al. (2019) assumed that anticipatory grief and living with a person who uses narcotics, can contribute to an emotional overload and can make the processing of grief more difficult for the bereaved. In line with stigma theories, this model also incorporates the possibility that those bereaved by DRDs, can experience negative attitudes and actions from those around them, such as networks, local communities and helpers. Following the findings of da Silva et al. (2007), Dyregrov et al. (2019) proposed that those bereaved by DRDs, experience conflicting feelings of grief, anger, guilt, self-blame and relief. As research into individuals, bereaved as a result of an unnatural death, has demonstrated an increased risk of grief complications (Dyregrov et al., 2003; Heeke et al., 2017), Dyregrov et al. (2019) also assume that parents, bereaved from a DRD, are at risk of experiencing complicated grief. The model also integrates the notion of disenfranchised grief among those bereaved by DRDs, indicating that experiencing a loss which is not acknowledged by others, may complicate the grieving process.

Importantly, the arrows between boxes will vary depending on the individual, reflecting that coping with grief and the grieving process, are unique and different. Therefore, the boxes’ themes must be understood in this context, as well as in relation to one another and as a whole. The reactions will also unfold during interaction within the social context surrounding each bereaved individual and each bereaved family (Dyregrov et al., 2019). Aside from knowledge relating to the “special grief” surrounding a DRD, an understanding of the factors that facilitate and inhibit natural grieving processes is required.

2.6 Intrapersonal and interpersonal processes in loss adaptation

This section highlights two dominant approaches to understanding how a person adapts to life challenges, using coping processes and emotion regulation (Marroquín et al., 2017, p. 254). Coping refers to “changing thoughts and acts that an individual uses to manage the external or internal demands of stressful situations” (Folkman, 2001, p. 565). In these situations, emotions shape how people interact, and emotion regulation plays a crucial role in generating correct responses (Gross, 2015). In line with Gross (2015), emotion regulation refers to our efforts to influence emotions in ways that we believe will increase the possibility of them being helpful rather than harmful. Depending on the context, emotions can either be harmful or helpful, depending upon whether they guide sensory processing to enhance, adequate decision-making, and provide information that leads to socially appropriate behaviour (Gross, 2015).

The DPM by Stroebe and Schut (1999) is a theoretical model of coping, that captures loss adaptation through coping processes and emotion regulation. The model explicitly describes flexibility in the coping process and that to cope in the best way, a bereaved person must oscillate between loss-orientation (LO) and restoration-orientation (RO). LO refers to coping processes that focus directly on the stress of the loss itself, including symptoms of grief-emotions, while RO embodies the processes used to cope with secondary stressors (e.g., having lost one's caregiving identity) that accompany one's new status as a bereaved person (Figure 3).

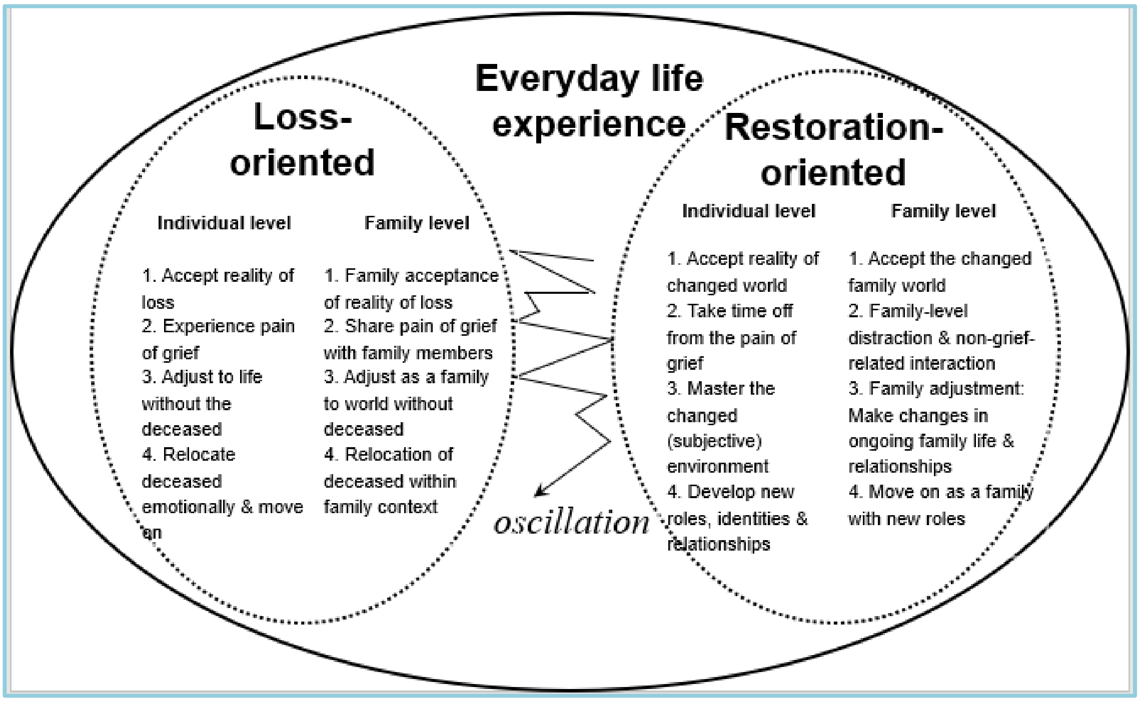

Figure 3 The Dual Process Model–Revised (DPM-R) by Stroebe and Schut (2015). Used with the permission of Professor Stroebe.

Besides processes, coping on an intrapersonal level refers to the strategies or styles of reducing, mastering or tolerating the loss (Stroebe & Schut, 2010). The strain on family life, due to the drug use pre-loss, and the complex consequences post-loss, add complexity to the DPM (see 1.3.1 – 1.3.3). The bereaved person's perception of having more than s/he feels able to deal with, i.e., overload, can inhibit his/her ability to oscillate (Stroebe & Schut, 2016), while family dynamics are understood to affect personal grief and vice versa (Stroebe & Schut, 2015). Therefore, the way in which a bereaved individual copes, is influenced by processes on an intrapersonal level (the bereaved) as well as processes on an interpersonal level (the surroundings)(Stroebe & Schut, 2015).

In addition to coping and emotional regulation, regulatory flexibility is an important concept, which helps understand how a person adjusts to life after a loss (Bonanno & Burton, 2013). Bonanno and Burton (2013) described three sequential components of regulatory flexibility: (1) sensitivity towards demands and opportunities in the situational context; (2) an available repertoire of regulatory strategies and (3) the ability to monitor and modify feedback (adjusting, maintaining or ceasing to use a strategy). Bandura (1982) describes self-efficacy as the perception that a person has the capability to react effectively and functionally to environmental demands. Bandura (1982) definition reflects that self-efficacy contains elements described as components of regulatory flexibility. Therefore, self-efficacy can be considered a personality resource, that can influence how a person copes with a loss.

A common feature for researchers studying coping, emotional regulation and regulatory flexibility is the fact that they agree upon the importance of individual differences in the degree of regulatory flexibility and the consequences of various strategies (Bonanno & Burton, 2013; Folkman & Moskowitz, 2004, p. 747; Gross, 2015; Kashdan & Rottenberg, 2010; Stroebe, Schut, et al., 2017). These are individual differences that evolve in the interplay between the bereaved's social context and individual personality factors. It is also important to bear in mind that processes or a given strategy are seldom adaptive or maladaptive for all individuals. Whereas adaptive rumination relates to one's emotional reactions, maladaptive rumination refers to repetitive thoughts regarding injustice or what could have been (Eisma et al., 2014). For the ultimate adaptation, Bonanno and Burton (2013) emphasize the importance of various strategies, rather than emphasizing whether a strategy is adaptive or maladaptive. Hence, regulatory flexibility seems especially relevant in DRD bereavement, given the range and complexity of the associated stressors (see Templeton et al., 2017).

Bowlby's attachment theory, that individuals form instinctive affectional bonds, is another influential theoretical framework, useful for understanding responses to loss (Boerner et al., 2015). The assumptions that attachment security is important in adjusting to bereavement (Boerner et al., 2015), and that the bereaved feel they have failed when a child (i.e., an attachment figure) dies (Shear et al., 2007), are both based on Bowlby's theories. This failure is often reflected in guilt and blame, that can also complicate the grieving process. In the case of the bereaved, avoidance (both emotional and situational) can lead to withdrawal from activities and can contribute to functional impairment (Shear et al., 2007). However, avoidance can also afford the bereaved respite from the pain and can facilitate processing of the loss. Thus, avoidance can be adaptive and can enable the grieving process, but at the same time can be maladaptive and can hinder this very process (Shear, 2010).

To which degree a person adjusts to life after a loss, is also affected by the way in which they find meaning in life (Neimeyer, 2019). The process of meaning-making may facilitate coping with the loss of a family member, through a complex reorientation in relation to the world. Bellet et al. (2019) argue that for those who have lost someone on account of stigmatizing circumstances, such as an overdose, certain social interactions can be particularly deleterious, as the loss and bereavement process is not consistent with cultural expectations. Therefore, Bellet and collegues argue that social environments can be a barrier to making sense of a loss, as the bereaved network can misinterpret or minimize the loss.

Lakey and Orehek (2011) claim that affect regulation is primarily relational and plays out in social interaction. Hence, the strong emotions of the bereaved will influence the consequences, thoughts and actions of, for example, a supporting friend, who will, in turn, influence the bereaved. Thus, in line with relational regulation theory (Lakey & Orehek, 2011), we need to focus on relational influences and processes to understand the handling of grief after a DRD (i.e., interpersonal processes).

DPM and the “special grief”-model were the two most central theoretical lenses in this doctoral project, which guided the choices of issues, assumed essential for examination. The models were used as a framework to shape research questions, identify relevant questions for the survey and to develop themes for the in-depth interview guide. However, this project has an inductive approach, and an exploratory research design was important. When carrying out data analysis, bracketing the models was necessary to protect and enhance the research process, so as to be open to results other than perspectives relating to DPM and the “special grief” model. Consequently, my role as a researcher is examined by accounting for self-reflexivity (see 5.2.2).

To show how the philosophy of science aligns with the paradigmatic stance, the rationale for this project’s methodology is described in the next chapter, “Methodology”.

3. Methodology

Philosophical assumptions shape the process of research and the conduct of enquiry (Creswell & Clark, 2017, p.34). In this chapter, I describe and explain the rationale for the philosophical foundation of this project, the overall research process and the research design. This chapter also contains descriptions of the choice of methods for each article, including recruitment, data collection and analysis.

A mixed methods research design was used for this doctoral project. Mixed methods research "is the class of research studies in which a researcher mixes or combines quantitative and qualitative research ideas, approaches, and techniques in a single research study" (Johnson & Christensen, 2016, p. 468). Mixed methods research was chosen due to the complexity of drug-death bereavement, which required that both qualitative and quantitative research questions were addressed. Hence, this doctoral project systematically mixes ideas, approaches and techniques from both quantitative and qualitative research.

3.1 Philosophical foundations

This doctoral project applies a pragmatist worldview as an overarching philosophy. A pragmatist researcher is not committed to any system of philosophy or theory. A pragmatist worldview is typically associated with mixed methods research, as within pragmatism, the research question governs the choice of methods used (Johnson & Christensen, 2016, p. 471). To elaborate on this project's philosophical foundations, I will reflect upon ontology and epistemology from a pragmatist perspective. Ontology reflects what the researcher considers to "be real", whereas epistemology reflects the researcher's views of how to gain knowledge (Creswell & Clark, 2017, p. 37).

As a pragmatist researcher, I understand what is assumed to be real or true in the world as pluralism, meaning that I appreciate objective, subjective and intersubjective realities, in line with Johnson and Christensen (2016, p. 471). Ontology is a vast topic in which one of the key concepts constitutes existentialist thoughts (Thompson & Cox, 2017, p. 130). When seeking to understand bereavement, existentialist thoughts refer to the assumption that change is constant, and that there are few certainties in life. The nature of death is perceived through existentialist thoughts, reflecting upon the fact that what we have now, can be taken away from us at any moment (e.g., losing a child). Other ontological topics, relevant when studying bereavement, are facticity and transcendence. Facticity refers to the fact that certain things are beyond our control, while transcendence means that we can control how we react (Thompson & Cox, 2017, p. 132). Consequently, death is beyond our control, however, the bereaved can influence the grieving processes. As such, from a pragmatic worldview, there are singular and multiple realities of how the loss is perceived among the bereaved, what they can control and the extent to which they themselves can influence the grieving process.

Through epistemology, we are offered perspectives of how we experience a loss, the consequences of grief, how we grieve and an understanding of bereavement (Attig, 2004). Within pragmatism epistemology, the entrance to knowledge is via the research questions we wish to answer, rather than through the methods. Hence, the way to approach the research question is to establish “what works” in a specific situation (Creswell & Clark, 2017, p. 38). As the philosophical foundations of this project endorse the fact that research conclusions are rarely absolute, both descriptive and analytic epidemiology were relevant for the current doctoral project. Descriptive epidemiology describes the population, whereas analytic epidemiology seeks to find explanations and correlations between different variables, in order to map risk factors (Laake et al., 2007). In this project, descriptive epidemiology was used to describe bereaved parents’ experiences, attitudes, needs, opinions and views regarding losing a child after DRD. Analytic epidemiology was used to analyse the consequences of losing a child, using predefined variables to investigate which predictors contributed to explaining complicated grief symptoms. Relying on pragmatic epistemology, meaning and knowledge is tentative and contextual, and the “truth” is changing over time (Johnson & Christensen, 2016, p. 471). Consequently, the knowledge and perspectives in relation to how bereaved parents experience DRDs and the consequences of their grief, may change over time.

The qualitative approach followed a phenomenological hermeneutical method by interpreting interview texts. Through phenomenological hermeneutics, the researcher aims to "disclose truths about the essential meaning of being in the life world" (Lindseth & Norberg, 2004). In the interviews, the parents' experiences were explored. The purpose was to disclose the parent's perceptions relating to the essential meaning of being in the life world, not searching for a single fundamental "truth", but searching for meaning in a continuous process. Exploring the phenomenon of drug-death bereavement was conducted by moving between phenomenology, which explains what the text says, and hermeneutics, which aims to understand what the text says (interpretation) (see Lindseth & Norberg, 2004).

Like all researchers, I have preferences and values that affect the choices I make. As in a transformative worldview, a pragmatist researcher "takes an explicitly value-oriented approach to research that is derived from cultural values. Values like democracy and equality are essential when arguing for social justice and advocate human rights (Johnson & Christensen, 2016, p. 471). The sociologist Howard Saul Becker (1967) argues that it is impossible not to take a side or to carry out research, untainted by personal and political sympathies. The question is not whether we should take sides, but how we take a side and how transparent we are in relation to taking that side. He claims that we usually side with "the underdog". Despite the high prevalence of DRDs, research shows that DRD bereavement is understudied and that the bereaved do not get the attention they need. This indicates that those bereaved by a DRD can be a marginalized group. My professional preferences with regard to marginalized groups are clear: I wish for a well-functioning welfare society that helps everyone, especially those at risk of social marginalization, without claims in return.

3.2 Research design and methods

There are many different mixed methods research designs (Creswell & Clark, 2017, p. 5). The core characteristic of different mixed methods designs is that the researcher organizes the components to provide the logic and the procedures for conducting the project. The typology of a mixed methods research design is based on two fundamental dimensions; (1) time orientation (concurrent versus sequential), and (2) paradigm emphasis (how qualitative and quantitative research is prioritized, weighted and supplemented) (Johnson & Christensen, 2016, p. 477).

This project's design is a qualitative driven concurrent design, as qualitative data results are used to investigate quantitative findings (see Johnson & Christensen, 2016, p. 478). The research approach is exploratory and inductive and, consequently, prioritizes the qualitative components of the project. The typology is:

"QUAL + quan"

Capital letters visualize the priority of qualitative research ("QUAL"), a plus sign represents a concurrent data collection, as qualitative and quantitative data were collected in parallel ("+"), and lowercase letters visualize the fact that quantitative research has a supplemental role in the project ("quan"). Prioritizing qualitative components and establishing that research questions should emerge over the course of the project, was a planned process (Figure 4).

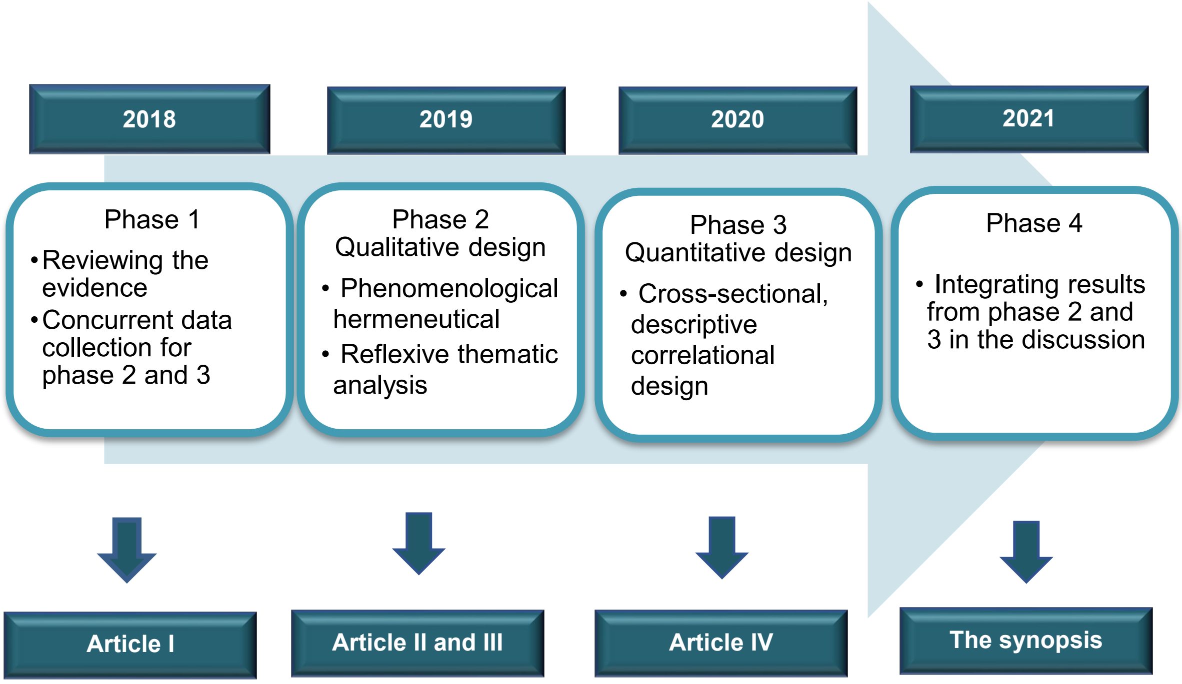

Figure 4 Overview of the research design - a qualitative driven concurrent design.

The mixed methods research approach has four phases. In phase 1, qualitative data from interviews and quantitative data from a survey were collected in parallel. In addition, a SR (Article I) was conducted to identify knowledge gaps and to inform research questions in relation to the articles in phase 2. In phase 2, the qualitative interview data were analysed (Article II-III). These results inspired the formulation of research questions for Article IV (phase 3). In phase 4, the results from Articles II, III and IV were integrated into a discussion (in this synopsis).

Based on the design for the doctoral project, four articles have been produced. Table 3 describe the research design, sample and methods applied in each article.

Table 3 Overview of the research articles.

	Article I	**Article II**	**Article III**	**Article IV**
Research question	How do family members experience DRDs, and how do they perceive the help and support they receive?	How do parents experience drug death bereavement and what different kinds of help and support do they receive?	How do drug-death bereaved parents adjust to life without the deceased and what seems to inhibit or promote adaptation during their grieving process?	Do Norwegian parents bereaved from DRDs suffer PGS as measured by PG-13, and if so, which predictors are key to explaining their high levels of PGS?
Design	SR	Phenomenological hermeneutical	Phenomenological hermeneutical	Cross-sectional, descriptive, correlational design
Sample	*n*=8 - Seven qualitative studies - One quantitative study	*n*=14 - Seven mothers - Seven fathers	*n*=14 - Seven mothers - Seven fathers	*n*=93 - 76 mothers - 17 fathers
Data	A systematic literature search for descriptive, qualitative, quantitative or mixed methods research, published as scientific articles, books and doctoral theses	In-depth interviews	In-depth interviews	Survey data: background information and five instruments
Analysis	Thematic synthesis	Reflexive thematic analysis	Reflexive thematic analysis	Descriptive and regression analyses

3.3 Phase 1: Reviewing the evidence and data collection.

3.3.1 Systematic review

Article I is a SR. Such a review was necessary to identify and tailor new research questions that could bring knowledge to the drug-death bereavement field, specific to the END-study, and subsequently, to this doctoral project. A systematic literature search was performed on this research question: "How do family members experience DRDs, and how do they perceive the help and support they receive?".

The Preferred Reporting Items for Systematic review and Meta-Analyses (PRISMA) (Liberati et al., 2009) guided the review. A review protocol was developed and published in PROSPERO, 17. July 2018 (available from PROSPERO).

The PRISMA approach to SRs recommends that authors specify the study characteristics and report characteristics (Liberati et al., 2009). The PIOS framework guided the elaboration of the eligibility criteria. PIOS is an acronym for Population (P), Intervention(s), exposure or phenomena of Interest (I), Outcome (O), and Study design (S). Identified articles were included in the review if: (1) the sample comprised close family members, bereaved by a DRD (i.e., a parent, child, sibling, spouse, partner or grandparent), (2) the death identified, was caused by the intake of substances classed as narcotics, i.e., overdose (intentional or unintentional), or was otherwise drug-related (e.g., caused by violence, an accident, an infectious disease, suicide or another health disorder related to drug use), (3) the types of outcomes constituted the reactions, symptoms and the coping abilities of the bereaved before and after the DRD, as well as studies reporting on how help and support influenced the bereavement process, (4) the study design was descriptive, qualitative, quantitative or mixed methods research, published as scientific articles, books or doctoral theses The PIOS-tool was also used to design the search strategy (see page 3 in Article I for more details about exclusion criteria, the systematic literature search and a critical appraisal of the included articles).

Thematic synthesis was used to identify, analyse and report patterns within the data of the included studies (see Thomas & Harden, 2008). The results of the studies were analysed by two researchers (KBT, SKL). Line-by-line coding of the text was conducted to develop descriptive themes, and together with the fourth author (KD), analytical themes that constructed new interpretations and explanations of the data, were created. The development of descriptive themes remained close to the primary studies, while the analytical themes represented a stage of interpretation.

3.3.2 Recruitment, inclusion criteria and data collection

Participants in the doctoral project were recruited through the END-study (Figure 1) survey. All participants in the survey were asked whether we could contact them for participation in an in-depth interview.

Survey: From March 2018 until the end of December 2018, we invited family members and close friends, bereaved by DRDs, to participate in the END-study. Recruitment took place in communities all over Norway, targeting, in particular, communities with high rates of DRDs. A flyer detailing the project was sent to all Norwegian municipalities' public e-mail addresses, and we contacted governmental and non-governmental personnel, associated with organizations working with those affected by drug use. We recruited participants using "snowball recruitment": information relating to the project was disseminated through municipal medical officers and crisis responders all over the country, using research networks and professionals in clinical practice and via participation in conferences and various media channels, such as television, radio, and social media (i.e., Facebook and Twitter). The bereaved were invited to fill in a survey, either on paper via post, or digitally, via e-mail. An e-mail reminder was sent out after 14 days to registered participants who had not completed the survey.

A total sample of 95 parents was enrolled in the END-study, in addition to 160 other family members and close friends (Figure 5). The inclusion criteria for this doctoral project specified that the participants:

- had lost a child due to a DRD at least three months prior to recruitment. No other restrictions were established in relation to the time since death.
- had less than 25% of missing responses in the PG-13 questionnaire

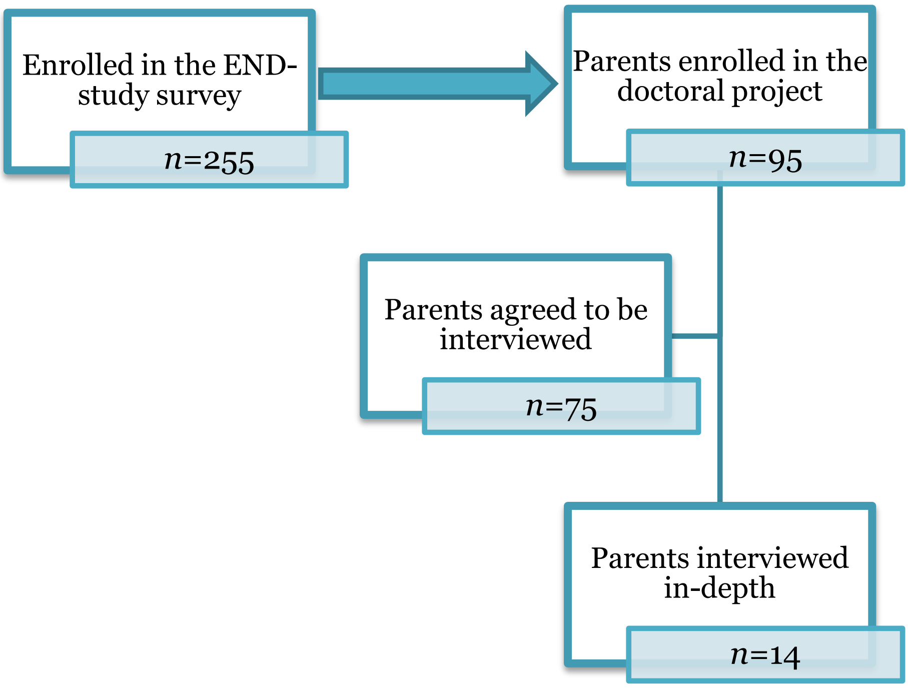

Figure 5 Overview of recruitment to survey and in-depth interviews.

In-depth interviews: The interview sample (*n*=14) was drawn from the total sample of parents that participated in the survey. Inclusion criteria, in addition to those mentioned above, were that the parents:

- represented width in terms of background variables
- spoke fluent Norwegian

Many more parents (*n*=75) agreed to be interviewed than could be included. The sample of parents to be interviewed was selected according to gender, age, place of residency of the parents (city/village and various geographical areas of Norway), time since death and the deceased's age and gender.

Malterud et al. (2016) have proposed a set of considerations relating to different dimensions that influence the sample size, such as the study's aim, sample specificity, theoretical background, dialogue quality and analysis strategy. To ensure the final sample's adequacy, we looked to Malterud et al. (2016) for their guidance regarding information power. After interviewing seven fathers and six mothers, we decided to balance the sample according to gender, should the descriptions specific to gender, became relevant to our discussion. Therefore, an additional mother was invited to participate. After interviewing this last participant, limited knowledge was achieved, and we concluded that we had reached a satisfactory level of information power.

3.3.3 Overview of sample

Table 4 is an overview of the participants included in the doctoral project. Of the sample of parents (*n*=95), two participants had more than 25% of missing responses in relation to PG-13 and were excluded from the survey sample.

Table 4 Demographic and loss-related variables for the survey and the in-depth interview sample.

Variables	***n***	**Survey**				***N***	**In-depth interviews**			
Men/women sample*	93	17 (18.3)/76 (81.7)				14	7 (50)/7 (50)			
Men/women deceased*	93	72 (77.4)/21 (22.6)				14	10 (71.4)/4 (28.6)			
Level of education*	93					14				
Primary school		10 (10.8)								
High school		29 (31.2)					3 (21.4)			
College/university		45 (48.4)					11 (78.6)			
Other		9 (9.7)								
Employment*	93					14				
Full-time job		31 (33.3)					7 (50)			
Part-time job		13 (14.0)					1 (7.1)			
On sick leave		4 (4.3)					1 (7.1)			
Retired		23 (24.7)					3 (21.4)			
Studying		1 (1.1)					1 (7.1)			
Other		22 (22.6)					1 (7.1)			
Sick leave before death*	92	34 (36.6)				14	4 (28.6)			
Sick leave after death*	92	69 (74.2)				14	11 (78.6)			
Relational closeness*	91					14				
Very close		79 (84.9)					12 (85.7)			
Close		8 (8.6)					1 (7.1)			
Somewhat close		3 (3.2)					1 (7.1)			
		M	SD	Md	range		M	SD	Md	range
Age of participant (years)	90	59.4	7.1	59	45-80	14	58.3	7.6	58	45-75
Age of deceased (years)	90	26.9	6.4	25	18-45	14	27.4	8.7	24	19-45
Demanding life loads	93	4.7	6.3	3	0-50	14	5.6	7.5	3.5	1-31
Number of DRD loss	93	1.2	0.5	1	1-4	14	1.1	0.3	-	1-2
Months since loss	92	79.5	80.4	59	3-420	14	37.9	38.5	18	3-126

**n* (%)

The parents were well educated. In the quantitative sample, 48% had more than 12 years of education, whereas 79% in the qualitative sample had more than 12 years. Annual household gross income was in the range of 28,500 to more than 143,000 dollars. The income level in Norway is high, and the participants' income was high compared with the average Norwegian annual household gross income (46,364 dollars in 2018). Forty two percent in the quantitative sample and 71% in the qualitative sample had an annual household gross income of over 85,500 dollars. Despite efforts to recruit bereaved parents from all classes in society, the risk of sampling bias is present, given that individuals from lower social-economic classes seem to be underrepresented.

3.4 Phase 2: Qualitative design.

Articles II and III are qualitative studies (phase 2, Figure 4). As stated, the research questions explored in phase 2 were: "How do parents experience drug death bereavement and what different kinds of help and support do they receive?" (Article II) and "How do drug-death bereaved parents adjust to life without the deceased and what seems to inhibit or promote adaptation during their grieving process?" (Article III).

3.4.1 Data collection

A semi-structured interview guide was developed for the interviews. The survey questions that we wished to explore in more detail inspired the interview guide. The guide consisted of five themes: (a) time before the death; (b) loss; (c) stigma from the environment and self-stigma; (d) help, support and ability to cope and (e) post-traumatic growth. Selected PG members who themselves had experienced a DRD, commented on the interview guide. Some of the questions were changed slightly or elaborated upon following their feedback. To ensure a common standard for the interviews, a checklist was developed for the interviewers. The checklist reminded interviewers what was needed for the interviews, such as consent forms, an interview guide and a sound recorder. The checklist also described how to start and end the interview, and what information should be provided to the bereaved (e.g., the END-study's aim and how the data would be stored).

In the preparation phase, the interviewing researchers discussed topics that were relevant for follow-up questions. During the interviews, the participants were encouraged to talk about the deceased, their relationship to the deceased, the deceased's living habits, the circumstances surrounding the death, their grief and how the death affected their health, work situation and leisure time. Concerning stigma, the participants were invited to talk about attitudes emanating from their surroundings (e.g., from family, friends, work colleagues) and how they and others within their network communicated details about their loss. The parents were invited to reflect on experiences of support from their networks and help from public services. The parents were also asked to share their thoughts about potential barriers to support and the help they needed, in addition to barriers or facilitators that influenced coping and meaning-making. First and foremost, the researchers aimed to capture the interviewees' thoughts and reflections.

3.4.2 Semi-structured in-depth interviews

The interviews were carried out during the period between 27. August and 4. December, 2018. To synchronize the interview method and pilot test the interview guide, the project leader (KD) conducted a trial interview with a bereaved parent, with the two other interviewers (SM, KBT) present. Following the interview, the form, content and style were discussed with the bereaved and the research interviewers. The guide was adjusted after discussion, before conducting the other in-depth interviews (Appendix I).

Following the completion of the informed consent process, the doctoral candidate (KBT) conducted six interviews, KD conducted five interviews and SM conducted three in-person interviews. All the interviewers are members of the PG. The interviews took place in a private setting chosen by the bereaved parent (home=9, work office=4, a private space=1). The interviews were audiotaped and transcribed verbatim by a research assistant. In addition, all interviewers noted their general impressions immediately after each interview. The length of the interviews ranged from one hour and 20 minutes to three hours and 10 minutes, including required or desired breaks. Altogether, the transcripts consisted of 431 single-spaced pages (range 20–39 pages).

3.4.3 Reflexive thematic analysis

Reflexive thematic analysis was used to analyse the data in Article II and Article III (see Braun & Clarke, 2019b). The interpretation of the interview texts followed a phenomenological hermeneutical method (see 3.1).

Braun and Clarke (2019b) describe a six-phase process for a reflexive thematic analysis: (1) familiarization with the data; (2) coding; (3) generating initial themes; (4) reviewing themes; (5) defining and naming themes and (6) writing up. The phases are sequential, each builds on the previous, and the analysis is, therefore, a recursive process. As recommended by Braun and Clarke (2019b), the interviews were analysed by moving back and forth between the different phases.

The analysis involved reading and re-reading the data to become immersed and intimately familiar with its content. Emerging meaning units and codes concerning the parents' grief were defined; the emergent codes were listed in the qualitative data analysis software, NVivo 12 (see QSR International Pty Ltd, 2018). After reading and re-reading all the interviews and coding the entire dataset, the codes and collated data, which helped identify significant, broader patterns of meaning (potential themes) were examined. Themes, defined as a pattern of shared meaning, underpinned by a central concept or idea (Braun & Clarke, 2019b), were then established. Moving back and forth between the phases, a clustering of themes was generated. Each theme's scope and focus were worked out, an informative name for each theme was decided upon and a table of themes was produced. I conducted the analyses (KBT, a social educator) in collaboration with the main supervisor and last author (KD, a sociologist). A consensus discussion was then facilitated with the co-authors (Article II with SM and MS (both psychologists) and Article III with MS). All authors agreed upon the coding framework, the interpretation of the data and the confirmation of codes and themes.

3.5 Phase 3: Quantitative design.

Article IV is a quantitative study (phase 3, Figure 4). A cross-sectional, descriptive, correlational design was used to analyse quantitative data from the END-study survey. The purpose of this study was to investigate whether Norwegian parents bereaved following a DRD, suffered PGS as measured by PG-13, and if so, which predictors were key to explaining their high levels of PGS.

Two primary aims were described: (1) to map the prevalence of PGS in a convenience sample of parents bereaved by a DRD and (2) to examine which predictors are most important in explaining parents' high levels of PGS, in relation to self-efficacy, perceived support and other moderators and mediators, identified in previous studies of unnatural deaths. Based on the findings in Article II and III, as well as previous literature relating to those bereaved following an unnatural death, hypotheses were formulated. Socio-demographic characteristics, such as female gender, a low level of education, unemployment, demanding life loads, a short time since death and a close relationship, were hypothesized as resulting in high scores in terms of PG-13. Furthermore, low scores with regard to self-efficacy and social support were believed to predict a high score on PG-13.

3.5.1 Measurements

The END survey consisted of 22 background variables and eight instruments that included 79 variables (standardized and open questions). Selected PG members who had experienced a DRD or were experts in the field, gave feedback on background variables and the included instrument (i.e., questions and rating scales). They found the final version to be applicable.

For this project, a moderator-mediator model was developed to guide the choice of variables. Five instruments that illuminate the research question and the model were included in the analyses (Table 5). Specific background variables, described as predictors for PG-symptoms in previous studies (i.e., gender, time since loss, level of education, employment, sick leave before and after death, number of DRDs, demanding life stresses and relational closeness) were also selected. Continuous background variables were rated on a 5-point Likert scale, scoring 1-5 (e.g., "not at all close" to "very close").

Table 5 Overview of measurement instruments used in the doctoral project.

Instruments	Measures	Instrument description	Reference
Prolonged Grief Disorder-13 **(PG-13)**	Prolonged grief	Diagnostic tool with 13 items that assesses the symptoms of PG. Summing the 11 symptom items (cognitive, behavioural and emotional) excluding the dichotomous time and functional criteria items. The items are rated on a 5-point Likert scale, scoring 1–5, with higher scores indicating more severe grief symptoms. Doctoral project: PG-13 was applied to measure levels of PGS. Sum-score was included.	Prigerson et al. (2009)
The General Self-Efficacy Scale, Short-Form **(GSE-SF)**	Coping/self-efficacy	Five items, developed to measure optimistic self-beliefs about coping with a variety of challenging demands in life. The items are rated on a 4-point scale, scoring 1–4, with higher scores indicating high levels of self-efficacy. Doctoral project: GSE-SF was applied to explore whether low levels of self-efficacy are a predictor of high PGS levels. Sum-score was included.	Schwarzer and Jerusalem (1995) Tambs and Røysamb (2014)
The Crisis Support Scale **(CSS)**	Positive and negative social support	Seven items that measure informal networks' social support after a crisis. The items are rated on a 7-point Likert scale, scoring 1–7, with a higher total score, indicating more support received. Doctoral project: CSS was applied to explore whether low levels of support constituted a predictor of high levels of PGS. Sum-score was included.	Elklit et al. (2001)
The "Special Grief" Questions (SGQ)	Aspects of anxiety/fear of death, anticipated grief, self-stigma/stigma/ guilt/shame, ambivalence and disenfranchised grief	Sixteen items that measure various experiences after losing a next of kin, as a result of a DRD. The items are rated on a 5-point Likert scale, scoring 1-5, with higher scores in each item indicating high levels of "special grief". The SGQ is not a distinct dimensional scale with sum- and cut-off scores. Doctoral project: five items were included in the analyses: "fear of disturbed sleep", "relief", "blaming myself", "ashamed to talk openly" and "others talk about me". A high score on one item was a predictor of high levels of PGS.	Dyregrov et al. (2019)
The Assistance Questionnaire (AQ)	Help and support	Twenty-two items that measure how the bereaved report their experiences, and their need for help and support. The items are rated on a 5-point Likert scale, scoring 1-5, with higher scores in each item indicating lower levels of support. The AQ is not a scale with a sum score or a cut-off score. Doctoral project: two items were included in the analyses: "others have withdrawn" and "I have withdrawn". A high score on an item was a predictor of high levels of PGS.	Dyregrov (2002)

3.5.2 Statistical analysis

Statistical analyses were performed using *IBM* (2019), *SPSS Statistics* version 26. A codebook containing complete and self-explanatory information for each variable in the SPSS file, was developed. A log described how data were handled.

PG-13 sum-score was chosen as the dependent variable, since the prevalence of PGS and the predictors for high levels of symptoms, constituted the primary outcome of our analyses. Missing scores were imputed by replacing them with the individuals' mean score for all items completed. No replacement was provided for the background variables, the SGQ and the AQ items. The internal consistency for PG-13 was "good", Cronbach's alpha (α) .893; for GSE-SF also "good", α .851 and for CSS "acceptable", α .709. No analyses were done for the SGQ and the AQ as scales (see previous remarks in Table 5). A cluster analysis to evaluate dependency in the data, indicated that parents responded independently of one other. Descriptive analyses of the sample's demographic characteristics and mean sum scores for the PG-13 scale, were conducted. Scatterplots, Spearman's correlation coefficient (for categorical variables) and Pearson's (for continuous variables) were created, to screen for associations between PG-13 and the potential explanatory variables (covariates). No outliers or extreme scores were revealed.

A three-step procedure to identify the strongest associations between a covariate and the outcome variable, PG-13, was conducted. A univariate linear regression analysis was performed (Step 1), followed by a multivariate linear regression, including only statistically significant variables at a 0.2 significance level in the univariate regression analyses (Step 2). To retain the most important covariates and increase the precision of the estimated regression coefficients, Step 3 was carried out, including only variables from Step 2, that were significant at a 0.05 level (Model 2). See Table 2, page 6 in Article IV for more details.

3.6 Ethical approval

This study was approved in February 2018 by the Norwegian Regional Committees for Medical and Health Research Ethics (reference number 2017/2486/REK vest, Appendix II). Ethical considerations are discussed in section 5.2.2.

4. Findings

This chapter summarizes the main findings from the four articles of the dissertation. Copies of the four articles are included at the end of this synopsis.

4.1 Article I: "How do family members experience drug death bereavement? A systematic review of the literature".

The SR concluded that drug-death bereavement is an understudied topic. Only eight studies, seven qualitative studies (Biong et al., 2015; Biong & Thylstrup, 2016; da Silva et al., 2007; Feigelman et al., 2018; Grace, 2012; Nowak, 2015; Templeton et al., 2017) and one quantitative study (Feigelman et al., 2011) of good methodological quality were identified.

Three analytical themes were generated from the thematic synthesis, "emotional roller coaster", "lack of understanding by the social world" and "meaning-making". The themes described an emotional and existential overload before and after death, as well as self- and social stigma. A lack of help and understanding, especially when they needed support with official processes after their loss, complicated their grieving process. However, many of the bereaved also reported that meaning-making was important, in order to live on after the loss of a family member. In making sense of the loss, the bereaved maintained that helping others or being politically active, were examples of how they tried to prevent others from experiencing the same situation themselves.

The SR concluded a need for research with larger samples and more precise research questions, which defined the family relationship to the deceased. Future studies should also investigate distinctive characteristics like the deceased's age, the time since death, whether the next of kin was aware of the drug use and whether the deceased died after first-time use or an overdose, versus drug use over time. Based on these findings, the research question for Article II was sharpened and focused.

4.2 Article II: “Sounds of silence. The ‘special grief’ of drug-death bereaved parents: a qualitative study”.

The results in the SR guided Article II. Parents were chosen to participate in the doctoral project, not parents and siblings as first planned in the tentative project plan. A sufficient sample size was aimed for, and questions regarding whether the parents were aware of the drug use and whether the deceased had died after first-time use, were investigated. Article II described Norwegian parents’ grief after a DRD.

During the interviews, it became clear that all parents knew about the drug use and that none of the children died after first-time use. Nevertheless, their child’s death came as a shock. Before death, the parents felt rejected from the Child Welfare Services and the Norwegian Labour and Welfare Administration, and that lack of cooperation due to confidentiality, had major consequences on the parents’ everyday life. The parents took on responsibilities which should have been handled by their child under usual circumstances. They continued to provide the child with all types of support. Living with a person with dependency was described as being in constant preparedness, both emotionally and physically.

Societal stigma and self-stigma complicated the parents’ grieving process. Some stated that the professionals’ lack of consideration of their child’s wishes and needs, mirrored the helpers’ stigmatization of people who use drugs. In addition, shame and self-imposed guilt for failing as a parent, triggered rumination that was always in the back of their minds.

When their child died, only one of the 14 parents received help from public services without asking for it. All the bereaved stated that their relationship with public services and with their social networks was complex. Getting help was a continuous struggle. However, most of the parents found that their social network provided the support they needed. Still, communication relating to the loss and their grief was challenging, both for the bereaved and the network supporters.

Article II’s findings elaborated on the “special grief” theoretical model of Dyregrov et al. (2019). For the parents, the “special grief” was also characterized by an “extended parenthood”. Extended parenthood reflects the consequences of children who need extended emotional, economical and practical support after reaching adulthood (Tysnes & Kiik, 2019). The parents who experienced anticipatory grief, had lived with their child’s drug use for many years, and anger was highlighted as a dominant, conflicting emotion, which characterized the parents’ experience. The findings showed that stigmatization on a group level during the period before the child died, as well as the self-inflicted stigma that the parents placed on themselves, were typical features of drug-death bereavement. This stigma could lead to disenfranchised grief, due to a lack of support and help.

These results shaped the research question for Article III, in an attempt to establish which factors inhibited or promoted parents’ adjustment to life following their loss.

4.3 Article III: “How do drug-death bereaved parents adjust to life without the deceased? A qualitative study”.

The findings in Article II showed that the parents did not receive help to adjust to life. Thus, Article III explored how the parents carried on with life.

There were three interconnected themes that described how the parents adjusted to life without their child. The parents processed grief emotions, especially ruminating about guilt, blaming others and adapting to external triggers. The parents gradually adjusted to life using strategies like cognitive strategies (i.e., worked on their mindset and their ability to think and react) and communication strategies. They also craved knowledge from experts relating to dependency and information relating to their child’s death, but gradually returned to day-to-day activities. Giving and receiving support strengthened the parents’ ability to adjust to life. To be needed by other children and grandchildren was highlighted as the most important factor in encouraging them to continue with everyday life.

Article III illustrated the specific parameters of the DPM in the case of parents, bereaved by a DRD. LO coping, such as rumination and using cognitive and emotion regulatory strategies, characterized the period after the loss. RO coping was typified by a changing role with the deceased's child(ren). The participants also reported oscillating between processes, such as actively grieving and putting grief on hold. These findings of alternation between stressors and other activities illustrated the oscillation process as an integral element of the means of coping with grief and grieving. Flexible adaptation and oscillation between the LO and RO processes promoted the adjustment to life for many of the parents.

Communication challenges and the complicated relationship with supporters and helpers were elaborated in Article III. The parents had preferences in relation to whom they preferred to talk to, more often close family members or a few close friends. They under-communicated their grief since other people seemed helpless with regard to talking about DRDs. Social ineptitude (see Dyregrov, 2006) was used to explain the withdrawal of network members, unsuccessful contact and communication problems, as experienced by those traumatically bereaved. Certain parents actively chose how and with whom they wanted to communicate about the loss, and described that this was therapeutic. Thus, openness and educating others as to how to support the bereaved were suggested as coping strategies.

Caring for others, was for the parents the main motivation for continuing with their lives, while those who had lost their only child or did not have other children who depended upon them, struggled more to adjust to life. Based on the results of Articles II and III, there was a clear need to investigate the parents who had struggled most in Article IV.

4.4 Article IV: "Prevalence and predictors of prolonged grief symptoms among those bereaved from a drug-related death in a convenience sample of Norwegian parents: a cross-sectional study".

Articles II and III clearly report that certain parents were struggling to adjust to life and that there was a need for research that highlighted the predictors for high levels of grief symptoms. This knowledge is essential for helpers in identifying the parents at risk of developing complicated grief.

High levels of PGS (M=30.69) were identified. The mean sum score for the mothers was 31.06 (SD=8.34), and for the fathers, 29.02 (SD=11.18) though the regression analysis did not support the fact that gender influenced the level of grief symptoms. Yearning for the deceased was reported to be a core symptom among parents bereaved from a DRD, and a negative correlation was identified between PGS and a feeling of relief. Since making sense of a loss was difficult for the parents, the importance of screening for yearning and a lack of feeling relief was emphasized to identify the parents who struggled most.

A low level of self-efficacy and a withdrawal from others were the strongest predictors of high levels of grief ($p<0.001$). However, contrary to the hypotheses, the female gender, unemployment, high-demanding life situations and a high-degree of perceived closeness, did not correlate significantly to high levels of PGS. Another unanticipated finding was that the lack of social support was not a statistically significant predictor in explaining high levels of PGS. As expected, a short time since death and a low level of education were associated with a high level of PGS.

There are several factors and processes that may explain why social support was not significantly associated with PGS. In Articles II and III, the parents reported that relating to other people was difficult due to stigma, self-induced stigma and challenging communication. These are variables that need to be further investigated, before it is possible to conclude that the absent effect of social support in relation to parents bereaved by a DRD, is significant.

5. Discussion

The research questions for the articles in this doctoral project were conducted in accordance with a qualitative driven concurrent design. Article I gave directions for more precise research questions, with a narrower focus, resulting in specific relations of the deceased being selected. As a result, only parents were included in this project. Thus, the doctoral project's main focus was to explore parental grief after a DRD, through the main research question: "How do bereaved parents experience a DRD, what are the consequences for bereaved parents and how do they cope with everyday life?". Article II described parents bereaved by DRD experiences, Article III highlighted how the parents coped and adjusted to life, while Article IV investigated predictors of high levels of PGS.

The section, "The 'special grief' of parents bereaved by a drug-related death" summarizes the main findings from Articles II, III and IV in an overall discussion. Finally, a discussion of the methodological issues and ethical considerations follows.

5.1 The "special grief" of parents bereaved by drug-related death

In the article, "Sounds of silence", a DRD was described as a special death that led to a "special grief" (Titlestad, Mellingen, et al., 2020). Following Doka and Martin's (2002) characterization of a special death, the parents described a death with high levels of trauma, an existentially problematic stigma and grief that was disenfranchised. The results from "*How do drug-death bereaved parents adjust to life without the deceased*?" (Titlestad, Stroebe, et al., 2020) and "*Prevalence and predictors of prolonged grief symptoms*" (Titlestad et al., 2021) elaborated on the findings from "*Sounds of silence*" with regard to "special grief".

Here in the discussion, the merged findings are discussed. Figure 6 illustrates an overall, broader description of parents' "special grief" when bereaved from a DRD. The circle outlines that the parents were continuously processing an overload of stress, due to constant preparedness in extended parenthood, as well as the perceived stigma and grief-related emotions and reactions. Their grieving process was affected by factors on an intrapersonal level (the bereaved) and an interpersonal level (the bereaved and their surroundings). The time arrow illustrates that the intensity of processing the overload decreased in the case of most of the bereaved as time went by.

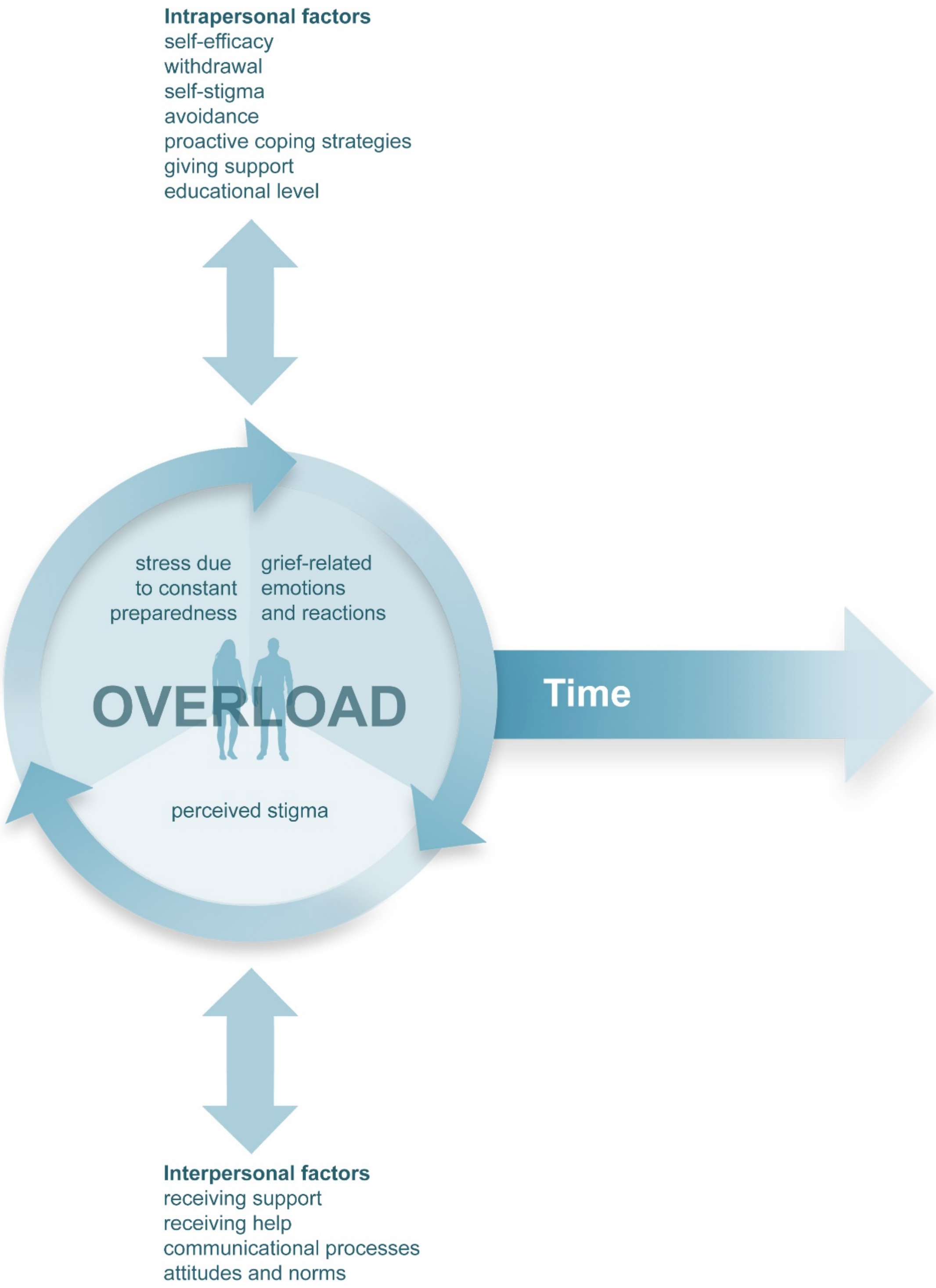

Figure 6 The "special grief" of parents bereaved by DRDs.

Article IV showed that mothers had higher levels of PGS than fathers (Titlestad et al., 2021). Others studies have reported that compared to fathers, mothers tend to grief more intense and have a greater need to talk about their loss (Dyregrov & Dyregrov, 2015). In this project, due to a skewed selection (77% woman in the survey), and the fact that the regression analysis did not support that gender was associated with level of PGS, it was not possible to draw any conclusions based on gender. Therefore, the findings from this project are described as applicable to parents, both mothers and fathers.

Four topics that illustrate the “special grief” are generated from Figure 6 and are examined under the following headings: (1) the complexity of the “special grief”; (2) the complications of spill-over stigma; (3) the challenges of providing and receiving support and (4) the oscillation between coping styles.

5.1.1 The complexity of the “special grief”

> *Why? Why, why couldn’t we? Why couldn’t we stop him, and should we have done something differently?*
>
> (a father in Titlestad, Stroebe, et al., 2020)

The parents described a constant preparedness to step in at any time if their child needed help. In the last few decades, there has been a significant change in the parental role. Today parents provide an ongoing source of support for their adult children and find themselves in an extended parent role, as their children tend to remain in education and live at home for a longer period (Kloep & Hendry, 2010; Maltman et al., 2019). Many parents find it difficult to let go. Some are reluctant to accept their child’s increasing autonomy (Kloep & Hendry, 2010), while other parents, e.g., parents of adult children who use drugs, are protective due to major concerns about their child’s wellbeing (Maltman et al., 2019). The parents who took part in the in-depth interviews, shared this concern. An overload of stress due to this extended parenthood, affected the parents’ grieving process.

Moreover, the parents lacked access to information which complicated the extended parenthood role. The parents described themselves as full-time helpers, without an official licence to help. They experienced that their children resisted or denied the problem, as well as a lack of cooperation from public services, due to barriers like confidentiality and societal stigma. The results from this project support Lindeman et al. (submitted 2021) and showed that the consequences of the child's drug dependency overshadowed all aspects of life for the parents. A lack of support and respite from helpers, in addition to barriers like confidentiality, hindered them from helping their child and were also difficult to process when the child died.

The parents reported an overload of emotions and reactions before and after death. Bowlby’s (1982) attachment theory suggests that the bereaved felt they had failed when an attachment figure (i.e., child) died, and that this failure was often reflected in guilt and blame. The data from the interviews supported Bowlby’s theory, as the parents reported that typical features of grief emotions and reactions were repetitive, recurrent thinking regarding guilt, anger and blaming others. This suggests that guilt rumination is a core characteristic of parental grief after DRDs.

As previously stated, anger was frequently reported by the parents, especially anger towards health and welfare services, although the negative emotion that conquered all grief emotions was failure. In a study by Maltman et al. (2019), parents reported that the burden increased when they felt they lacked the skills to manage the child’s drug use. In this project, the demographic data showed that the interviewed parents were economically resourceful. Consequently, these parents might have experienced a greater degree of self-perceived failure when the child died, as they did not manage to live up to either their own or society’s expectations. This self-perceived failure may have triggered guilt and shame, which developed into a maladaptive rumination relating to guilt and blame. Such processes illustrate the interplay of individual emotions and societal norms, and the complexity of “special grief”.

The complexity of grief-related emotions and reactions, documented from the interviews, was supported by data from the survey. Withdrawal from others was strongly associated with high levels of PGS, and a feeling of no relief and a yearning for the dead child, were reported to be the core PG symptoms of parents, bereaved by a DRD. Potentially traumatizing deaths can lead to suicidal thoughts (Stroebe et al., 2005). An evaluation of suicidal thinking should be part of an assessment of complicated grief (Shear, 2015). To identify the parents who struggle the most, questions relating to the feeling of relief and yearning, should also be part of the assessment, as yearning is an important marker that can help clinicians differentiate between grief complications and depression (see Prigerson et al., 2009), and identify parents with suicidal thoughts.

Putting emotions aside was adaptive for the parents in this project, but they also reported maladaptive avoidance, as the act of putting emotions aside could turn into an avoidance mechanism that worsened their grief. In line with Shear (2010), avoidance was reported as being both maladaptive and adaptive in this project. However, avoidance behaviour in the "special grief" of parental bereavement after a DRD, is complex. The PG-13 item with the lowest mean score in this project was the avoidance item ("tried to avoid reminders that a loved one is gone"). This discrepancy between the quantitative and the qualitative data was discussed in Article IV, and addressed the fact that the issue of avoidance during bereavement after a DRD, is more complex than simply avoiding reminders that a loved one is gone (e.g., Article III avoiding external triggers). Agreeing with Maccallum et al. (2017), it is necessary to adopt a more nuanced approach to avoidance than the PG-13 item relating to avoidance measures.

The complexity of grief emotions and the reactions that parents bereaved by DRDs experienced, were characterized by guilt rumination, avoidance and withdrawal. Rumination is associated with depression and post-traumatic stress (van der Houwen et al., 2010), and is a strong predictor of complicated grief (Eisma et al., 2013). This highlights that the parents required help to avoid a complicated grieving process; those who experienced high levels of PGS needed professional help. This help should follow Huber and colleagues' (2011) proposal of a dynamic understanding of health, which suggests that the adverse health outcomes, associated with bereavement, may be less associated with disease, and are more a function of the interaction of the parents with their surroundings. Understanding functioning as a dynamic interaction between a person's health condition, environmental factors and personal factors (Huber et al., 2011), bereaved health challenges also affect the parents' daily lives. For some of those bereaved, the grief could be so all-encompassing that it could lead to difficulties in maintaining meaningful relationships with family and friends and an inability to take care of themselves. In this project, the time since the loss was associated with a reduction in PGS. This showed that most bereaved parents adjusted to the loss eventually. However, little is known about the trajectories of a DRD and with regard to certain parents, their capability to function and participate in society, would probably never be the same again.

5.1.2 The complications of spill-over stigma

> *So, you're looking for it, the blame in other people's eyes, you see it, even when it's not there*
>
> (a mother in Titlestad, Mellingen, et al., 2020)

The interviewed parents described how societal stigma turned to self-stigma, causing feelings of shame and guilt for having failed as parents and for not living up to society's expectations. The consequences of stigma were also discussed with regard to the survey's findings. The quantitative data showed that low levels of self-efficacy were the strongest predictor of high levels of PGS. Thus, the belief in oneself could have been negatively affected after many years of living with a possible societal stigma. The parents' descriptions are in line with the characteristics of stigma, reported by Link and Phelan (2001). People who use drugs are labelled as different from others; drug use is defined as a criminal act and is, therefore, perceived by society as negative. The discussions (e.g., in media) are influenced by the separation of "us" from "them", and the child and bereaved parents are discriminated against, as they do not receive the help to which they are entitled.

All six types of stigma that can potentially have an impact on health (see Sheehan & Corrigan, 2020), were reported in the findings. The stigmas reported were public, structural and experienced, perceived through a lack of help for the person with the dependency, and a lack of help for those bereaved by the death. Anticipated ("felt") stigma and associative stigma seem to be internalized in the bereaved, as they worry about others' perceptions of them as parents, and this stigmatization is due to their association with the drug-using child. The resulting influences on the health of the bereaved can be serious. Withdrawal from the network, refraining from help-seeking and complex relationships with their surroundings, are all moderators for different physical, psychological and social health challenges (Sheehan & Corrigan, 2020). Thus, perceived stigma is a central element of the “special grief” experienced by parents after a DRD. Figure 6 illustrates how intrapersonal (e.g., self-stigma) and interpersonal processes (e.g., attitudes and norms in society) influenced the overload of processing perceived stigma. In addition, the documentation of the serious health effects of stigmatization, confirms the clear need for help and support for parents, bereaved by DRDs.

We know from the interviews that the Norwegian parents did not get the help which they are entitled to, in accordance with the Norwegian white paper, "*The Psychosocial Interventions in the event of Crisis, Accidents and Disasters*" (Norwegian Directorate of Health, 2016). This white paper recommends that community helpers in the municipalities should provide early and active outreach, broad spectrum and adapted help for all family members, as well as psycho-social follow ups over time. Hence, there is a need for change in Norway at society level.

However, individual help and support are not sufficient. The results of this project clearly show that bereavement by DRDs is not being acknowledged. There are reasons to believe that bereaved parents in this project took on social and cultural norms and attitudes during the grieving process and hence believed that they were not worthy of accessing help. Individual and group experiences of bereavement by DRDs are largely influenced by the social context in which they occur (see Berger & Luckmann, 1991). The attitudes, norms and values of people, helpers, bureaucrats and politicians towards people who use drugs, are internalized in the bereaved and this complicates the bereaved parents’ grieving process. This internalized self-stigma affects the health, functioning and participation of the bereaved. Corrigan, Larson, et al. (2009) reported that internalized stigma is linked to depression, low self-esteem and reduced self-efficacy. Therefore, low self-efficacy and social isolation, reported in this project, can be due to years of labelling, discrediting and devaluation as a parent. In addition, the lack of help from public services on all levels, showed that society did not acknowledge the grief after losing a child from a DRD. Disenfranchised (i.e., not acknowledged) grief is, therefore, another core characteristic of “special grief”.

The perceived stigma after a DRD is supported by the UK study (Templeton et al., 2017) and the study by Feigelman et al. (2018). The bereaved in these studies also described various, negative experiences when meeting first responders or engaging in various official processes, on account of the death. DRDs in the UK require the involvement of the police and the coroner, or the procurator fiscal. Examples of delays and a lack of compassion and consideration for the situation of the bereaved, were described. The parents interviewed in the doctoral project did not describe perceived stigmatization from first responders, and they also reported that they were open regarding the cause of death. US parents, conversely, reported that they had difficulty talking openly about their child's death with others, they felt ashamed or afraid that they would dishonour the child (Feigelman et al., 2018).

Another means of inhibiting the consequences of stigma, is to take action to influence the social processes determinedly. Feigelman et al. (2018) argue that the communication challenges between those bereaved by DRDs and their surroundings, were due to stigma. The results from the doctoral project, however, suggested that challenges in the interaction between the bereaved and their surroundings were more complex. The findings suggested that withdrawal and avoidance, in the Norwegian context, can also be a consequence of challenging relationships with one's surroundings.

5.1.3 The challenges of providing and receiving support

> *There is no unwillingness, they don't know how to reach out*
>
> (a mother in Titlestad, Mellingen, et al., 2020)

There is a need for action to enhance the relationship between parents bereaved by DRDs, their supporters and the potential helpers. An overall finding in the doctoral project was that relationships with public services and social networks were complex. Both intrapersonal (e.g., self-efficacy, withdrawal, avoidance and self-stigma) and interpersonal factors (e.g., communication challenges, attitudes and norms) affected these challenges. Figure 6 illustrates how these factors acted as moderators in affecting the processing of grief-related emotions and reactions.

A lack of support from professional helpers before and after the death was clear. Self-stigma disturbed the dynamics of the communication of parents with people in their network. Though the parents considered the support from family and friends to be good, communication relating to their loss was difficult for both parties involved. The bereaved interpreted the lack of communication as the insecurity of social networks, and the parents under-communicated their grief to protect them. This challenging relationship was also supported by quantitative data that suggested a link between “others have withdrawn”, “ashamed to talk openly” and high levels of PGS.

Dyregrov and Dyregrov (2008, pp. 123-133) maintained that the bereaved and the people in their social networks lacked a shared understanding of a framework for communication, following an unnatural death. They investigated this phenomenon in light of Berger and Luckmann (1991) theories relating to the dynamic influence of individuals and groups on the social context, as well as Briggs (1986) communication and interaction model. Such theories are important tools in understanding the challenges between the bereaved and their supporters, according to Dyregrov and Dyregrov (2008, p. 125). Through a common understanding that communicating details relating to DRDs is challenging and perhaps extreme for the parties involved, both the bereaved and their supporters can enhance interaction and communication. Thus, parents bereaved by DRDs can influence and improve relationships by openly communicating their personal needs and by educating others as to how they can be supported. Even more importantly, the networks of family and friends need to be informed of their potential healing role as respectful and empathetic listeners.

This doctoral project supported the previous findings of parents’ experiences of emotional overload before death (see Orford et al., 2010), and provided new insight into the extended overload after the loss of a child from a DRD. Withdrawal in association with high levels of PGS was one of the main findings. It is not clear from the data when the parents started to withdraw from others. The results suggest that the overload before death triggered the withdrawal process. The parents experienced living a life on the edge of society, struggling with the problems that other parents of adult children did not have. Other unnatural deaths, like suicide may also involve an overload before (Wayland et al., 2020) and after death, had the deceased suffered from a prolonged illness pre-loss (Feigelman et al., 2011). Still, the overload might be more extensive and harder to process for parents bereaved by a DRD, as the overload of grief-related emotions and reactions is combined with an even more intense societal stigma.

This project demonstrates the need for a shared understanding regarding how to communicate and interact after a DRD. Quinn and colleagues (2017) believe that society needs to focus on why stigmatized people experience the need to conceal themselves, in order to understand the lack of openness. A lack of responses from society and the bereaved who struggle with relationships and communication with people in their surroundings, is a very unfavourable dynamic. Therefore, actions to reduce stigma and a proactive society, can improve the relationship between parents bereaved by DRDs and their surroundings.

5.1.4 The oscillation between coping styles

> *Just as I approach the edge, then I know I must do something*
>
> (a father in Titlestad, Stroebe, et al., 2020)

Bereavement after a DRD and how parents adjust to life after losing a child, were described as an individual experience. However, the way in which a person's resources can alleviate the perceived overload of stress before and after a child's death, the stigma and the grief-related emotions and reactions, were highlighted.

The value of communication coping strategies and adaptive avoidance have already been discussed. This section focuses on adjusting to life by oscillating between LO and RO stressors, functional-support-giving and proactive coping (Article III). As well as the results that documented the importance of self-efficacy, as high levels of self-efficacy were associated with a low PGS level (Article IV).

The importance of various strategies for ultimate adaptation was argued by Bonanno and Burton (2013). There were mainly two components identified in this project's findings: the ability to adjust to strategies and an available repertoire of regulatory strategies. Most parents described that they took control of their thoughts through proactive coping strategies, such as deciding when to grieve. Many of them oscillated between LO coping (actively grieving) and RO coping (putting grief on hold due to resuming day-to-day activities). Being needed by others facilitated coping with the loss in the case of parents with children or grandchildren who depended on them (Article III). Thus in line with the relational regulation theory (see Lakey & Orehek, 2011), functional-support-giving can explain how the parents managed to be flexible and cope with the loss.

How family dynamics affect personal grief, and vice versa, was elaborated upon in a revised model of the DPM by Stroebe and Schut (2015) (Figure 3). This project's finding showed that the RO strategy (taking care of and being needed by other children) was a distraction from the loss itself, and functional-support-giving was also an essential part of the meaning-making process. Challenging family dynamics and the loss of a caregiver identity (i.e., those who had lost their only child or did not have other children who depended on them) inhibited both adaptation and making sense of the loss. According to Bonanno (2013), the adaptive value of flexibility is relevant to the question of meaning-making. Article IV showed that high levels of yearning and not feeling a sense of relief, were associated with high levels of PGS. Hence, making sense of the loss can be assumed to be difficult, and can hinder meaning-making for the parents who struggled most.

A high level of self-efficacy was the intrapersonal factor that most clearly promoted emotion regulation, regulatory flexibility and adjustment to life for the parents in this project. In a study of refugees with PGD, difficulties in emotion regulation and a lower perceived self-efficacy, was associated with a greater severity of PGD, while other potentially traumatic events did not cause such difficulties (Lacour et al., 2020). These findings support the results in Article IV which indicated the importance of positive beliefs for the parents in this project, with regard to their ability to influence events. Self-efficacy is also positively associated with problem-focused coping (Konaszewski et al., 2019). In line with Konaszewski et al. (2019), the results in this project showed that those who believed that they could influence the grieving process by taking control of their mindset, had strategies for coping with their grief and were able to cope, to a greater extent, with the overload of emotions and stress reactions. The regression analyses also indicated that high levels of self-efficacy hindered withdrawal, suggesting that the consequences of using proactive coping strategies and a high level of self-efficacy had positive outcomes in relation to the parents' health, functioning and participation. Thus, parents bereaved by DRDs, can benefit from enhancing emotion regulation and perceived self-efficacy.

The level of education was identified as an essential personality resource for the parents in this project. Low levels of PGS were associated with a high educational level in the regression analyses, as is supported by research into those bereaved by other unnatural deaths (Dyregrov et al., 2003; Heeke et al., 2017). Dyregrov et al. (2003) reported that a higher level of education was also associated with greater access to professional help, more support from networks and the use of proactive coping strategies. In this project, the qualitative sample had a higher educational level than the quantitative sample (Table 4). Though the parents in the interviews reported that they asked for help and used proactive strategies to cope with the loss, they also represent parents with a higher education. Based on the project's findings and those of Dyregrov et al. (2003), there are reasons to believe that parents with a lower standard of education asked for help or used strategies to help themselves less frequently, as they scored highly on PGS. This finding suggests that parents with a lower education level might struggle more due to a limited access to resources.

As with the consequences of avoidance, researchers have demonstrated that several other behaviours and strategies (e.g., rumination and meaning-making) are seldom adaptive or maladaptive (Bonanno & Burton, 2013). Due to this complexity, identifying and understanding grief reactions is essential, both for the bereaved and for professionals in the health and welfare services. Such knowledge can be used to enhance the bereaved person's ability to adjust to life and to improve services when needed (Crunk et al., 2019; Stroebe, Schut, et al., 2017). Consequently, an increased understanding of ways of coping after losing a child to a DRD, is necessary. Both intrapersonal and interpersonal processes are highlighted in Figure 6, as adjusting to life is affected by a constant dynamic relationship between the bereaved and their surroundings.

5.2 Methodological and ethical considerations

In this section, the methodological issues are discussed with regard to the doctoral project's methodological quality. The discussion regarding what characterizes high-quality research, has been disputed primarily in terms of the concepts of reliability and validity (Creswell & Clark, 2017, p. 216). Therefore, as recommended by Creswell and Clark (2017), the reliability and validity of the data's quality, the results and the researchers' interpretation of the data, are evaluated.

Ethical considerations related to the research and the researcher, are also discussed to highlight the issues and processes considered in this project. Research should never take precedence over the well-being of research participants. Therefore, national and international codexes are developed to ensure and secure ethical clearance (e.g., the Declaration of Helsinki). Validity strategies that could be relevant in discussing both the methodological and ethical section, are described in the ethics section (e.g., feedback and reflexivity). This overlap illustrates that validity issues are intertwined and influence a range of research aspects.

5.2.1 Reflection on research reliability and validity

This section begins by clarifying how reliability and validity are used and understood in this synopsis. I refer to research reliability as existing "when the same results would be obtained if the study were conducted again" (Johnson & Christensen, 2016, p. 283). Research validity is referred to as "correctness or truthfulness of the inferences that are made from the results" (Johnson & Christensen, 2016, p. 283). Although validity is an essential concept, required to evaluate the quality of the research, it is a controversial term in qualitative research (Creswell & Clark, 2017, p. 249-250). In line with Johnson and Christensen (2016, pp. 282-313), validity and trustworthiness are used as synonyms in this synopsis regarding qualitative research.

An overall reflection on the project's general aspects of the methodology, is followed by reflections on the qualitative design and results, and the quantitative design and results. Validity strategies, used to promote qualitative research, are emphasized, since the qualitative component was prioritized in this project. Reliability is only discussed in relation to the quantitative research, as reliability plays a minor role in qualitative research (see Creswell & Clark, 2017, p. 218).

Reflections on general aspects of the chosen methodology

Exploration is essential when little is known about a topic (Johnson & Christensen, 2016, p. 22). Thus, exploring parental drug-death bereavement, using a qualitative driven design, was a strength of this project. To conceptualize or measure fundamental aspects of grief is difficult, as it is a complex emotional phenomenon (Stroebe et al., 2003). This complexity calls for investigating bereavement from a broad range of perspectives, and therefore, qualitative and quantitative research complement one other when seeking to shed light on parental bereavement from a DRD.

Methodological pluralism is particularly useful in studies of complex phenomena, such as bereavement (Stroebe et al., 2003). Triangulation is, therefore, the most central strategy used to promote research validity in this project. Triangulation can be defined as "cross-checking information and conclusions through the use of multiple procedures or sources" (Johnson & Christensen, 2016, p. 299). The strategy is central, as it can enhance the study's trustworthiness (Johnson & Christensen, 2016, p. 482). In accordance with a pragmatic worldview, multiple research methods (i.e., in-depth interviews and survey) have been used. Also, multiple investigators were involved in collecting data, interpreting data and writing up the results.

Transparency throughout the research process and articulating reflexivity, were essential in fulfilling the objective of reducing researchers' bias and being a reflexive researcher. Researchers' bias, meaning that the results are consistent with the researchers' findings, is a potential threat to research validity (Johnson & Christensen, 2016, pp. 299-300). The central strategy to prevent research bias is reflexivity. Reflexivity can be defined as "Continual self-awareness and critical self-reflection by the researcher on his or her assumptions, biases, predispositions, and actions, and their impact on the research situation and evolving interpretations" (Johnson & Christensen, 2016, p. 299). To reduce research bias and strengthen the research's external validity, the theoretical understanding of bereavement and the project's methodological assumptions, was clearly articulated in the synopsis, as supported by Bradbury-Jones et al. (2014).

In this project, feedback has been obtained from various actors in different phases of the research process. Describing how the researcher has obtained feedback from participants or conducted member checking, as well as conducting a peer review regarding the interpretation of the results and conclusions, is another strategy that can enhance the quality of the research project (Johnson & Christensen, 2016, p. 299). Firstly, PG members, professionals and user representatives have played an essential role in enhancing the project's content validity. Content validity is a subjective assessment that refers to which degree the instrument is adequate for the construct or the phenomena under investigation (De Vet et al., 2011, pp. 154-155). Selected PG members, who had experienced a DRD or were experts in this field, assessed the content validity. They commented both on the interview guide and the survey, and found the questionnaire and interview guide (i.e., questions and rating scales) to be acceptable and relevant to the area of its applicability.

Adding strength to this project's validity are the co-authors who participated in discussions regarding the research questions, planned the studies, analysed the data and wrote up the results. They are all experts in their different fields, encompassing both clinical practice and research. They also have extensive experience from substance use services (SKL, SM), mental healthcare services (MTS, SM), bereavement research (MS, KD) and evidence-based practice (HL). The co-authors also represent a broad spectrum of health and social care professions, including a social worker (SKL), a sociologist (KD), three psychologists (SM, MTS, MS), physiotherapists (HL, KD) and the doctoral candidate, a social educator (KBT).

Another strength of this project is that the articles' research questions are built on a review of the literature. Following up on the results of the SR (Article I) that recommended further research to devise more precise research questions, in order to define the family relationship to the deceased and to establish a sufficient sample size, also adds strength to this project. Precise research questions were formulated, specifying that parents constituted the focus of study. I argue that the sample size is sufficient as, to our knowledge, this project has the largest sample of parents, bereaved by a DRD, of any study to date.

Reflections on the qualitative design and results

The sample in the qualitative articles represented both mothers and fathers, with variations in age, time since death and geographical locations, including both urban and rural areas. As such, information power was a strength in this project.

Trial interviews, reflexive journals and supervisor supervision were strategies used to reduce research bias. A trial interview was conducted using the pilot interview guide, followed by a discussion with the interviewees. Reflexive journals were written by all interviewers after each in-depth interview, containing information about the interviewers' subjective responses to the setting and the participants. This strategy was chosen, as an interviewer's personal style might affect the results of an interview. The analysis was always followed by a critical discussion with the main supervisor, to ensure that the analysis was not confined to only one perspective.

Conducting a reflexive thematic analysis by Braun and Clarke (2019a), was another strategy to strengthen the quality, transparency and transferability of the project's results. There are pros and cons regarding the choice of the type of thematic analysis to apply, and thematic analysis has been described as an "anything goes" approach (Braun & Clarke, 2006; Majumdar, 2019, p. 205). However, Braun and Clarke have faced this criticism and have developed guidelines to assess the quality of qualitative research analysis (Braun & Clarke, 2019a; Clarke & Braun, 2019). These guidelines were followed closely to strengthen the qualitative results. The guidelines enabled us to stay close to the data from the participants and thereby be empirically faithful to the cases included, providing explicit and transparent links between the conclusions and the data material.

Another central strategy, used to ensure research validity, is the search for disconfirming evidence. Searching for divergent findings is similar to cross-checking information, using triangulation searching for the convergence of results (Johnson & Christensen, 2016, p. 298). Searching for disconfirming evidence is a procedure for constructing a credible narrative (Creswell & Miller, 2000). When analysing the data from the interviews in this project, the first step was to establish the preliminary categories. The authors then searched for data that was consistent with or disconfirmed the results, examining multiple perspectives on the data.

Articles II and III contain value-adding analysis. The aim of value-adding analysis is to go beyond the identification of themes and to "seek to construct out of grounded empirical data general concepts that characterize findings at a more abstract level." (Eakin & Gladstone, 2020). Qualitative research is criticized for producing little new knowledge due to shortages of analysis; by conducting value-adding analyses, new knowledge can be generated (Eakin & Gladstone, 2020). In Article II, the value-adding analysis aimed to "theorize" data relating to "special grief", and Article III, focused on coping with a loss, in light of DPM. As such, value-adding analysis strengthens the external validity of the project's results by contributing to new theoretical knowledge about parental drug-death bereavement, i.e., comparable to the concept of theoretical generalization (Kvale, 2007).

As previously mentioned, participants' feedback is an important strategy in enhancing the validity of the project. One type of validity is interpretive validity, which is defined as the degree to which the "researcher accurately understands research participants' viewpoints, thoughts, feelings, intentions, and experiences, and successfully portrays them in the research report"(Johnson & Christensen, 2016, p. 301). Interpretive validity can be achieved with feedback from the participants. To achieve internal validity in this project, the interviewer repeated the in-depth interview data for the participant, encouraging the participant to adjust or modify the interviewer's interpretations and to add additional information. In addition, the interviews were transcribed verbatim. Verbatim is a low-inference descriptor that provides the participants' exact words (Johnson & Christensen, 2016, p. 301). By reading verbatim quotes, the reader of the article can experience the participants' voices and personal meaning and can, therefore, understand the participants' perspectives.

Transparent and rich descriptions are aimed for, particularly in the "Method" and the "Result" chapters in the articles. Leaning to pragmatic philosophy, value positions and desired outcomes need to be accounted for explicitly, and the research is valuable if it leads to explanation, prediction and detailed description (Johnson & Christensen, 2016, p. 469). Therefore, the result chapters in Article II and III contain rich verbatim extracts from the interviews, enabling the reader to make judgements as to whether the final themes are an honest reflection of the participants' accounts.

Articles in this project highlight the fact that drug-death bereavement is an understudied topic and that parents, bereaved by a DRD, do not receive the attention and help to which they are entitled, which constitutes social injustice. The research may also be regarded as positive if it leads to social justice and fewer inequalities (Johnson & Christensen, 2016, p. 469). In "Implication for practice", I argue that the doctoral project and the END-study are raising awareness of drug-death bereavement, and the Norwegian health authorities are beginning to take cognizance of this issue. Hence, the authority's recent awareness of the social injustice towards those bereaved by DRDs, constitutes a strength of this project.

Reflections on the quantitative design and results

The methods, used most widely, to assess reliability (e.g., test-retest and internal consistency) are generally relevant when developing and evaluating instruments' measurement properties (Johnson & Christensen, 2016, pp. 164-170). The instruments included in the survey were mainly developed by others, therefore, few methods for computing reliability were assessed in this project.

Before the linear regression analyses, internal consistency was calculated. One of the most widely-used methods for reporting reliability is internal consistency reliability, measured by Cronbach's alpha (DeVellis, 2017, as cited in Mellinger & Hanson, 2020)). The results from calculating internal consistency demonstrate "the degree to which the items are interrelated" (Johnson & Christensen, 2016, p. 168). Three validated instruments were included in this project (i.e., PG-13, CSS, GSE-SF). Cronbach's alphas were found to be satisfactory and indicated that the proportion of variance in scores, could not be attributed to other underlying variables.

Cross-sectional research has several limitations (Johnson & Christensen, 2016, p. 401). Though it is advantageous that data relating to many people can be collected within a short time, it is challenging to determine whether the exposure or the outcome comes first. Therefore, when using the concept predictors resulting from regression analysis, associations in terms of findings and not causality, were highlighted.

Another limitation regarding survey data is the fact that data are measured at a single time point, and it is difficult to measure changes that occur over time (Johnson & Christensen, 2016, p. 402). In addition, going back in time can increase recall bias. Although serious life events are often remembered with great clarity, recall bias might have occurred, as many parents lost their loved one a long time ago, or the average time since the loss was considerable. However, items included in the analyses essentially related to the present time, which may have strengthened the validity of the results.

Using validated and well-known instruments of bereavement research after an unnatural death (i.e., PG-13, GSE and CSS), was a strength of this project, yet a lack of transcultural validations for the Norwegian context is a limitation. There are also certain limitations regarding the use of the instruments. PG-13 is a diagnostic tool used by clinicians in structured clinical interviews (Prigerson & Maciejewski, n.d.), but was used to collect self-reported data. However, using PG-13 to collect self-reported data is a common and widely used approach in similar studies (Pohlkamp et al., 2019), as well as in the Norwegian context (Johnsen et al., 2012). Therefore, assumptions relating to meeting the criteria of PGD were not made, and the levels of PGS were reported.

In addition to cross-cultural differences, there are several administrative issues that can affect reliability. Online administration and translation of surveys are some of the issues that pose a threat to reliability (Mellinger & Hanson, 2020). The collection of certain data by digital means and certain data on paper, could have negatively affected the reliability. Using logs and codebooks, and ensuring that two researchers were always present to verify the scores when transferring data from a paper to a digital version, is likely to have reduced the possibility of errors.

Mellinger and Hanson (2020) argue that only scales, not single items, should be summarized and tested statistically. Even though researchers draw conclusions on single item(s), they state the importance of being cautious when interpreting a single result, as the external validity could be less significant. Due to a lack of instruments that measure the phenomena under study, single items were used in this project to shed light on the bereaved after a DRD. Single items from SGQ (Dyregrov et al., 2019) were used to explore the various experiences of bereavement after a DRD. The 16 single items in SGQ measured various aspects that are described in the literature regarding bereavement following special deaths (see Table 5). There is a need to develop instruments that measure these aspects. I argue that when a suitable survey instrument is lacking, single items can highlight aspects which other instruments, commonly used in bereavement research, cannot. In this project, the choice of variables for the regression analyses was built on the results of interviews with the parents. Until a scale measuring the “special grief” is constructed and validated, single items can inform the results, but the results must be interpreted with caution.

This project’s results are not presented as statistically generalizable findings, representing an objective outsider viewpoint of those bereaved by a DRD. The participants were not randomly selected. As no data from the registry of bereaved parents were available, we sought to recruit widely by all possible means for one year, resulting in the world’s largest sample of parents, bereaved from a DRD. The sample size is small, considering an adequate sample study for a prevalence study, and as the prevalence of PGS is derived from a convenience sample, this limits the findings’ generalizability. Still, this project has the largest sample of parents bereaved by a DRD in a research project (i.e., the sample size in the survey was n=93), which increases the project’s relevance. Despite our efforts to recruit bereaved parents from different classes in society through different recruitment strategies, parents from lower social classes were under-represented. As such, the risk of sampling bias is present in this project. The fact that women are predominantly represented is in accordance with previous studies relating to this population (Feigelman et al., 2011). However, the fact that women were overrepresented in the project is a limitation (81.7% in the survey).

Hence, external validity in the sense of the results' generalizable validity is, therefore, not discussed. However, the results must be appraised in light of their contextual information, namely, the population included, the phenomena of our research interest and the way in which participants were recruited. Therefore, rather than the potential of the results be extrapolated across populations, phenomena or geographical aspects, the external validity of this project relates to the transferability of evidence of the theoretical concept of parents, bereaved after DRDs in Norway. Statistical generalization must, therefore, be made with caution.

5.2.2 Research and researchers' ethics

The concept of ethics can diverge into ethical issues and processes related to the research and the researcher. Research ethics refer to the way in which research participants are treated and how their human dignity, self-determination and integrity are protected (e.g., informed consent and confidentiality). Researchers' ethics refer to the researchers' responsibility in relation to research and the research community (e.g., transparency and reflexivity) (Kalman & Lövgren, 2012). In this project, I have strived to meet the ethical obligations of both viewpoints. As in all studies, several ethical questions also arose in this doctoral project and to exemplify, one dilemma is discussed ("the recruitment dilemma").

Researchers' ethics

Reflexivity can be defined as "Continual self-awareness and critical self-reflection by the researcher on his or her assumptions, biases, predispositions, and actions, and their impact on the research situation and evolving interpretations" (Johnson & Christensen, 2016, p. 299). I acknowledge that there is a relationship between the researcher and the researched, and that researchers must reflect on how identity can affect the interaction. At the beginning of the doctoral project, my personal presuppositions and assumptions were written down. Briefly summarized, I assumed that losing a child is one of the most traumatic experiences an adult can go through, and that parents bereaved by DRDs have genuine thoughts relating to guilt. I also considered the challenges regarding how to rehabilitate people who use drugs. I believe that it is challenging to motivate a person with a drug dependency to stay in rehabilitation. I reflected on the ambivalent situation, namely, that I was aware that people who use narcotics cause harm to the society, however, I was worried about making such a statement and consequently being perceived as stigmatizing or derogatory.

The narrow format of a scientific research article does not allow much room for descriptions of reflexivity. However, the doctoral articles contain certain descriptions that reflect reflexibility. As recommended by the standards for reporting qualitative research (Malterud, 2001; O'Brien et al., 2014), the characteristics and role of the researchers were accounted for in the articles (e.g., "the analyses were first conducted by the first author (a social educator)"). Further details on the researchers' identity were provided in Titlestad, Stroebe, et al. (2020), as the journal asked for author biographies. In the biography, I highlighted issues from my own situation, for example, that I have a sister with a moderate intellectual disability, who requires support in her daily activities. I also stated that my father was dying while I was conducting the interviews with the bereaved parents. Although I do not know what it is like to lose a child or to live with a person who uses narcotics, I do know what it is like to grow up with a sibling with additional needs, and in adulthood, I have a responsibility for a sister who requires extensive help with everyday tasks. I also have experienced anticipatory grief over a long period. Similar to parents bereaved by a DRD, I have experienced living with an overload of care responsibilities and the need to find strategies to cope with everyday life and grief reactions. As such, it is likely that the text in the biography discloses aspects of my identity as a researcher. However, the text allows the readers to reflect upon whether my personal experiences and attitudes, actually affected the research question, analyses and results. There is no way of being certain as to whether my own experiences have affected my research, however, I do believe that gaining more knowledge about grief and grief reactions, has made it easier to work with my own grief.

Writing this synopsis is an opportunity to elaborate and reflect on my role in this doctoral project. My role as a doctoral student has also entailed tasks relating to the END-study, in addition to this doctoral project. Together with my main supervisor (KD), I searched for relevant instruments for the survey. Since we were unable to find any relevant, existing surveys which measured bereavement following a DRD, we developed one after consulting user representatives and experts in the field. Together we developed a paper version and an online version of the survey. I also worked with KD on an application to the Norwegian Regional Committees for Medical and Health Research Ethics for the END-study, including the application for this project. As part of this application, information leaflets and consent forms were developed for the survey and the in-depth interviews (Appendix III and IV). We also developed the recruitment flyer. Like the other END-members, I participated in the recruitment of participants and was in charge of the registration of participants and the sending of feedback and reminders to all the participants (e.g., parents, siblings and friends). I was also responsible for uploading data relating to all the participants of the survey to the research server, including data from the in-depth interviews with parents. In addition, I plotted all the data in SPSS and NVivo. My main supervisor monitored this work. I wrote the doctoral project plan, led the work with analyses of the data, wrote up the articles and submitted the articles to the journals.

Research ethics

All procedures were conducted following the Declaration of Helsinki (The World Medical Association, 2018). As stated in the Methodology chapter, the END-study application that included this doctoral project, was approved by the Norwegian Regional Committees for Medical and Health Research Ethics (Appendix II).

The well-being of research participants was a prioritized focus throughout the research process. Participants who agreed to take part in an interview, also received written information before the interview, and the issues of consent and confidentiality were repeated verbally at the interview (Appendix IV). We assured the participants' anonymity, confidentiality and the option to withdraw from the study at any time. We also confirmed that all identifying information concerning survey data, transcripts and recordings was de-identified and stored on the research server at the university. To accommodate the parents experiencing great hardship, they were allowed to decide where the interviews were conducted, e.g., in their homes where they felt safest and most comfortable.

To support the value and need for studying parents bereaved by a DRD, a lack of knowledge and previous research on an understudied population, are accounted for in the introduction. The fact that a DRD is an unnatural death and that bereavement after unnatural deaths has serious consequences, are also well documented in the introduction and serve as arguments for the value of the doctoral project. In addition, value is ensured through the members in PG and AB. Bereaved and national and international colleagues have also been consulted throughout the research process.

The researchers' integrity was achieved by following the Vancouver Convention on authorship by the International Committee of Medical Journal Editors (2020). The recommendations intend to ensure that only contributors who have made substantive intellectual contributions, are given credit as authors. Moreover, by endorsing the recommendations, all authors are responsible and accountable for the content that is published (International Committee of Medical Journal Editors, 2020).

When applying theory to this project, I aimed to articulate my theoretical understanding and adopted a critical, flexible and creative attitude. Transparency in the work, such as explaining the research process, was also important in fulfilling this intention. While compiling the doctoral articles, I aimed to be transparent and to give a precise description of the research process from establishing the initial outline to developing the methods and reporting the findings. Reporting guidelines were used to undertake this transparency and to account for reflexivity: "PRISMA" (Liberati et al., 2009) in Article I; "*Standards for Reporting Qualitative Research: A Synthesis of Recommendations*" (O'Brien et al., 2014) in Article II and III and "*STROBE Statement*" (ISPM, 2007) in Article IV. Hammersley (2007) points out that there is a spectrum of critical opinions regarding such guidelines, especially concerning qualitative research. He also states that there are some who use reporting guidelines simply as a criteria checklist that needs to be completed, and others who use it as a list of considerations. In my case, as an early-stage researcher, checklists have been necessary and useful tools in terms of planning the study, collecting data, carrying out analysis and writing up the results.

The recruitment dilemma

Recruiting participants from lower social classes was a major ethical dilemma in this doctoral project. The Declaration of Helsinki (The World Medical Association, 9. July 2018) states that "While the primary purpose of medical research is to generate new knowledge, this goal can never take precedence over the rights and interests of individual research subjects". Furthermore, the declaration emphasizes, "Some groups and individuals are particularly vulnerable and may have an increased likelihood of being wronged or of incurring additional harm. All vulnerable groups and individuals should receive specifically considered protection". As mentioned, drug-death bereavement is associated with adverse health outcomes and higher mortality than bereavement due to other causes of death (Christiansen et al., 2020). With this in mind, those bereaved by a DRD can be understood as a potentially vulnerable group.

The ethical dilemma regarding recruitment arose when potential participants did not respond to the survey they had asked to receive. We, the researchers, were not permitted by the Norwegian Regional Committees for Medical and Health Research Ethics to reach out to the participants, even though they had contacted us first. This was a dilemma: how to facilitate the participation of vulnerable individuals in a research study?

It is reasonable to assume that the bereaved who struggle in everyday life may also struggle to complete a survey or attend an interview session. This became clear to us when one parent, who also had a drug dependency, reached out to us via a caseworker, asking whether the caseworker could guide the bereaved through the survey questions. Furthermore, another parent did not attend the interview, despite several attempts to find a suitable interview time. The parent explained that the failure to attend was due to challenges relating to substance use. In general, few recruited participants asked for help, although the researchers in the END-study agreed that if a bereaved parent tried to contact us, we would facilitate their participation.

Consequently, there is a risk that important details associated with bereavement by DRDs, are not captured. The participants, interviewed in this project, reported positive experiences from participating and many expressed gratitude for being able to share their stories during the interviews, although, they did say that they felt tired afterwards. The ethical codex that hinders researchers from reaching out to participants is especially problematic, as evidence has shown that the benefits of participation for most people outweigh the risk (Blades et al., 2018; Dyregrov, 2004a, 2016; Omerov et al., 2013). During the entire interview process, Dyregrov (2004a) recommendations concerning research into vulnerable populations, were followed. For example, the participants were made aware of the possibility of contacting the project manager, if answering questions relating to difficult life experiences, prompted a need to talk to someone subsequently. Also, an agreement with a local crisis centre to assist if necessary, was arranged. Using these measures, I argue that compassion was shown to vulnerable, bereaved parents who participated in this project. Hence, the ethical codex constitutes an ethical dilemma, which acts as a barrier to vulnerable groups and might deter them from participating in the research, despite that fact that the benefits of participating outweigh the drawbacks.

6. Conclusion and future perspectives

The issue of DRDs is an understudied topic. Parents bereaved by a DRD, experience an overload of stress due to constant preparedness, an overload of perceived societal and self-stigma, as well as an overload of grief-related emotions and reactions. How they cope with the loss is influenced by factors on an intrapersonal level (e.g., level of self-efficacy and using proactive coping strategies) and factors on an interpersonal level (e.g., attitudes and norms, and receiving professional help). The results identify a gap between the parents' needs and the help and support provided. The parents who struggled the most reported low self-efficacy, withdrawal and long-lasting grief. The knowledge generated is of national and international relevance and may, to a certain degree, be transferable to other forms of unnatural death.

The following describes the implications of the findings in terms of practice, policy and further research. Accordingly, there is a need to act at an individual, group and societal level (Figure 7).

Figure 7 Need for actions at an individual, group and societal level. The arrow illustrates that the levels overlap and are intertwined (images from Shutterstock).

6.1 Implications for practice

The doctoral project's main contribution is to assemble knowledge relating to the need to provide proactive support to the bereaved immediately after a DRD. This finding calls for services in line with the white paper, "*Psychosocial Interventions in the Event of Crisis, Accidents and Disasters*"(Norwegian Directorate of Health, 2016). When the child died, many of the parents in this project were overloaded by the stress under which they had been living. Many who were offered help from the surrounding networks were not able to respond to this care. All had felt rejected by public services when they asked for help for their child. Some also felt rejected when they reached out for help after their loss, while others reported that they did not know who to ask for support. Therefore, perceived disenfranchised grief could hinder parents, bereaved by DRDs, from receiving important help, which should be offered automatically and immediately after a DRD.

This project highlights the need for a range of measures to enable access to public services, i.e., "a toolbox", in order to help the bereaved. After the shock of death had subsided, the parents who received help emphasized that individual therapy helped them cope with their loss. They learned how to understand grief reactions and self-perceived guilt, and learned strategies enabling them to cope with their emotional burden and to handle their day-to-day living. The findings suggest that professionals must pay special attention to parents who experience an enduring overload before and after the death and to those who ruminate about guilt and describe their grief process as one of being stuck in either rumination or avoidance. Individual therapy for complicated grief, e.g., CGT (Shear & Bloom, 2017), could be offered to those who struggle the most. If individual therapy is not sufficient, medical treatment for PGD cannot be dismissed as an option. Due to the complexity of bereavement after a DRD, and the fact that an evaluation of suicidal thinking should be part of the assessment of complicated grief (Shear, 2015), health professionals should screen bereaved individuals, who struggle with PGS, for suicidal thoughts.

More specifically, this project contributes knowledge relating to the bereaved's need for information to improve their coping skills, enabling them to continue with life. The bereaved craved information on dependence, the triggers and why it is challenging to quit. Many parents also ruminated about the time leading up to the death of their loved one, and wanted to know who was present or involved. Being informed of this led to a reduction in grief reactions associated with guilt, and facilitated coping with and accepting the loss. The healing effect of insight through follow-up interviews of those bereaved from a DRD with a forensic pathologist, has been studied previously (Abiragi et al., 2020); other studies have also highlighted that the documentation of the death scene investigation helps bereaved parents cope with their loss, e.g., Heltne et al. (2016). Follow-up interviews with professionals should, therefore, be part of the individual follow-up for the bereaved.

A range of available measures for professionals to support the bereaved is also needed at group level. The advance knowledge, obtained by this project, indicates that the parents called for the organization of support groups, specifically for those bereaved by DRDs. The parents argued that talking to other bereaved individuals, who had experienced a DRD, would be beneficial. Even though the scientific literature on support groups for the bereaved is scarce, research highlights the increased benefits of peer-support groups (Bartone et al., 2019), rather than support groups organized by professionals (Maass et al., 2020). As peer support appears to be especially valuable for those bereaved by unnatural deaths, such groups should be created. Here web-based support can be considered, especially in the case of Norway, as it is an elongated country with outlying areas. Supporting the call for a range of measures has also been reported in a recent project, conducted by the END. Fjær and Dyregrov (submittet 2021) summed up the participants' answer to an open question in an END-survey, which asked those bereaved by a DRD, what advice they would give to politicians to improve bereavement services. They found four central themes: broad spectrum, routine, respect and competent help.

Furthermore, this project contributes knowledge regarding how to communicate with and provide support for parents bereaved by DRDs. Dysfunctional communication between the bereaved, their network and helpers complicated the grieving process, and both the bereaved and those around them can take action to improve this interaction. The findings show that the bereaved's social network and the helpers must try again, even if rejected the first time they reach out. Most of the bereaved reported that the shock after death rendered them unable to receive help and support, but that the supporters who did not give up on them, later became crucial in helping them adjust to life. To improve the interaction, the bereaved require knowledge about the advantages of openness, and how to educate helpers as to the best way of supporting them (see Dyregrov & Dyregrov, 2008). Proactive, bereaved individuals can help those in their social networks to take the first challenging step in talking about DRDs. Therefore, social networks can benefit from being informed that support must be provided on the terms of the bereaved and over a period of time, and that listening with respect and empathy can enhance communication with the bereaved (e.g., guidelines from UK-study).

6.2 Implications for policy

On a societal level, the doctoral project's findings support a call for action to erase the "us" and "them" assumption and to take measures that de-stigmatize drug use and dependency. Attitudes, norms and values in society towards people who use drugs were internalized in the bereaved, which complicated the bereaved parents' grieving process. The socio-demographic data showed that the deceased and their families were essentially families living «ordinary Norwegian lives», meaning there were no evident indications that their child would end up with a drug dependency and would die. During the child´s drug dependency and after the DRD, the families all experienced stigmatization, and their children were criminalized and treated derogatorily. Therefore, grief in the aftermath of a taboo-laden and stigmatized death must be understood in a broader perspective, linked to a country's policies. Hence, bureaucrats and politicians play an essential role in proposing new policies that can change attitudes towards drugs, people with drug dependence and their close relatives.

The authorities acknowledge that people with a dependence and the situation of their next of kin, represent serious public health issues. A recent Norwegian Official Report (NOU 2019:26, 2019) suggests moving the social response to drug use from the justice sector to the public health sector. This move was widely praised by experts, hoping that this will help reduce the stigma. Whether it is the health or the justice sector which administers drug policies, will affect a society's citizens, attitudes to drug use and ultimately how society relates to those bereaved by DRDs. A change in policies and norms will influence the interventions and services that authorities will be obliged to offer those affected by DRDs. Importantly, there is a need to challenge the discrepancy between the Norwegian white paper's obligations to provide a follow-up after an unnatural death (Norwegian Directorate of Health, 2016) and the lack of help following DRDs.

In many ways, Norway is at the forefront by stating the authorities' obligations to provide all the aforementioned help for those bereaved by unnatural deaths. The obligations and measures are described in the white paper, "*Psychosocial Interventions in the Event of Crisis, Accidents and Disasters*" (Norwegian Directorate of Health, 2016). This doctoral project documented a strain before, when the child dies, and after the death, experiences that can result in lifelong burdens and consequences for parents, bereaved by DRDs. In addition, the findings support the need for a better organization of public services across other services. The parents reported a lack of cooperation between the person who uses drugs, their next of kin and public services, due to confidentiality-issues. It is reasonable to believe that the lack of cooperation between services affected the lack of measures offered to the bereaved. The parents also reported that different public services did not pass on relevant information, required by other services to do their job (e.g., passing information from the police to a crisis team, after an overdose). Against this background, there is a call for adherence to the white paper and an acknowledgement of DRDs as unnatural deaths, to enhance public recognition and create an awareness of the need to provide a better organization of services. The parents need holistic care. A range of measures from which the bereaved can benefit on an individual, structural and organizational level, are described in this white paper.

The Norwegian Directorate of Health has acknowledged the significance of the END-study and the need for further measures for those bereaved by DRDs in another white paper relating to drug policy, so as to reduce drug overdoses (Norwegian Directorate of Health, 2019). The Directorate refers to the END-study and states that it will ensure the involvement of the bereaved in all local overdose prevention work. The Directorate will also involve the bereaved in any upcoming strategy work and will contribute to supporting the END-study. As such, this doctoral project has provided research-based knowledge to the Directorate relating to the bereaved parents' experiences and needs. This project's results provided personnel in public services, bureaucrats and politicians with a new discourse. The discourse encompasses how to facilitate recovery for those bereaved by DRDs and how to help decrease the societal stigma that the parents experience. Hopefully, the findings from both this doctoral project and the END-study have and will continue to contribute knowledge of major significance both in Norway and internationally.

6.3 Implications for further research

This doctoral project's findings support a need for change in the way in which researchers approach research in the drug field. The role that research-based knowledge plays in policy-making in the drug field, depends on the institutional and historical context in which this knowledge is developed (Fjær, 2001). Fjær (2010) argues that drug policy lacks social research, due to polarization in the Norwegian drug debate. Polarization occurs when the researchers' role is to provide reliable and neutral knowledge, based on the knowledge required, or to present alternative images of the situation from an ironic distance. Fjær (2010) encourages researchers to be politically incorrect and to enter the exciting and challenging space for critical research between these two roles. She states that it is necessary to recognize many sources of knowledge to surmount the ongoing polarized debate. This doctoral project's knowledge base goes beyond previous research in the drug field. Experience-based knowledge and user experience influenced the research questions and the exploration of normative questions relating to social values and citizens' rights and duties, as obtained from members of the END-study. Thus, the project aims to influence the field of practice, as well as politicians and bureaucrats, by contributing knowledge based on the needs of families who experience drug dependency.

There is a need for research that reduces the condemnation of people who use drugs. Article I identified the necessity for more research into the negative attitudes and stereotypes among the networks of those bereaved from DRDs, their community and the general population. Self-stigma and societal stigma are clear findings in this doctoral project, especially in Article II. However, the complexity in terms of stigmatization and how it pervades different levels of society needs further research.

Article II and III highlighted the negative consequences, and the lack of help and support for the bereaved. Descriptions of meaning-making, for example, being needed by others, and characteristics of support that facilitated the adjustment to life, were also described. However, research into the factors which enhance the quality of life and daily functioning of bereaved parents is needed, as well as the identification of important predictors for coping and ensuring post-traumatic growth. This is supported by the parents' call for peer support groups. Whether parents, bereaved by a DRD, benefit from facilitating or participating in peer-support groups is, therefore, an essential topic in need of further investigation. This also concerns research regarding the conditions needed to promote a natural grieving process, including enriching bereaved parents' opportunities to focus on facilitating the grieving process, not just the challenging elements of bereavement from a DRD. Importantly, further study is needed to address the challenging communications between the bereaved by a DRD and their social networks, to facilitate the bereaved's natural healing process.

Article IV highlights the parents' levels of PGS. However, research is required that elaborates on these findings, to identify what promotes or inhibits self-efficacy and withdrawal, and what contextual conditions trigger and maintain grief reactions. As time since death was associated with a reduction in PGS, more research into the period required to adjust to the loss, is also needed.

This project adds knowledge on a societal level, maintaining that there is a need for public recognition and awareness of those bereaved by a DRD. The doctoral project's findings can help understand the complexity of drug-death bereavement and should be of interest to health and welfare services, regarding the way in which they relate to DRDs. Thus, it is important to explore why professionals do not class DRDs as traumatic, unexpected or violent deaths, which in line with the white paper, "*Psychosocial Interventions in the Event of Crisis, Accidents and Disasters*" triggers proactive crises help for those bereaved by a DRD. At an organizational level, elements like culture, resources, processes and systems should be explored. Accordingly, and based on the barriers identified, policy and competence-enhancing measures to extend the professional's expertise relating to drug-death bereavement, must be implemented.

Research shows that assessing barriers to the use of knowledge is an important factor in successful knowledge translation (Graham et al., 2006). A SR that summarized barriers of cooperation among help systems around the world found that health care organizations typically struggled with poor organizational culture, inadequate or poor infrastructure and dysfunctional external relations (Vaughn et al., 2018). This lack of cooperation among the help system is not just a Norwegian phenomenon. The doctoral project's findings should, therefore, be of international interest. The consequences of professional confidentiality should be further investigated and modified, as this poses a barrier for cooperation between and across services, and between services and parents, both before and after the death.

This project's findings indicated a need for instruments that can map "special grief" and stigma experiences. SGQ (Dyregrov et al., 2019) can be a good starting point for developing an instrument that explores experiences after losing a next of kin, due to a "special death". Further development of the questionnaire with the intention of creating a scale is necessary. This project's findings also call for the establishment of a consensus of concept and terms including DRD, complicated grief, resilience, coping processes, strategies and styles in relation to general bereavement research.

This doctoral project also has implications for the END-study. This project is the first to publish results from the main study. The knowledge gap that has been identified and the project's findings, provide direction for the research focus for many publications, planned in the END-study. It also provides knowledge for the END-research circle (see 1.4), one of the END-study's knowledge translation initiatives.

In conclusion, we found that the findings of the project can extend beyond the Norwegian context. The degree of the findings' transferability has been discussed in the synopsis, and the importance of adapting research to context has been outlined.

Implications for practice will largely depend upon the welfare responsibilities in each country. Nevertheless, when a US father reached out by e-mail and indicated that Norwegian parents' experiences are recognizable in other parts of the world, we, as authors of Article III, suggested that the correspondence be published as a commentary piece (see Thomas et al., 2020). The commentary indicated the similarities between this US father and the Norwegian parents' experiences.

6.4 Final remarks

I presumed that losing a child would be the most traumatic experience a parent could go through. This assumption is strengthened by my empirical findings and acquired knowledge from the scientific literature, describing unnatural death consequences. I have learned that when the cause of death is drug-related, this complicates the grieving process immensely, because bereavement by DRD is greatly affected by contextual factors. Meeting the parents, interviewing them and analysing data from the survey, have provided new insights. I now know that the parents have thoughts about guilt. Furthermore, ruminating over guilt is one of the most vital reactions after death, but one that is also associated with grief complications.

The parents I met are just like every other parent. However, they had all fought a long and tough battle for their children. Many felt they had failed - the child, themselves and society. This made the most significant impression on me. As the parents struggled to get a foothold, they were also trying to find their place in society – a society that instead of offering support, reduced their chances of recovery, due to negative attitudes towards their deceased child who used drugs.

I am still struggling with how to debate the negative consequences of narcotic use, both for the individual, their network and society, without being perceived as stigmatizing or derogatory. To advocate support for the bereaved is easier, as then I am able to focus on the parents. I aim to make supporters, helpers and policymakers aware of what they can do from my position as a researcher. By contributing research-based knowledge and communicating the experiences of the bereaved and their need for help and support, I hope that their voices will be heard, and that services for their benefit will be put into regular practice.

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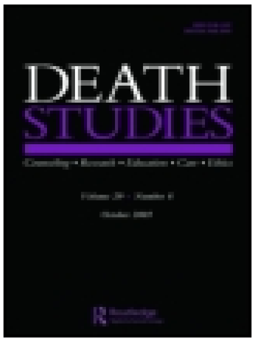
PART II: ARTICLES AND APPENDICES



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How do family members experience drug death bereavement? A systematic review of the literature

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ABSTRACT
Despite high rates of drug-related deaths (DRDs), drug-related bereavement has been sparsely investigated. A systematic literature search for qualitative and quantitative studies was conducted. Studies on bereaved DRD family members and systems influencing bereavement were eligible for inclusion. Eight studies were included. Three themes emerged from the thematic analysis (Emotional Roller Coaster, Lack of Understanding by the Social World, and Meaning Making) describing an emotional and existential overload, stigmatization and lack of understanding and help from support systems. The results also shed light on life after the loss. Directions for further research were subsequently outlined.

Despite increased focus and extensive preventive actions, reducing drug-related deaths (DRDs) remains a major public health challenge in all parts of the world (Centers for Disease Control and Prevention (CDC), 2018; European Monitoring Center for Drugs and Drug Addiction (EMCDDA), 2018). DRDs are deaths caused by the intake of substances classed as narcotics and "deaths among drug users and their social circle where the cause of death is violence, accidents, infectious disease, and other health disorders which in different ways may be linked to drug use" (Norwegian Directorate of Health, 2014, p. 14). In the United States, DRDs reached what could be described as epidemic proportions in 2016 when drug overdose deaths reached a new record high (CDC, 2018). Death from drug overdose continues to be a public health burden in the United States as the age-adjusted rate of such deaths in 2017 (21.7 per 100,000) was 9.6% higher than the 2016 rate (19.8) (Hedegaard, Miniño, & Warner, 2018). In Europe, the mortality rate due to overdose in 2016 was estimated at 21.8 deaths per million population aged 15–64 (EMCDDA, 2018).

For every person deceased by a DRD, there will be at least ten next of kin left behind who are likely to suffer the effects of bereavement (Dyregrov, Møgster, Titlestad, Løseth, & Lorås, 2018). Bereavement is understood as the situation of losing a loved one through death. It is associated with serious mental and physical health difficulties, increasing even the risk of early death of the bereaved person (Stroebe, Schut, & Stroebe, 2007; Stroebe & Schut, 2016). The Dual Process Model of Coping with Bereavement (DPM) (Stroebe & Schut, 1999) is a recognized scientific bereavement model (Dyregrov & Dyregrov, 2017) developed by Margaret Stroebe and Henk Schut. The DPM describes the processes of how people often come to terms with their losses through oscillating between facing the reality of the loss and going on with their lives. Balancing the loss- and re-orientation processes can prevent complicated grief reactions as it increases the chance for the bereaved to integrate memories of the person who died and simultaneously go on with life in new ways (Dyregrov & Dyregrov, 2017; Stroebe, Schut, & Boerner, 2017; Stroebe & Schut, 1999, 2010, 2016).

Inspired by the DPM and research evidence, Kari Dyregrov has developed a theoretical model that can shed-light on drug-death bereavement (Dyregrov, Møgster, et al., 2018). The model is based on the fact that many relatives and close friends face a demanding situation and are part of societal efforts to help drug users while they are still alive. Despite offering this support, family members of users commonly face years of uncertainty, despair, stigma, hopelessness, and powerlessness, often, unfortunately, culminating in the premature death of the drug user due to overdose or some other drug-related cause. Sometimes the strain becomes so bad that the supporter can find him

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or herself oscillating between sadness and hope that the death of the drug user arrives so that such a burden may be eased (Feigelman, Jordan, & Gorman, 2011; Templeton et al., 2017). In line with theories of stigma, there is also reason to believe that those bereaved by DRDs can experience negative attitudes and actions from those around them (networks, local communities, support services) through being associated with the stigmatized drug abusers themselves (Corrigan, Rafacz, & Rüsch, 2011; Dyregrov & Dyregrov, 2008). Studies show that "unnatural deaths", i.e., those that are sudden and unexpected, self-inflicted or violent, are more likely to produce complicated grief in the bereaved (Dyregrov, Nordanger, & Dyregrov, 2003). Also, unnatural deaths can both shorten lifespan and produce serious long term grief and trauma reactions (De Leo, Cimitan, Dyregrow, Grad, & Andriessen, 2013; Feigelman et al., 2011; Li, Precht, Mortensen, & Olsen, 2003).

Despite high rates of overdose and the potential burden for the bereaved, as described, the intricacies of bereavement after DRDs have been sparsely investigated. To the best of our knowledge, no systematic review (SR) has examined the experiences of people bereaved through DRDs, although a scoping review was carried out by Valentine, Bauld, and Walter (2016). Valentine and colleagues have also conducted the first large scale research project in Britain concerning the experiences of adults bereaved through a drug or alcohol-related death. The project resulted in guidelines with five key messages that were identified from research interviews with 106 bereaved adults and focus groups that were attended by 40 workers and bereaved adults (Cartwright, 2015). The scoping review examines both drug- and alcohol-related deaths, so called substance misuse deaths. In our study, however, a distinction is made between drug- and alcohol-related deaths and we focus only on drug death bereavement. The two types of death likely differ, firstly because using drugs is an illegal activity. Since it is illegal, as Corrigan, Schomerus, and Smelson (2017) point out, the addiction stigma is likely to be worsened by criminalization as drug use is conflated with felonious conduct. Furthermore, a study of Templeton et al. (2017) shows that the people who die of overdose tend to differ from those who die of other substance use like alcohol. The deceased is more likely to be male, young and to suffer a death that occurs early in the path of addiction; sometimes even the very first time the drug is taken.

A systematic review is called for to tailor new research questions that will bring knowledge to the field and subsequently enable the tailoring of interventions for the bereaved. Such a review aims to collect, appraise and synthesize all available studies that have relevance to a predefined research question. It follows strict, reproducible and systematic methods that minimize bias, with the overall aim being to produce reliable results, on which future decisions can be based (Lund, Juhl, & Christensen, 2016). This study will, therefore, be carried out as a systematic review.

The aim of this study was to identify and synthesize patterns in qualitative and quantitative studies that shed light on how family members experience drug death bereavement. We wanted to understand in particular, (1) the experience of family members before and after losing one of their next of kin; and (2) how they perceive the help and support they receive and its influence on their bereavement processes.

Methodology

The review was guided by the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) (Liberati et al., 2009). Thematic synthesis methodology as described by Thomas and Harden (2008) was used. A review protocol was developed and published in PROSPERO 17. July 2018 (PROSPERO 2018 CRD42018100455, available from: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018100455).

Eligibility criteria

As recommended in PRISMA (Liberati et al., 2009), the PIOS elements were used to define eligibility criteria. PIOS is here an acronym for participants (P), intervention/phenomena (I), outcome (O) and study design (S) (Liberati et al., 2009). Identified articles were included in the review if: (1) the sample comprised close family members bereaved after a DRD; the next of kin, i.e. a parent, child, sibling, spouse, partner or grandparent, (2) the death identified was caused by the intake of substances classed as narcotics, i.e. overdose (intentional or unintentional), or was otherwise drug-related (e.g. caused by violence, accident, infectious disease, suicide or other health disorders related to drug use), (3) the types of outcomes were the reactions, symptoms and the coping abilities of the bereaved before and after the DRD of a family member, as well as studies reporting on how help and support influenced the bereavement process, (4) the study design was descriptive, qualitative, quantitative or mixed-method published research as scientific articles, books and PhD-theses. No language, publication date, or publication status restrictions were imposed.

Identified articles were excluded if the sample was bereaved from a substance-related death, yet it was impossible to distinguish whether it was drug or alcohol related. We also excluded randomized trials, as they are not suitable for addressing the review questions. Studies appraised as being of low methodical quality, masters' theses or articles where the full text or information was not attainable, were also excluded. In addition, we excluded duplicates and articles or books describing the same study. The selection criteria for articles or books describing the same study were that we chose the one that corresponded best to the research question. Studies that used data only from friends and family of the bereaved, not the bereaved themselves, or used only journalist/researchers' descriptions of the bereaved, were also excluded.

Search strategy

The PIOS-tool was used to design a search strategy. To include as many relevant articles as possible, we combined different search terms built of text words and subject headings reflecting the appropriate PIOS-elements. The search strategy was piloted and adjusted accordingly (Supplement I).

A systematic search of the literature was performed in January 2019. Five major electronic databases PsycINFO (Ovid) (1806-), CINAHL (EBSCO) (1981-), SocINDEX (EBSCO) (1908-), Web of Science (1950-), ProQuest Dissertations and Theses (ProQuest) (1861-) were searched by an academic librarian (GA). Citation and reference searches and a search for gray literature were completed by first (KBT) and second (SKL)-authors.

In addition, Idunn, a Scandinavian digital publishing platform for academic journals and books and SveMed+, a database with references to Scandinavian journal articles, were searched. Two independent reviewers (KBT, SKL) performed a citation search in Google Scholar based on the included studies and examined their reference lists for possible relevant studies. Hand searches in "Drugs: Education, Prevention & Policy", "Journal of Substance Use", "OMEGA – Journal of Death and Dying" and "Death Studies" were carried out on studies from the past five years and websites for gray literature including government documents (nationally and internationally produced) and other reports were browsed. The authors of selected articles were contacted for information on recent publications and we saved all hits within the respective databases and fed them into the reference manager software EndNote.

Study selection and data extraction

Two reviewers, the first and second authors (KBT, SKL), independently examined the title and the abstract of all references based on the prescribed inclusion criteria for potentially relevant studies using the Rayyan application (see Ouzzani, Hammady, Fedorowicz, and Elmagarmid (2016) for more information about Rayyan) and all references were classified into the groups, "Include" or "Exclude". To ensure that both reviewers had a common understanding of the inclusion and exclusion criteria, the first ten articles were screened together and only those studies classified by both reviewers as "Exclude" were excluded. Any disagreement raised was resolved through discussion and as a next step we retrieved the full text of the remaining studies. The two reviewers screened the remaining full-text articles and sorted them again into "Exclude" or "Include" based on eligibility criteria. Any further disagreement was again resolved through discussion. Five of the excluded studies were also checked by the third and fourth authors (HL, KD) to confirm exclusion. A PRISMA flow chart visualizing the screening process is shown in Figure 1.

Data on the characteristics of included studies were extracted by the first author (KBT) using a preplanned extraction sheet and checked for accuracy by the second author (SKL). The extracted data include specific details about the sample, phenomena, study design and location, and results of significance to the review question (Table 1). All full-text articles excluded in this stage of the selection process are presented in an "Excluded Studies" table together with the reason for the exclusion (Supplement II).

Critical appraisal

The CASP Checklist for qualitative research (Critical Appraisal Skills Programme, 2018) was used for critically appraising qualitative research. For critically appraising cross-sectional/prevalence studies, the Checklist for Prevalence Study (Cross-Sectional, questionnaire, survey) from the Norwegian Institute of Public Health (2014) was used. Two independent reviewers (KBT, SKL) assessed methodological validity using checklists suitable for the studies' design. Any

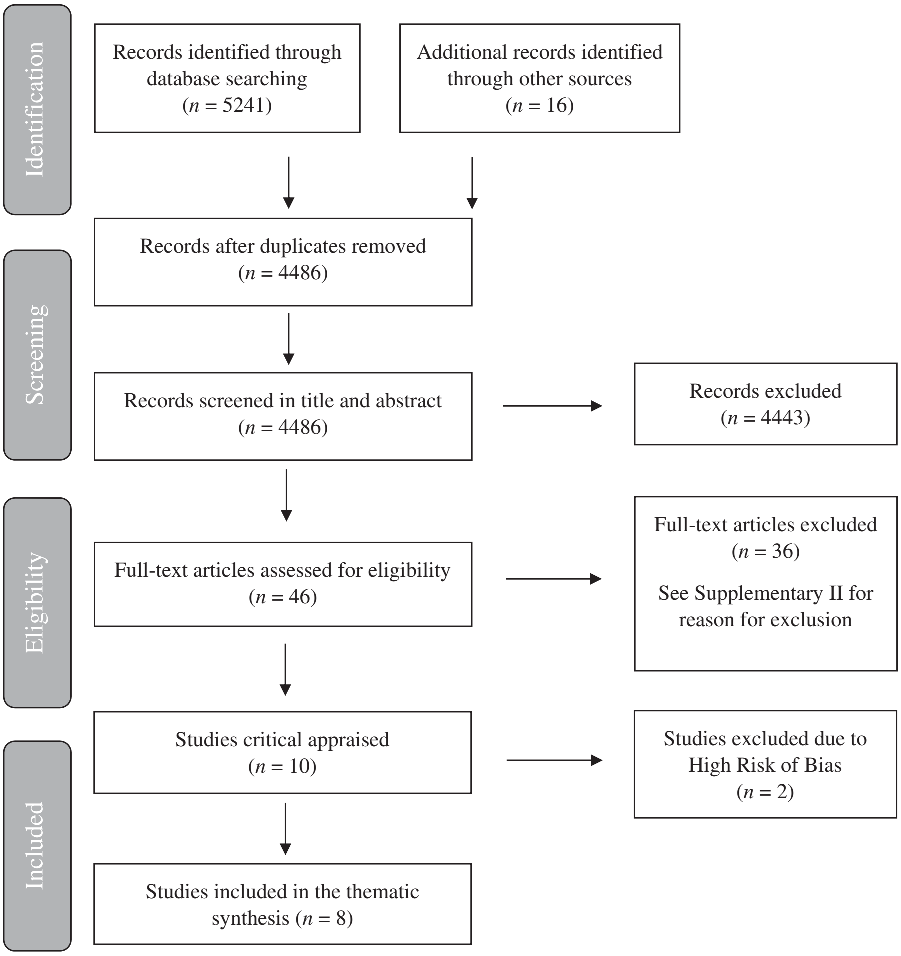

Figure 1. The PRISMA flow diagram.

disagreements that arose between reviewers were resolved through discussion, or with the third and four authors (HL, KD).

The overall rating of the studies' quality was defined as "risk of bias". The meaning of the term quality varies across review groups (Viswanathan et al., 2011). Consequently, the Cochrane Collaboration (Higgins & Green, 2011, Chapter 8.2.2) argues for wider use of the phrase "risk of bias" instead of quality, as "an emphasis on the risk of bias overcomes ambiguity between the quality of reporting and the quality of the underlying research". We will here use the term risk of bias to define the extent to which all aspects of a study's credibility, the design and the conduct of it, are evaluated. Questions in both checklists were rated as "Yes", "Can't Tell" and "No". The study's overall rating was described as *Low Risk of Bias* =/< 2 Can't Tell; *Unclear Risk of Bias* > 2 Can't Tell or 1 No; *High Risk of Bias* =/> 2 No. Only those studies that were found to fit the research question of the present systematic review and appraised as having a low risk or unclear risk of bias were included in the final analysis.

Thematic synthesis analysis

We conducted a thematic synthesis combining both qualitative and quantitative data. We structured it around the experiences of bereaved before and after the DRD of a family member and how they perceived that help and support influenced their bereavement processes. Thomas and Harden (2008) describe three stages in conducting a thematic synthesis; (1) the coding of text line-by-line; (2) the development of descriptive themes; (3) the generation of analytical themes. We analyzed the results sections of the studies and, as recommended by Thomas and Harden (2008), two researchers (KBT, SKL) conducted line-by-line coding of the text to develop descriptive themes. Malterud (2001) recommends as a starting point for further inductive elaboration of each theme, to choose an index study characterized by high methodological quality. We chose Templeton et al. (2017) as an index study since the study also had rich data and a systematic presentation. We looked for themes described therein in other studies, in addition to new ones. Together with the fourth author (KD), analytical

Table 1. Characteristics of included studies.

First author	Year	Country	Design	Aim/purpose	Sample	Results
Biong	2015	Norway	In-depth and focus group interview	Experiences with death by overdose	$n = 8$. Seven mothers and one girlfriend aged mid 20's to late 60's. Two of the respondents participated in in-depth and focus group interview	Experiences were described in three phases; before, during and after the death. Three themes emerged: "I would have done anything to help", "There were things he/she hid from me", "I felt the abyss beneath my feet"
Biong	2016	Denmark	Semi-structured interviews	Experiences in the period up to, during and after an overdose	$n = 5$. A child, spouse/partner, significant other, brother. Three women and two men aged 35 to 65. Six deceased as one person lost two people	Three themes emerged; "We started to be on really bad terms", "I was shocked", "It's a miracle that I've survived"
da Silva	2007	Brazil	In-depth interviews	Experiences with death by overdose (a pilot study)	$n = 6$. Mother (47), father (64), sister (39) (Unaware) and a mother (60), father (55), sister (42) (Aware)	Those unaware experienced feelings of anger, guilt, helplessness, and felt deprived of information that could allow them to take action. Those aware, seemed to feel a "veiled preparation" for a possible death by overdose, bringing ambivalence; grief and relief.
Feigelman	2018	USA	In-depth interviews	Are the longer-term drug-death bereaved more amenable to posttraumatic growth than the shorter-term?	$n = 11$. Nine mothers and two fathers aged 59 to 74. The deceased children were white, ten men and one woman, average age 26.8	Five themes; "the death spiral", "the crash", "initially sharing the details", "longer term routine situations", "memorialization and posttraumatic growth"
Feigelman	2011	USA	Survey	Comparing four sub-groups of bereavement; drug death, suicide, accidental and natural death survivors.	$n = 48$. Bereaved parents; 44 mothers and four fathers. Main study: 571 parents who had lost children to various death causes: **48 to drug-related deaths and overdoses,** 462 to suicide, 24 to natural death cases, and 37 to mostly accidental death cases.	Results did not show any appreciable differences in terms of grief difficulties, mental health problems, posttraumatic stress and stigmatization between suicide bereaved parents and those losing children to drug-related deaths. Contrasted against accidental and natural death loss cases, a consistent pattern emerged showing the former group was consistently more troubled by grief and mental health problems than the latter two sub-groups.
Grace	2012	England	Semi structured interviews	How do children and young people deal with parental substance-death bereavement?	$n = 2$. Two girls, bereaved from drug-related death aged 15 and 16. Total sample: Four girls aged 14–16 years	Life for all the girls was difficult and complicated by their parents' troubled lives. Their lives were marked by multiple losses and adverse childhood events both before and after their parental death. The results demonstrated that children are vulnerable to complicated grief when this

(*Continued*)

Table 1. Continued.

First author	Year	Country	Design	Aim/purpose	Sample	Results
						network of balancing support is not available.
Nowak	2016	USA	In-depth interviews	To generate theory that reflected the grief experience after drug overdose death.	$n = 8$. Six mothers and two fathers. The children deceased after an overdose, seven men and one woman, age range 18–27.	Six themes emerged: the stigmatized grief experience, making sense of the death, discovering comfort in the loss, identifying helpful support, the transformation of grief, the transformed identity.
Templeton	2017	England and Scotland	In-depth interviews	Experiences of those bereaved by overdose, how their experiences differ from other substances-related deaths.	$n = 32$. 23 female and nine males. 19 were mothers, four fathers, four friends, three siblings and two partners. Deceased were male ($n = 29$), age range 17/18–43.	Five themes emerged: "drug use", "the death", "official processes", "stigma", "overdose awareness and prevention".

themes that constructed new interpretations and explanations of the data were created. The development of descriptive themes remained close to the primary studies, while the analytical themes represented a stage of interpretation. All authors agreed upon the coding framework, interpretation of data, confirmation theme categories and analytical themes.

Results

Study selection results

The systematic search yielded 4486 records after the removal of duplicates, 16 records were identified from the gray literature (official reports etc.). The selection process resulted in the inclusion of ten studies: nine qualitative (Biong, Sveipe, & Ravndal, 2015; Biong & Thylstrup, 2016; da Silva, Noto, & Formigoni, 2007; Feigelman, Cerel, McIntosh, Brent, & Gutin, 2018; Grace, 2012; Guy, 2004; Guy & Holloway, 2007; Nowak, 2015; Templeton et al., 2017) and one quantitative (Feigelman et al., 2011). These studies then underwent a thorough critical appraisal process to determine their appropriateness to the research question of this review and the risk of bias.

Comprehensiveness of reporting

Two studies (Guy, 2004; Guy & Holloway, 2007) were rated as *High Risk of Bias* and therefore excluded in accordance with the exclusion criteria. The author(s) had not described the recruitment strategy, data analysis nor ethical issues. Five of the studies were rated as *Unclear Risk of Bias*. All these five studies had one common feature, namely that none of the authors had accounted for self-reflexivity.

Characteristics of included studies

Detailed descriptions of the included studies are presented in Table 1. The following section provides an overview of the included studies' characteristics.

Sample and the relationship to the deceased

The number of participants in the studies varied from two to 48. The qualitative studies ($n = 7$) involved between two and 32 participants and the quantitative study 48 participants. The total sample included 87 mothers, 14 fathers, six siblings, four children and 11 with other or unclear family relations. Few studies accounted for the deceased's characteristics. Those that did highlight that the majority of the deceased were male (23:1) with a mean age of 26.8 (Feigelman,

Table 2. Number of studies on descriptive themes.

#	Descriptive themes	Number of studies	Analytical themes
1	Consequences of drug involvement	7	Emotional roller coaster
2	Fear of death	6	Emotional roller coaster
3	The trauma of death	6	Emotional roller coaster
4	Complex and chaotic emotions	8	Emotional roller coaster
5	Guilt reflections	6	Emotional roller coaster
6	Stigmatization	7	Lack of understanding by the social world
7	Stigmatization as a barrier to support	8	Lack of understanding by the social world
8	Lacking help in crisis	7	Lack of understanding by the social world
9	Making sense of the loss	4	Meaning making
10	Individual differences in what helps	7	Meaning making
11	Important support from peers	4	Meaning making

Feigelman, & Range, 2018) or an age range of 17–43 (Templeton et al., 2017) or 18–27 (Nowak, 2015). Biong and Thylstrup (2016) and Templeton et al. (2017) clarify that some of the participants were themselves substance users at the time of the interview, or had been previously.

Only one study had illuminated how children of under 18 experience the loss of a parent (Grace, 2012) and we included data from interviews with the two girls who had experienced DRDs. Data describing the other two girls experiences were excluded as they were bereaved from alcohol-related or unclear substance use death. In the quantitative study, Feigelman et al. (2011) compared four sub-groups of bereavement; drug death, suicide, accidental and natural death bereaved. In line with inclusion criteria, we only extracted data that was explicitly about DRDs.

Study design, recruitment, location, and publication year

The study design in the qualitative studies were in-depth ($n = 5$), focus group ($n = 1$) and semi-structured interviews ($n = 2$), and a survey was conducted in the quantitative study. Most studies recruited participants from local services and support groups, both bereavement and drug services/groups. One study used only snowball sampling (da Silva et al., 2007). The studies were conducted in Scandinavia ($n = 2$), the United Kingdom ($n = 2$), South America ($n = 1$) and North America ($n = 3$). They were published between 2007 and 2018, but the majority of the studies were published after 2015 ($n = 5$).

The aims of the studies

The aims of the studies were to provide insights into the experiences of those bereaved by overdose ($n = 5$) or by DRD ($n = 3$). One study aimed to generate a theory to reflect the grief experience of bereaved parents who lost a child to a drug overdose (Nowak, 2015). In addition, two studies tested the following hypotheses. Feigelman, Feigelman, et al. (2018) examined whether longer-term drug-death-bereaved parents would be more amenable to post-traumatic growth than shorter-term bereaved parents. The results suggested that as time goes by, drug-death-bereaved parents "are able to arrive at a "new normal" and make important and worthy contributions reflecting their own posttraumatic growth" (Feigelman, Feigelman, et al., 2018, p. 17). Feigelman et al. (2011) tested if a similar or a significantly higher degree of stigmatization, grief difficulty, post-traumatic stress, and psychological difficulty would be experienced when comparing those dealing with suicide or DRD with natural or accidental death. Results did not show any appreciable differences in terms of grief difficulties, mental health problems, posttraumatic stress and stigmatization between suicide bereaved parents and those losing children to drug-related deaths. Contrasted against accidental and natural death loss cases, a consistent pattern emerged showing the former group was consistently more troubled by grief and mental health problems than the latter two sub-groups.

Synthesis

Our thematic synthesis of the data within the eight included studies revealed eleven descriptive themes that illuminate how family members experience drug death bereavement (Table 2). These descriptive themes were further categorized into three analytical themes: *Emotional Roller Coaster*; *Lack of Understanding by the Social World; Meaning Making.*

Emotional Roller Coaster

The analytical theme *Emotional Roller Coaster* was derived from all eight primary studies and comprised five descriptive themes; *the consequences of drug involvement*, *the fear of death*, *the trauma of death*, *complex and chaotic emotions* and *guilt reflections*. The theme reflects an emotional overload; e.g. an enduring strain on bereaved family members living with a person with severe drug use problems. The family member experiences years of uncertainty, despair, fear, hopelessness, and powerlessness and following this, the drug user often dies. Many of the bereaved held down a demanding job and made use of social support that was in place to help drug users while they were alive. The roller coaster, with its elevated track, tight turns, and steep slopes and loops, symbolizes very effectively what many bereaved family members experience. They oscillate between deep sadness and the fear of losing a loved one, yet the time before death is also often characterized by hope when the drug user was perhaps in treatment, got a new job or a new place to live. Deborah, in Nowak (2015, p. 99), illustrated the Emotional Roller Coaster as follows: "I tell you what, heroin doesn't just take the [addicted] person; it takes everybody right down the toilet with them. The emotional toll of living with the addiction for as long as you do and having hopes and when they die, the hopelessness you feel because you couldn't do it [make them stop]. It's really tough". Some of the bereaved also described guilt reflections/rumination: "Where did I go wrong? I spent all that time blaming myself, arguing with my wife, whose opinions on the issue always differed from mine" (da Silva et al., 2007, p. 304).

Such emotional fluctuations may continue even after the drug user has died. "What I'm going to say is strange, but when my son died, I had ambivalent sensations: on one hand, immeasurable pain, the pain of irreparable loss; on the other hand, relief. Relief from his suffering as well as ours" (da Silva et al., 2007, p. 304).

Lack of understanding by the social world

The second analytical theme *Lack of Understanding by the Social World* was also derived from all eight primary studies and comprised three descriptive themes; *stigmatization*, *stigmatization as a barrier to support* and *lacking help in crisis*. This theme symbolizes the experiences of an absence of support and help from support systems. The overwhelming feeling of a lack of understanding is reflected in a lack of help when in crisis, as experienced by the bereaved. The lack of knowledge about what bereaved people need after a DRD in terms of help and support is described in seven of the included studies. As Templeton et al. (2017, p. 63) summarizes the participants' experiences: "Interviewees' experiences of official processes included numerous examples of delays, often without explanation, and of responses from officials which were found wanting because they lacked compassion and consideration of their situation."

In addition to a lack of help from services, the bereaved also found that their social network did not know how to respond: "These parents reported that relatives and friends often rejected or avoided them entirely after their child died. People did not know what to say to the bereaved person, so said nothing. When confronted, potential comforting people said things like, "I thought you wanted to be alone" (Feigelman, Feigelman, et al., 2018, p. 11).

This theme also describes the bereaved person's experiences of stigmatization from society, as well as self-inflicted stigmatization. This stigmatization seems to be based on a lack of understanding of why some people are drug users and cannot stop using and also on preconceived attitudes about drug users' families. Daisy in Nowak (2015, p. 95–96) described these attitudes in this way: "People look at you like, well, yes, if you're using drugs [An overdose death] is an expected outcome… .People don't treat us the same way and they think [the decedent] deserved it [to die], it was their choice [to use drugs], they asked for it, and [therefore] pay the price."

Meaning making

The third analytical theme was also derived from all eight primary studies and comprised three descriptive themes; *making sense of the loss*, *individual differences in what helps* and *important support from peers*. The construction of meaning is assumed to be an essential part of how we adapt to traumatic events (Bonanno, 2013) and the process of meaning making may facilitate coping with the loss of a family member through a complex reorientation to the world (Neimeyer, 2019). Bonanno (2013) argues that not all meaning-making is healthy and Eisma and his research group distinguish between adaptive (e.g. rumination about emotional reactions) and maladaptive (e.g. rumination about injustice) forms of ruminative thinking in grief (Eisma et al., 2014).

Many bereaved also reported that meaning-making was important to be able to live on after the loss of a family member. In making sense of the loss, the bereaved described that helping others or being politically active were examples of how they tried to prevent others from having to experience the same situation themselves. An example from one study was "…the sense that all girls had, of wanting something good to come out of their bad experiences, of helping others, so they 'don't have to go through what I've gone through'"(Emma) (Grace, 2012, p. 125).

A mother who was dedicated to raising awareness of the risks of opiate use also stated: “He [the deceased son] will give me a big hug and he will say, you done good mom, that’s what you were supposed to do.” The participant went on to say that this was the job she was meant to do because it was the only way she could make sense of the death and she felt that if she didn’t do it that the deceased’s life wouldn’t have counted for anything (Nowak, 2015, p. 90–91).

Finding that others feel the same way helps some bereaved people to go on living: “Until today we attend the meetings with the family members of the Narcotics Anonymous and try to share our experience with families that are going through similar situations, and we have the sensation that our pain has an echo: other people feel the same, so solidarity helps us deal with the loss” (da Silva et al., 2007, p. 304). However, what helps an individual can differ greatly. A parent who experienced peer support from support groups describes his experience: “They want me to give them reassurance, but I can’t do that, and I cannot provide emotional support to others because I have not experienced emotional resolution from the loss of my son” (Nowak, 2015, p. 104).

Discussion

This is the first systematic review of the literature that synthesizes how family members experience drug death bereavement. The search and critical appraisal identified eight studies of good methodological quality that satisfied the inclusion criteria. This configurative review indicates that many family members experience significant emotional and existential burden both before and after the death, a lack of understanding and help from support systems and stigmatization. It also shed light on how family members go on living after the death and the individual differences displayed in coping with the loss of a family member. Even though few studies are included, we consider the results to be relevant, especially for care providers and policymakers. The results show that the bereaved have a great need for a culture of caring and for tailored, integrated and coherent user pathways. In this way, the kind of support required from health, social and welfare services can be detailed.

Following the loss of a loved one, the bereaved differ considerably in their ways of coming to terms with the loss. Still, many face the same or similar challenges, such as coping with emotional pain or setting new goals and finding renewed purpose in life, finding meaning in the death and maintaining a bond with the deceased (Gillies & Neimeyer, 2006; Stroebe et al., 2017). Research suggests that the bereaved, after sudden and unexpected, self-inflicted or violent deaths (so-called “unnatural deaths”), experience more symptoms of grief than those who are bereaved by natural deaths. General health problems, post-traumatic distress and complicated grief reactions are common problems experienced following the death (Dyregrov, Dyregrov, & Kristensen, 2015; Dyregrov et al., 2003; Eisma, Shut, Stroebe, Voerman, et al., 2015; Milman et al., 2017; Spillane et al., 2017). The results of our review confirm the experiences of the bereaved from other kinds of unnatural death.

A lack of understanding and help from support systems is also reported in studies of those who are, for example, bereaved by suicide. In a Norwegian study of suicide-bereaved parents, Dyregrov (2002) found a discrepancy between what the bereaved asked for (i.e. outreach and immediate assistance, and long-term follow up) and what the services offered. Stigmatization as a barrier to support is also reported in research on suicide bereavement (Scocco, Preti, Totaro, Corrigan, & Castriotta, 2019). In addition to stigma toward suicidal behavior, perceived stigma may alter the ability to seek help and support. An SR from Hanschmidt, Lehnig, Riedel-Heller, and Kersting (2016) showed that stigma can be a serious concern also for a significant proportion of those who are bereaved by suicide, as opposed to those bereaved by a natural loss. Similarly to those bereaved by DRDs, those bereaved by suicide experienced stigma within their social networks as well as from legal institutions in different settings. Along with this stigma comes social isolation, which is internalized as an intense feeling of shame. As in our review, Hanschmidt et al. (2016) found that an absence of clear social norms on how to interact with those bereaved by suicide and traumatic death might contribute to patterns of insensitivity from the bereaved person’s social networks and a lack of communication, which can be perceived as stigmatizing.

Complex and chaotic emotions are reported in SR synthesizing studies that investigate the grieving process of those bereaved by suicide. Shields, Kavanagh, and Russo (2017) encountered a range of difficult feelings following suicide including blame, guilt, and emptiness and concluded that these feelings are affected by participants’ ability to make meaning of the event. These meaning-making processes are reported to occur within a difficult social context in which both those bereaved by suicide and members of the wider community struggle to interact with each other in a beneficial way. Insecure communication and the subsequent emotional impact/overload can form interactive barriers between the bereaved and their networks. This is also documented after the loss of a family member in other traumatic events and even following a natural death (Dyregrov, Kristensen, & Dyregrov, 2018; Wilsey & Shear, 2007). Milman et al. (2017) studied the impact of violent death loss. In their study, they demonstrate that meaning made mediates the impact of violent death loss, both contemporaneously and longitudinally.

Even though research is relatively clear about the potentially serious consequences of unnatural deaths, this review is important as it fills a gap in the knowledge we have of those bereaved by DRDs. Five of the eight studies report on experiences of those bereaved by overdose. As stated, bereavement following an overdose will probably differ from bereavement following other kinds of substance use (Templeton et al., 2017) as drug use carries social condemnation (Corrigan et al., 2017) and the level of stigma attached to the use of drugs is higher than that ascribed to other stigmatized groups (Lloyd, 2013). There is a reason to believe that the rollercoaster of complex and chaotic emotions experienced before and after the drug user dies complicates the grieving process due to the perceived and self-inflicted stigma the bereaved experiences. Templeton et al. (2017) and Guy and Holloway (2007) advocate for describing experiences with overdose deaths and associated bereavements as "special deaths". The overload described in the DPM by Stroebe and Schut (2016), an overload that can complicate the balancing of loss- and re-orientation, is documented in our synthesis, along with the burden felt in advance of and following the death. It is a burden that is too heavy to process, as described in the theoretical model of Kari Dyregrov (Dyregrov et al., 2018). The model, which is based on a broad knowledge of bereavement, suggests that serious drug use, anticipated grief, a stigmatized death and overwhelming experience of complex and ambivalent emotions may lead to complicated forms of disenfranchized grief. It is important to take this scenario seriously as it is well documented that unnatural deaths can lead to shortened lifespan and reduced daily functioning for the bereaved. These effects seem to occur because of long term, serious grief and trauma reactions (de Leo, Anile, & Ziliotto, 2015; Feigelman et al., 2011; Li et al., 2003; Spillane et al., 2017). The consequences for the bereaved can be lifelong as enduring problematic bonds to the deceased, as well as the inability to find further meaning in life, increase the risk of a complicated grief processes (Boelen, Stroebe, Schut, & Zijerveld, 2006; Milman et al., 2017) and increase the prevalence of complicated grief (Boelen, Reijntjes, Djelantik, & Smid, 2016; Dyregrov et al., 2003; Kristensen, Weisæth, & Heir, 2012). A lack of meaning in life can also lead to suicidal thoughts (Hanschmidt et al., 2016; Stroebe, Stroebe, & Abakoumkin, 2005). We, therefore, call for further research to explore the consequences of both the emotional overload and the stigma associated with DRDs in greater depth and recommend the creation of tailored research questions to explore the prevalence of and processes surrounding complicated and disenfranchized grief.

Based on the findings of the current review, there are several important areas that should be explored using both qualitative and quantitative methods. Five studies explored the experiences of family members bereaved by overdose, whereas three studied those bereaved by drug-death in general. Because sudden death from overdose may influence the bereavement process differently than deaths due to long-time drug use, further research should clarify the cause of death and discuss whether and how this influences the bereavement process. Only one study exploring bereaved children was identified in our review (Grace, 2012). Even though all of the 11 categories in Table 2 were recognized in the data material of Grace (2012), we have reason to believe that bereaved children's experiences differ from those of other family members and that there are unique risks for children who experience parental death. The girls in Grace (2012) described an adverse childhood, made difficult and complicated by their parents' troubled lives and lives marked by multiple loss and traumatic events occurring both before and after the deaths of their parents. Bereaved children and adolescents have, in general, an increased risk of developing psychological, physical, social and educational challenges later in life (Dyregrov & Lytje, 2018; Pham et al., 2018). Thus, further research about bereaved children is called for.

Making sense of the loss is explored in four of the eight studies (da Silva et al., 2007; Feigelman, Feigelman, et al., 2018; Grace, 2012; Nowak, 2015). Neimeyer (2019) has summarized the evidence linking a struggle for meaning with bereavement complications and found that successful meaning making is linked with more positive adaptation over time. We recommend that meaning making after DRDs should be further investigated. Bellet, Holland, and Neimeyer (2019) argue that for those who have lost someone to stigmatizing circumstance as overdose, some social interactions can be particularly deleterious, as the loss and bereavement process are not consistent with cultural expectations. Furthermore, they argue that social environments can be a barrier to making meaning of loss as the network of the bereaved can be perceived as a misunderstanding or that they are minimalizing the loss. In light of this and our findings in general, we also recommend further research to explore the bereaved people's experiences of lack of help and support.

Seven of the eight included studies are qualitative primary studies. Qualitative data relates to the transferability of qualitative evidence on a conceptual, theoretical, or logical level, rather than generalizability (Malterud, 2019). Malterud (2019) points out that contextual knowledge is essential for intersubjectivity about how the results of a primary study are developed and that contexts in included studies in a meta-synthesis have a strong impact on transferability. Thus, we argue that the results presented in this SR shed light on the concept of bereaved family members' experiences after DRDs and that the results might be transferable to other contexts but considering the context within which the primary studies were conducted. We acknowledge how important it is to appraise the result in the light of contextual information and that recommendations for practitioners and policymakers should be based on research that is transferable. For that, more research in different settings where the context, especially in support and welfare systems, is clearly described is needed.

Strengths of this review include the rigorous methodology. A systematic review follows a pre-defined and logical methodology that is explicit in all its steps where the potential strength lies in the transparency of each phase of the synthesis process (Lund et al., 2016). Another strength is the application of the often used PRISMA framework (Liberati et al., 2009), which guided transparent reporting.

The review was limited to scientific articles, identified through a systematic search of the literature and a search for gray literature. Though comprehensive, it is possible that the search overlooked some studies that could have been useful to this review. On the other hand, a trained academic librarian conducted the literature search and guided the development of the strategy in collaboration with experts from the field that was being explored. Other limitations of this systematic review include the risk of bias assessment when evaluating the overall quality of the included evidence and our choice of method for analyzing data from included studies. Literature about quantitative and qualitative data in a systematic review does not describe only one approach that is better than all others and we recognize that approaches other than thematic analyses could be appropriate. On the other hand, the use of thematic synthesis enabled us to stay close to the data from the primary studies and thereby be empirically faithful to the included cases, providing explicit and transparent links between our conclusions and the text of the primary studies. We will argue that the external validity in our study relates to the transferability of evidence of the theoretical concept of bereaved family members after a drug-related death, rather than the potential of the results to be extrapolated across population, phenomena or geography. Results should be viewed with caution but are useful in formulating research questions for further studies about the population in our study.

Readers should be mindful of several limitations of the included studies in the review. Few studies were included and the sample size varied from only two to 48 participants, including 87 mothers, 14 fathers, six siblings, four children and 11 with other or unclear family relations. Further research should aim for a larger sample in addition to clearer research questions (e.g. questions that define the family relationship to the deceased). In addition, future research should investigate distinctive characteristics like the deceased's age, the time since death, whether the next of kin was aware of the drug use and whether the deceased died after first-time use or an overdose, versus drug use over time. We believe these variables might influence the bereavement processes (e.g. overload or anticipated grief) and must be clarified in future studies. In addition, we encourage researchers to account for self-reflexivity and to carry out studies with a high-quality recruitment strategy.

Conclusion

This review poses a call to the field for more rigorous studies, interviews and surveys of the bereaved after DRDs to better assist them and their natural support networks. In addition to identifying issues of importance to bereaved family members, this review uncovered several areas where evidence gaps exist. We documented that those bereaved from DRD represent an understudied group, as only eight studies with good methodological quality investigated this field of bereavement. This SR suggests that those bereaved from DRDs perceived a heavier emotional impact, more stigma and a lack of help and understanding than they believe characterized people bereaved by other modes of unnatural and natural deaths. More research on the negative attitudes and stereotypes among the networks of those bereaved from DRDs, as well as their community and the general population is needed. Due to few studies, the results should be viewed with caution but can be useful for generating research questions for further studies about the population in our review.

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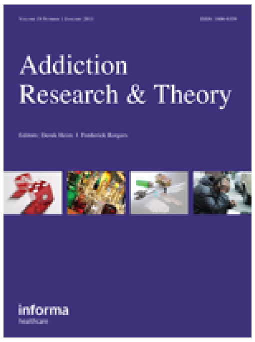

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Sounds of silence. The “special grief” of drug-death bereaved parents: a qualitative study

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ABSTRACT

Background: Drug-death bereavement is an understudied topic. We explore what bereaved parents experience after losing their child to drug use. The aim of the paper is to provide knowledge about what drug-death bereaved parents go through and study the kinds of help and support they receive.
Method: Reflexive thematic analysis is used to analyze 14 semi-structured in-depth interviews with Norwegian parents.
Results: We generated four main themes: (I) ‘constant preparedness’ describes the burdensome overload that the parents experienced before death; (II) ‘stigmatization’ represents public and self-induced stigma; (III) ‘emotional overload’ refers to the parents’ complex and ambivalent emotions, such as anger, guilt and shock after the loss; and (IV) ‘complex relations’ describes the parents’ relations with public services and their personal social networks.
Discussion: We discuss how overload, before and after the loss experience, causes a special grief. How this overload, silence from helpers, self-stigma and complicated interactions with social networks contribute to the grief of these parents is also discussed. Potential implications for policy and practice are subsequently outlined.

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Introduction

Bereavement after unnatural deaths (e.g. murder, suicide, early child death) is associated with serious mental and physical health difficulties (Dyregrov et al. 2003; Li et al. 2005; Stroebe et al. 2017), low levels of health-related quality of life (Song et al. 2010) and even an increased risk of early death for the bereaved parent (Li et al. 2003). Bereaved parents after unnatural deaths who struggle with grief-related emotions and reactions can potentially benefit from individualized help provided by public services and support from their social network, helping them to avoid major health problems (Stevenson et al. 2017; Dias et al. 2019). In order to offer the right kind of help, we need knowledge of the grief they experience.

Losing a child due to a drug-related death (DRD) is unnatural. Definitions of DRD vary, and there is a need for the clarification of terms regarding DRDs (Robertson et al. 2019). In the absence of any consensus about the term, we define DRDs as deaths caused by the intake of substances classed as narcotics and deaths among people who use narcotics where the cause of death is violence, accidents, infectious disease or other health disorders, which in different ways may be linked to drug use. DRD has reached epidemic proportions in the US; the age-adjusted rate of overdose deaths increased significantly by 9.6% from 2016 (19.8 per 100,000) to 2017 (21.7 per 100,000) (Centers for Disease Control and Prevention 2019). In Europe, the mortality rate due to overdoses in 2017 was estimated at 22.6 deaths per million population (European Monitoring Centre for Drugs and Drug Addiction 2019, p. 80). Norway, where this study took place, has one of the highest reported prevalence rates of overdose in Europe (Norwegian Directorate of Health 2019, p. 5). As other research on bereaved persons following sudden and unexpected, self-inflicted or violent deaths has demonstrated that unnatural deaths are related to an increased prevalence of complicated grief among this population (Dyregrov et al. 2003; Heeke et al. 2017), there is need for particular attention to the situation of bereaved left behind after DRDs. Prolonged grief disorder (PGD) is by far the most common form of complicated grief. PGD is characterized by persistent separation distress and combined with cognitive, emotional and behavioral symptoms, resulting in functional impairment for at least six months following death (WHO 2020).

Turning to scientific investigations of relevance to DRD bereavement: Oreo and Ozgul (2007) reported parental grief even before the child died from DRD. Parents described reactions such as cognitive intrusions, avoidance behavior

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and emotional distress due to the child's drug use. Orford et al. (2010) outlined how family life with a person who is using drugs can be highly stressful, with constant conflicts. Coping alongside a person who uses narcotics can be an oscillation between sacrificing one's own interest versus withdrawing from him or her. It can entail being fearful to act versus feeling the need to contact services to deal with urgent concerns about their child (Maltman et al. 2019).

How family members experience drug-death bereavement has hardly been investigated. A systematic review by Titlestad et al. (2019) identified only seven qualitative studies from Norway, Denmark, Brazil, the US, England and Scotland (da Silva et al. 2007; Grace 2012; Biong et al. 2015; Nowak 2015; Biong and Thylstrup 2016; Templeton et al. 2017; Feigelman et al. 2020) and one quantitative study from the US (Feigelman et al. 2011) which satisfied the inclusion criteria and were of good methodological quality. This systematic review suggested that family members who were aware of the drug use experienced years of uncertainty, despair, stigma, hopelessness and powerlessness before the loss. The results indicate that those bereaved as a result of a DRD perceived a heavier emotional burden and lacked even more support from their social environment than those bereaved by other types of unnatural and natural deaths.

A distinction is frequently made between drug- and alcohol-related deaths; research has covered both of these, either jointly or singly. Valentine and colleagues conducted the largest in-depth study covering both of these so-called substance misuse death, interviewing 106 bereaved by drug- and alcohol-related deaths, in England and Scotland. Drug- and alcohol-related death are likely to have different consequences for the bereaved (Valentine and Bauld 2018, p. 2, 7). Using drugs is an illegal activity and the addiction stigma is likely to be worsened by criminalization, since drug use is conflated with felonious conduct (Corrigan et al. 2017). Furthermore, people who die from an overdose are more likely to be male and young and to suffer a death that occurs early in the course of addiction (Templeton et al. 2017).

Most of the literature from the UK does not distinguish between the two different types of deaths described above. However, an article by Templeton et al. (2017) did report specifically on their drug-death bereaved sample *($n = 32$)*. Templeton et al. (2017) argue that their findings support Guy and Holloway (2007) descriptions of drug death as a 'special death', highlighting the difficult circumstances surrounding the death, the stigma associated with DRDs, interactions with public services and an unworthiness about grieving. Special deaths are deaths characterized by a high level of trauma and can be socially stigmatizing or existentially problematic, with the attendant grief being frequently disenfranchized (Doka 2002). Templeton et al. (2017) also reported that many of those bereaved after a DRD described living with a feeling of loss and grief, including before the loss, so-called 'anticipatory grief' (Rando 1986, p. 24), and that the bereaved struggled in accessing support from both formal and informal circles.

Valentine et al. (2016) described substance misuse deaths as 'stigmatized' deaths. For the bereaved, they were said to be associated with disenfranchized grief. 'Disenfranchized grief' follows a loss that is not, or cannot be, openly acknowledged, depriving the bereaved of the opportunity to share their experiences with others and therefore the opportunity to receive social support (Doka 1999). It has long been understood that stigma exists in the relationship between an attribute with a person/group and some audiences who view that attribute as abnormal, as described in Goffman (1963, p. 3). Goffman (1963) stated that stigma is 'in the eyes of the beholder' and can be perceived from several perspectives. From a social psychological perspective, stigma has two dimensions (Corrigan et al. 2009). One is public stigma, i.e. negative attitudes of the general public toward individuals who possess an undesirable characteristic, such as substance abuse (Corrigan et al. 2011), and the other is self-stigma, i.e. the internalization of public stigma and a consequential reduction in self-efficacy and self-esteem (Corrigan and Watson 2006). Stigma toward people who use drugs is well known (Corrigan et al. 2009). Goffman (1963) wrote about 'spill over', where an individual's 'stains' spill over to the next of kin in such a way that the social discredit affects them to the same degree. In this way, family members themselves become stigmatized through association with a relative who uses drugs (Corrigan et al. 2017).

In sum, while scientific investigation has recently increased understanding of grief following DRDs, there is much still to learn about this special type of grief, particularly to inform health care professionals and affected families. To fill the knowledge gap regarding bereavement following DRD, a large Norwegian study called 'The Drug-death Related Bereavement and Recovery Study' (in Norwegian, 'The END-project') was launched in the spring of 2017 at the Western Norway University of Applied Sciences. The purpose of the main project was to contribute to a greater understanding of the consequences of DRD for the deceased next of kin, their situation and needs, as well as enhancing quality and competence in health and welfare services. The main study is a mixed-method study, collecting quantitative data through a survey and qualitative data through interviews (ResearchGate 2019).

Since there have scarcely been any empirical investigation into bereaved parents' grief following a DRD or about what help and support they need (Titlestad et al. 2019), the aim of this sub-study is to explore how parents' experience drug-death bereavement and what different kinds of help and support do they receive.

Methods

This sub-study is an explorative, inductive study. To generate a phenomenological, hermeneutic understanding of how parents experience DRD, we used reflexive thematic analysis as described by Braun and Clarke (2019). We searched specifically for a variety of grief experiences which can characterize drug-death bereavement. Semi-structured in-depth interviews were carried out, and NVivo 12, qualitative data analysis software (QSR International Pty Ltd, 2018), was used in the data analysis process. This paper was guided by 'Standards for Reporting Qualitative Research: A Synthesis of Recommendations' (O'Brien et al. 2014).

Recruitment and sample size

In the period from March 2018 until the end of December 2018, drug-death bereaved family members and friends were enrolled on the main project. They were invited to fill in a questionnaire, either on paper or digitally. A flyer that described the project, and invited participants to take part in a survey, was sent to all Norwegian municipalities' public email addresses. We also contacted personnel who were engaged in the Norwegian Directorate of Health project to reduce drug overdoses, involving 28 municipalities at that time. Recruitment was also facilitated through non-governmental organizations working with drug use, treatment centers, the Norwegian Labor and Welfare Administration (NAV) and crisis teams (either by mail or by handing out flyers). We disseminated information about the project through participation at conferences and various media such as television, radio and social media (Facebook and Twitter). 'Snowball recruitment' by participants and by collaborators in other research networks or professionals in clinical practice was another important recruitment strategy employed.

The interview sample in this sub-study was drawn from a total sample of parents ($n = 95$) who participated in the survey. There were 75 parents' who agreed to be interviewed and were eligible for interview. The participants spoke fluent Norwegian and had lost a child to DRD at least three months prior to recruitment. No other restrictions were set for the time since death. A matrix describing the eligible parents' characteristics was developed. The sample to be analyzed in this paper was selected according to pre-defined selection criteria; (1) gender, (2) parents' place of residence (city or village, northern/central/western/southern/eastern geographical parts of Norway), (3) gender of the deceased, (4) time since loss, (5) participants' age, and (6) age of the deceased.

Malterud et al. (2016) have proposed a set of dimensions that to help determine sample size. These include the study's aim, sample specificity, theoretical background, dialog quality and strategy for analysis. We adhered to Malterud et al. (2016) for their guidance on 'information power' to ensure adequate size of the final sample. During the recruitment process, one mother withdrew for personal reasons and one of the recruited participants failed to attend the planned interview. We were unable to reach out to the latter individual, either during or after the interview time, and no explanation was given as to why the potential participant decided not to keep the pre-planned appointment. Sample size was constantly evaluated with regard to information power and after interviewing seven fathers and six mothers, we decided to equalize the sample according to gender, in case the descriptions specific to gender became relevant to our discussion. Another mother was therefore invited to participate. After interviewing her, and given that the contribution of new knowledge was limited, we concluded that we had reached a satisfactory level of information power.

Semi-structured in-depth interviews

A semi-structured interview guide, built on the questions in the survey that we wanted to explore in detail, was developed for the interviews. The guide consisted of five themes: (1) the time before the death, (2) the loss, (3) stigma from the environment and self-stigma, (4) help, support and coping, and (5) post-traumatic growth. In the preparation phase, the interviewing authors discussed codes that could possibly be relevant as follow-up questions in the interviews. During the interviews, we encouraged the participants to tell us about the deceased, their relationship to the deceased, the deceased's living habits, the circumstances surrounding the death, their grief reactions and how the death affected their health, working situation and leisure time. In relation to stigma, we talked about attitudes emanating from their surroundings and how they and others in their network communicated about the loss. We encouraged the parents to reflect on support from family, friends, colleagues, social networks and support groups and help from health and social services, the police, ambulance personnel, priests, crisis teams etc. We also asked the participants to share their thoughts about potential barriers to support and what help and support they needed, in addition to barriers or facilitators of own coping and meaning making. However, first and foremost, the interview method followed the principle of 'following the interviewee', as the interviewer pursued the thoughts and reflections of the parents during the interviews, implying that the main themes in the guide were covered, but not necessarily in set order. Also, the interviewers welcomed new topics relevant to the research questions.

The interviews were carried out in the period August to December 2018. To synchronize the interview method and pilot-test the interview guide, the last author conducted a trial interview with a bereaved parent, with the first and second authors (interviewers) present. The interview was discussed with the bereaved and the research interviewers. The interview guide was adjusted according to discussions after the trial interview and prior to other in-depth interviews.

Following completion of the informed consent process, the first, second and last author conducted interviews in a private setting selected by the participant (home = 9, work office = 4, a hotel (sheltered space = 1). The interviews were audiotaped and transcribed verbatim by a research assistant. In addition, all interviewers noted their general impressions immediately after each interview. The length of the interviews ranged from 1 h and 20 min to 3 h and 10 min, including required or desired breaks. Altogether, the transcripts consisted of 431 single-spaced pages (range 20–39).

Sample

The sample consisted of 14 parents: seven women and seven men, who were parents to 14 deceased persons in total. One parent represented two deceased people and a divorced couple represented one deceased person. All the parents were aware of the drug use and none of the deceased had died after first-time use. Ten of the parents had lost a son and four parents had lost a daughter. The time since death ranged from three to 126 months (mean = 38) and all parents reported (on a five-point Likert scale) to have been close to the deceased (12 reported to have been very close). Nine of the deceased died of a not-intentional overdose, one of an intentional overdose (suicide), two of illness, accident or violence, and two of unclear causes. The age of the deceased varied between 19 and 45 years (mean = 27.36) and the age of the parents ranged between 45 and 75 years (mean = 58.29). The participants came from all parts of Norway (north $n=2$, central $n=2$, west $n=5$, south $n=2$ and east $n=3$), with eight living in a village and six in a town. Twelve of the parents were married/cohabitants, while one had a boyfriend and one was divorced. Only two of the 14 participants were still married to the other parent of the deceased. The parents were well educated (79% had received higher education beyond 12 years). Annual household gross income was in the range from 25,000 to over 125,000 euros and 42.9% had an annual household gross income of 75,000–99,999 euros. The income level in Norway is high, and the participants' income was high compared to the average annual household gross income.

Reflexive thematic analysis of interviews

Braun and Clarke (2019) describe a six-phase process for reflexive thematic analysis: (1) familiarization with the data; (2) coding; (3) generating initial themes; (4) reviewing themes; (5) defining and naming themes; and (6) writing up. The phases are sequential; each builds on the previous one, and the analysis is therefore a recursive process. We analyzed the interviews as recommended by Braun and Clarke (2019), conducting a reflexive thematic analysis with movement back and forth between different phases.

In order to become immersed and intimately familiar with their content, the first author (a social educator and PhD student) read and reread all the interviews, and as codes were developed, they were generated in NVivo. This was a back and forth process, suggesting codes, re-reading the interviews, changing/adjusting codes after discussions with the last author (a sociologist and senior researcher). The first and last authors examined the codes and collated data to identify significantly broader patterns of meaning (potential themes), then altered the codes in accordance with consensus discussions with the coauthors (two psychologists). Themes, defined as patterns of shared meaning, underpinned a central concept or idea (Braun and Clarke 2019). The clustering of themes was generated by moving back and forth between the phases. Led by the first author, all authors worked out the scope and focus of each theme, deciding on an informative name. A table of the codes and themes was then produced.

Trustworthiness of the findings was enhanced by thorough discussions among the coauthors. All authors agreed upon the coding framework, the interpretation of the data and the confirmation of descriptive and analytical themes. Researchers' background and position affects what we choose to investigate, how we investigate, which findings we consider most relevant, and how we conclude (Malterud 2001; Palaganas et al. 2017). We aimed for an inductive approach, although we discussed that we - as researchers - needed to be aware of our contributions to the construction of meanings and of lived experiences throughout the research process.

Ethical considerations

All procedures were conducted in accordance with the Declaration of Helsinki (The World Medical Association, 9 July 2018). This study was approved in February 2018 by the Norwegian Regional Committees for Medical and Health Research Ethics (reference number 2017/2486/REK vest).

All participants were informed, in writing when consenting to participate, and it was repeated verbally at the onset of the interview, what the purpose, method and procedure of the study was. It was further explained that the data would be published in a non-identifiable manner. The parents signed a written consent form and were assured of anonymity, confidentiality and the option to withdraw from the study at any time. The interview data were treated confidentially. All identifying information concerning transcripts and recordings was de-identified and stored on the research server at the university.

Care was provided to the participants during the entire interview process according to Dyregrov (2004) recommendations concerning research on vulnerable populations. The participants were made aware of the possibility to contact the project manager if answering questions about difficult life experiences prompted a need to talk to someone afterwards. All the participants reported positive experiences relating to their participation, and many expressed gratitude for the opportunity to share their stories during the interviews, although they acknowledged feeling tired afterwards.

Results

Four main themes were generated from the analyses: (I) constant preparedness; (II) stigmatization; (III) emotional overload; and (IV) complex relations (Figure 1). Each main theme contains several codes reflecting the content of numerous meaning units from all parents. Descriptions of drug-death bereavement include experiences from the time before the loss, such as dealing with a child with a severe drug problem and society's attitudes toward people who use drugs, and how these experiences influenced the parents' grief. After the loss, the parents described their grief on two levels: the intrapersonal level and the interpersonal level. The intrapersonal level deals with the bereaved (e.g. (III) emotional overload), while the interpersonal level relates to the bereaved and their surroundings (e.g. (IV) complex relations). Meanwhile, (II) stigmatization connects with both levels (self-stigmatization and stigmatization by others).

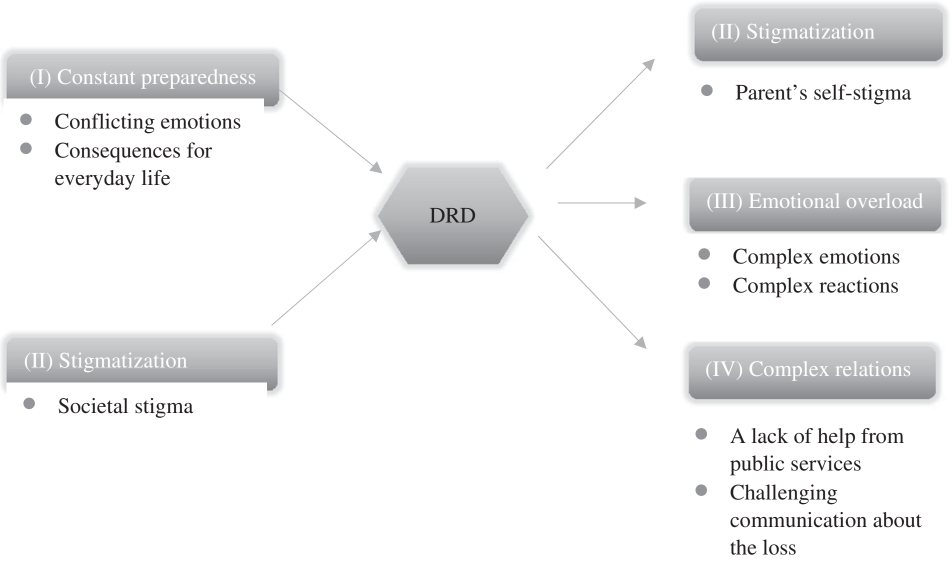

Figure 1. Generated codes and the four main themes describing drug-death bereavement.

(I) Constant preparedness

The parents reported that their child's use of narcotics had an enormous impact on their everyday life. This theme represents the time before the loss, when the parents prepared for the worst-case scenario. They were in constant readiness, prepared to step in if their child needed help, while putting their own life on hold. This period was described via the two codes: (a) conflicting emotions; and (b) consequences for everyday life.

Conflicting emotions

All the parents knew about the drug use prior to the death. They talked about how, over the years, they had feared they would lose their child. This fear was exacerbated by the child's way of life. Several of the deceased individuals had taken multiple overdoses prior to the lethal overdose. In addition, some of the children had revealed that they had given up on life. They communicated distress over the fact that life had not turned out the way they had hoped, and that they had ceased trying to quit using narcotics. Although the fear had increased over time, many parents were still shocked and overwhelmed at the time of death.

Many also felt rejected. As their child's drug use escalated, the parents said they felt helpless. Health and social workers' obligations concerning professional secrecy kept them in the dark, and it was hard being kept out of the loop, not getting the information they needed to help their son or daughter. Neither knowing what to do, nor being in a position to help caused a high level of emotional stress. They described the situation, on the one hand, as hopeless; on the other hand, all of them had hoped for recovery at one time. To have a child with severe drug use problems was described as a roller coaster of complex emotions, which on many occasions was difficult to deal with. A father described the variety of emotions, oscillating between exhaustion and optimism:

> It is extremely difficult to live so close, [the deceased] becomes a very demanding person. These extreme situations, where we had to call the police, are very demanding, it is shocking. And, especially, it is very demanding to constantly have a person who is sick, right? It rarely goes well. Then things went well for a period of time, I was optimistic, and then it went downhill, right, it was like a roller coaster. (ID 42)

The heights represented feelings like hope but, as is typical for a roller coaster ride, the drops got steeper and steeper for many, especially for the parents who lost a young adult. These parents witnessed how their adolescent offspring's drug use escalated rapidly over a short period, feeling that their child was slipping through their fingers, unable to stop the motion.

Parents who for decades had dealt with their child's drug use expressed an additional emotional conflict. Like other parents, they had hoped for a drug-free life for their child, especially after drug-free periods; but, at the same time, they experienced grief reactions. One mother described 20 years of anticipatory grief, as she had been in constant preparedness for her child to die (ID 160).

Consequences for everyday life

The child's way of life had major consequences for the parents' everyday life. While other parents experienced their child becoming independent, these parents reported that their child's need for support escalated. They also reported that they felt rejected by the Child Welfare Services and the Norwegian Labor and Welfare Administration (NAV) and described confidentiality as a major barrier to cooperating with the services, especially during the child's transition period from adolescence to adulthood. One mother described her hopeless position in terms of someone who has responsibility, but without the permission to take action:

> I had called the Child Welfare Services, I had called the general practitioner, and the grandfather had called the mental health team, which did not have time available. There wasn't much

> more we could do. I called the Child Welfare Services, and they said the only thing I could do is to admit her, but I didn't have the authority to admit her anywhere. As I said, you don't feel that you are getting help. And, all this time, there's no one. It's an eternal struggle. (ID 62)

(II) Stigmatization

This theme reflects parents' reports about experiences of stigma: (a) societal stigma; and (b) parents' self-stigma. The parents described how the stigmatization of people who use drugs was reflected in societal attitudes, that is, people presuming that being addicted to drugs is self-inflicted. They did not report that they perceived stigmatization by virtue of being parents bereaved due to a DRD, although they often struggled with self-inflicted stigma.

Societal stigma

According to the parents, society's attitudes to drug use are reflected in stigmatizing statements, especially in online discussion forums where it is stated that people who have a drug addiction chose this life and need to get a grip on themselves. Many referred to comments that described people who use drugs as an outcast group in society. Such comments were perceived as prejudicial statements, and some pointed out that these comments are not in line with up-to-date best practices, which treat addiction as an illness.

Some of the parents also experienced stigma from professionals working within health and welfare services. In meetings with NAV, they found that their child was not taken seriously and sometimes not even spoken to. This mother ponders whether lack of communication is due to negative attitudes toward the person who uses drugs and lack of skills about addiction:

> He [the deceased] said then, "Mom, they treat me differently when you're with me". I could give them the extra information, most likely […] They [people who use narcotics] are not treated very well in many places […] the attitudes the health professional has to the person who uses drugs. Honestly, I think they know too little about addiction problems […]One has to be very skilled to be able to handle addiction, and if you were to do it, it's a long learning process (easy laughter) and you can't give a three months' stay and say "out, now you're done". (ID 7)

Professionals' lack of consideration of their child's wishes and needs mirrored helpers' attitudes, the parents said. Some parents also described that they felt shamed by helpers in situations where the parent – in desperation – had contacted public services for emergency help.

Parents' self-stigma

Shame and guilt for failing as a parent characterized the self-inflicted stigma which they reported to have imposed on themselves. In the process of self-examination, several of the parents felt that they had failed because they had not been able to protect their child or prevent their death. A father described his feeling of failure in this way:

> As a parent, you have a role, one that we couldn't really live up to, as we failed to play our role. You are supposed to protect [your child], make your child independent and get them to leave the nest, right? And, somehow, it does not work out. You haven't finished the task, and it's kind of shameful, yes, you've failed a bit in living up to the society's expectations? Maybe in relation to your own social standing. I know it's not like that, but the feeling associated with this, that's what the feeling says to me, well, that's what makes it a little difficult. (ID 39)

Parents stated that they were aware that the stigma they had imposed on themselves did not necessarily reflect other peoples' thoughts or attitudes. A mother explained that she felt like she did not live up to society's standards about how to be a responsible parent and therefore she over interpreted others' behavior:

> Well, I know everyone thinks it […] if you have a child who uses drugs, then, in a way, you haven't been good enough. So, you're looking for it, the blame in other people's eyes, you see it, even if it's not there. (ID 125)

Although they ruminated about whether people looked down on them, many of the same parents pointed out that there was an absence of stigma from their social support network. They were comforted by people in their social network, who reassured them about being good parents and stated that this could have happened to anyone. However, it was very difficult for them to absorb such opinions, as views of people in their network were overridden by their own inner self-inflicted stigma.

(III) Emotional overload

The parents reported that their search for answers to their child's troubles and death affected their emotional life and behavior. After the loss, they experienced an overload of complex and ambivalent emotions as well as complex reactions due to the loss of their loved one. This overload was connected to two codes: (a) complex emotions; and (b) complex reactions.

Complex emotions

All 14 parents expressed a breadth of emotions triggered by the loss. The most striking feelings were anger, guilt, relief and shame. Especially during the first years after the loss, many parents described a rapid oscillation between various feelings mixed with rumination. The emotion that was most often expressed was anger, especially anger toward different health and welfare services:

> So angry […] I'm angry at her [the deceased], I'm angry at the healthcare services. I'm looking for someone to blame, so if I can't blame myself, then I must be able to blame someone else and then it must have been someone else's fault […] probably the healthcare services or child welfare or the police. (ID 62)

Guilt and shame were commonly described, for failing as a parent and particularly guilt for not being able to stop their child from using drugs. They found that shame caused by society's ideals or expectations was easier to put aside than feelings of guilt. Some of them expressed relief on behalf of the deceased, relief for others or relief on their own behalf. Parents who expressed relief had either lost a child after decades of drug use, or the load prior to the death from their perspective was so heavy that no other solution than a tragic outcome was to be expected. All the parents described their child's resources and dwelt on the life that the child had never had.

Complex reactions

Even though the parents feared for their child's life, their death was described as a shock and they reacted both mentally and physically to the loss. The consequences were social isolation and an increased concern for and a fear of losing others. Those who apparently struggled the most were parents who either had lost their only child or their child had been an enduring strain on them. These parents also lost an important part of their identity: the role as a full-time helper and/or as a parent. Like this father, a few parents struggled to find purpose in life:

> You become a parent, and the world changes. And then you lose your child, then the world changes again, it's not the opposite of becoming a parent, maybe much bigger on many levels […] Everything is about the child […] So when all that disappeared, then all our tasks disappeared, so, we are in such a very big vacuum in terms of figuring out what, what now, what should we do next, what should we do, why, what is the point really? (ID 39)

Thinking of the deceased, and what they could have done differently, kept some of the parents awake at night. Other reactions, such as sleeping problems, and physical reactions, such as feeling tired, nauseous, dizzy, exhausted and anxious, were also described.

(IV) Complex relations

Overall, the bereaved stated that relations with public services and their personal social networks were complex. As was the case during the time before death, most experienced a lack of help from public services. In general, they considered the support from family and friends to be good, although communication about the loss was difficult for both parties involved. Such complex relations were described in terms of two codes: (a) a lack of help from public services; and (b) challenging communication about the loss.

Lack of help from public services

All of the parents described that they did not get the help they needed from public service, though the meetings with first responders (i.e. police, doctors, paramedics, priests and undertakers) were described as professional. Most bereaved experienced that they got information about what had happened, and that priests and undertakers facilitated a dignified memorial service for the deceased. When the funeral was over, however, only a few representatives from the public services reached out to the bereaved. Those who received help had to ask for this themselves and only one of the parents was offered help from a local crisis team.

> The first to arrive were the doctors and the ambulance staff, and then came the police and morticians, and somebody told me that, if I needed to talk to someone, I could call someone [laughter]. I received the number for a crisis relief team, I tried to call once, around Christmas, but they closed at 8 p.m., so there wasn't much help in that. (ID 123)

Those who asked for help sought help primarily from a general practitioner. Sickness benefits from the National Insurance Scheme, graded from 100% down to 20%, were used as a return-to-work strategy. A few parents also reached out to their child's case manager and asked them for a follow-up appointment so they could go through what had happened in the days up to the death. Although this help was appreciated, the bereaved had an unmet need to talk to professionals, especially concerning how to cope with their ruminations about 'what went wrong'.

Challenging communication about the loss

Most of the parents found that their social network, such as family members, colleagues, friends and friends of the deceased, provided the support they needed. Despite being in shock, and not being able to respond to the care from their surroundings, they stated that people in their networks whom they were close to never gave up on them, although they differed in their views concerning how the loss had affected their way of communicating with others. Some said that losing their child had made it easier to talk to others and to share feelings and experiences. Others said that they had pulled back and only shared thoughts with a few close family members. Some were afraid that their grief was an unbearable burden to place on others, while others found that people were insecure and did not know what to say, which this mother and other bereaved interpreted as an indication of not wanting to hurt the bereaved parent:

> I think others do not know what to say and how I will react. Some people find it very difficult if others gets very emotional, starts crying for example, others find it very difficult to handle that […] I have siblings who are health professionals, I thought that maybe they would try, but it seems difficult even for them. There is no unwillingness, they don't know how to reach out. (ID 15)

Discussion

The themes identified from the data, (I) *constant preparedness*, (II) *stigmatization*, (III) *emotional overload* and (IV) *complex relations*, support the suggestion that DRD is a special kind of death. In line with Doka's (2002) definition of a special death, the parents in this study experienced stigma both before and after their child's death. Before the death, there seemed to be a spillover effect from the stigmatized drug user (especially in meetings with helpers), while, after the death, the parents experienced an intrusive kind of self-stigmatization. This self-stigma was triggered by shame and guilt about failing as a parent and not fulfilling society's norms about successful parenting. There seem to be high levels of stress inherent in the parents' descriptions of constant preparedness and oscillating between conflicting emotions. We maintain that the emotional overload before and after death, combined with the self-inflicted stigma that the parents experience, imposes a considerable burden resulting in both a special death and a special grief.

The special grief of drug-death bereaved parents

This study supports previous findings about parents experiences of emotional overload before death and their constant fight to find help for the child (Oreo and Ozgul 2007; Orford et al. 2010; Maltman et al. 2019). The descriptions of a constant preparedness showed how difficult it can be to live with a child using narcotics. Rejection from the Child Welfare Services and NAV, as well as a lack of cooperation due to confidentiality, had major consequences for the parents' everyday life. The children were all over 18 years and therefore considered 'adult' in Norway where this study took place. However, to put this in perspective, the transition from childhood to adulthood in industrialized societies takes longer than it used to (Arnett 2000). Many young people still need emotional, economic and practical support after receiving the age of majority. The term 'extended parenthood' reflects the consequences that this extension has for parents who have children who need this continued support (Tysnes and Kiik 2019). Although the person who used drugs was considered an independent adult at the time before their death, the lack of tailored help from health and welfare services led to the parents in our study experiencing a need for extended parental involvement. The parents took over responsibilities which normally – at this time in the child's life – should have been handled by their child him- or herself. They had continued to provide the child with all types of support, while, at the same time, dealing with their own emotional 'roller coaster'. These findings illustrate that drug-death bereavement is complex and that an overload before death affects the parents' grief after death (Figure 2). These results also speak to the need to enhance cooperation between the person who uses drugs, their next of kin and public services.

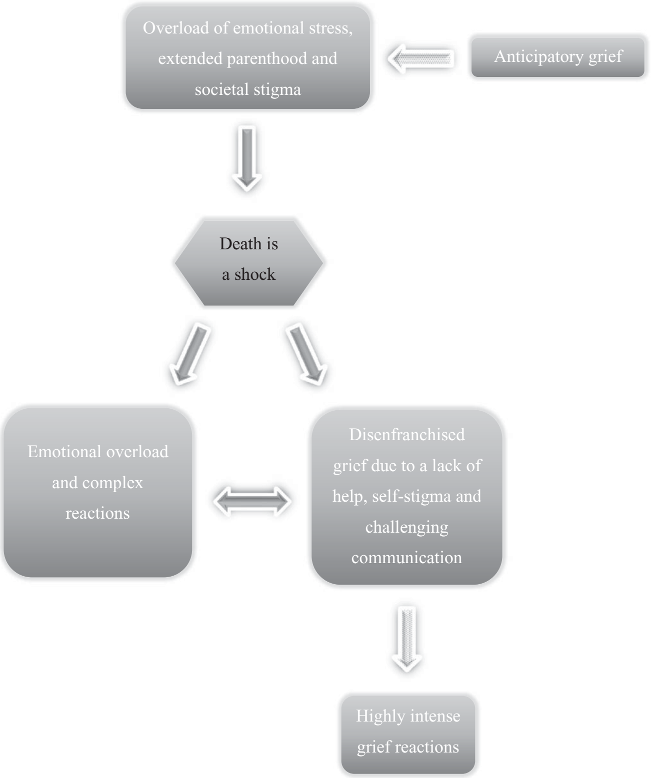

Figure 2. What the parents go through and what characterizes and triggers the "special grief".

Even though all of the parents were aware of their child's drug use and feared losing their child, many nevertheless experienced their child's death as a shock. As reported by da Silva et al. (2007), a chaos of conflicting emotions and reactions, such as grief, anger, guilt, self-blame and relief, followed the unexpected death. The bereaved who had years of experiences with their child's drug use and who described anticipatory grief reported the same spectrum of complex grief emotions or reactions as those bereaved with less preparation and/or forewarning.

The parents in our study were essentially angry with public services. Excessive bitterness or anger related to the death are typical reactions to bereavement (Stroebe et al. 2007). In the Brazilian study by da Silva et al. (2007) secrecy regarding drug use followed by DRD aroused strong feelings of anger, while Templeton et al. (2017) reported that anger was directed toward those they believed were involved in or responsible for their loved one's death. By contrast, characteristics of the Nordic welfare states are a high degree of equality in services, a high level of taxes and a high level of public spending on welfare (Greve 2007). We believe there is a difference between the Brazilian/UK and the Norwegian studies, that the Norwegian parents' anger is for not giving them public services they expected to get from the welfare state. Our results also show that, after their child's death, the parents ruminated about why the child had not received this help, as well as why they themselves were not offered help to cope with the loss. Based on this study's findings and other studies about drug-death bereaved in different countries of the world, it can thus be suggested that anger and frustration, reflected in rumination, is a central feature of the special kind of grief following a DRD.

We have reasoned that disenfranchized grief was described in our findings, although in different forms than in previous studies of drug-death bereavement. Livingston (2017, p. 231) and Valentine et al. (2016) described losses that were unacknowledged and/or forbidden, while, in our study, the parents described their losses as acknowledged (i.e. by their social networks). Still, there are different types of disenfranchized grief (Thompson and Doka 2017, p. 178). Disenfranchized grief can also be self-imposed, in which the bereaved take on the social and cultural norms and attitudes of those around them in relation to what deserves to be grieved over (Doka 1999). Although it is unclear how self-stigma determined whether or not the parents in fact grieved in public, several of the bereaved described the stigma that they had imposed on themselves, since they felt shame and guilt about failing as a parent. In addition, a lack of public services could have contributed to a feeling of unacknowledged grief. A national guideline *Psychosocial Interventions in the Event of Crisis, Accidents and Disasters* recommends municipalities to activate psychosocial crisis teams for the bereaved after a sudden and potentially traumatic death (Norwegian Directorate of Health 2016, p. 31–35). Despite this recommendation, when their child died, only one of the 14 parents received help from public services without asking for it. The finding that the drug-death bereaved are less likely to access public services after such a traumatic, unnatural death is in line with the findings of other studies (Biong et al. 2015; Valentine et al. 2016).

We believe that stigmatization on a group level during the time before the child died, as well as the demonstrated self-inflicted stigma that the parents placed on themselves, is a typical feature of drug-death bereavement. Shame and guilt about failing as parents characterize one of the extra burdens that the parents had imposed on themselves and, according to Jie Li et al. (2019), guilt might be a core symptom of grief complications and depression. Complicated grief has been reported as being high in studies of other bereaved samples after a DRD (Templeton et al. 2016). As illustrated in Figure 2, highly intense grief reactions were described, albeit primarily by those who had lost their only child or those who had witnessed how their child's drug use escalated rapidly. These parents also described an enduring overload before death and a high level of rumination after death. They felt emotionally and physically exhausted and described a variety of negative consequences for their physical, mental and social health. Years of discredit and devaluation had left their mark. Along with self-stigma came social isolation and an intense feeling of shame which prevented participation in society for some of the parents. These reactions had lasted for more than six months, alerting us to the possibility of complications in the grieving process.

From the general literature on grief and bereavement and taking into consideration the results from studies on drug-death bereaved, it is possible to make some assumptions about bereavement after DRDs. A theoretical model, 'The special grief', describing components of drug-death bereavement has been developed by Dyregrov et al. (2019). Dyregrov et al. (2019) accept that anticipatory grief, in addition to the stress of living with a person who uses narcotics, can contribute to an emotional overload and make the processing of grief more difficult for the bereaved. In line with theories of stigma, the model also incorporates the possibility that those bereaved by DRDs can experience negative attitudes and actions from those around them, such as networks, local communities and support services. In addition, the model integrates the notion of disenfranchized grief among the drug-death bereaved, indicating that experiencing unacknowledged losses could complicate the grieving process. Our study's findings elaborate on the elements and the dynamic within the described theoretical model by Dyregrov et al. (2019). Accordingly, we identified an extensive overload of emotions and we suggest that the consequences for daily life can be explained in terms of an 'extended parenthood' (Figure 2). Our findings also elaborate on the elements complicated and disenfranchized grief, suggesting that, for these parents, silence from helpers, self-inflicted stigma and complicated interactions with their social networks can increase the risk of complications. In addition, we discuss stigma as a possible reason for lack of help from public services, a result that is a potential factor which is appropriate for further investigation.

Methodological issues

We recognize that multiple realities exist. We have outlined personal experiences and viewpoints that may have resulted in methodological bias, although we have aimed to clearly and accurately present the parents' perspectives. To improve methodological rigor, we have endeavored a transparent and clear description of the research process from the initial outline through the development of the methods and the reporting of the findings. Reflexive journals were written after each in-depth interview, containing information about our subjective responses to the setting and the participants. In addition, the results section contains key, illustrative, verbatim extracts from the interviews. Describing reflexivity is important to enhance a study's validity. As recommended in standards for reporting qualitative research (Malterud 2001; O'Brien et al. 2014), we described the characteristics and the role of the researchers in the paper. We argue that the checklist for reporting standards strengthens the transparency of this study and enhances the transferability of its findings to other contexts. The systematic review by Titlestad et al. (2019) calls for more rigorous studies and, as recommended in this review, we have investigated and described distinctive characteristics such as the deceased's age, the time since death, whether the next of kin was aware of the drug use, and whether the deceased died after first-time use or drug use over time.

One strength of this study is the wide use of different recruitment strategies. Nevertheless, despite our efforts to recruit bereaved parents from all classes in society, the risk of sampling bias is present, particularly given that people from lower social classes are under-represented. On the other hand, the size of our study sample has sufficient information power, in accordance with Malterud et al. (2016) descriptions.

There are pros and cons in the choice of applying a thematic analysis. Thematic analysis has been described as an 'anything goes' approach (Braun and Clarke 2006; Majumdar 2019, p. 205). Braun and Clarke (2019, 2006) have addressed this criticism in recent years, developing guidelines for assessing the quality of qualitative research analysis. We argue that, by following the stages involved in reflexive thematic analysis, we strengthen the quality, transparency and transferability of this study. In addition, the use of thematic analysis enabled us to stay close to the data provided by the participants and thereby remain empirically faithful to the included cases, providing explicit and transparent links between our conclusions and the data material.

Conclusion and implications for practice and policy

The findings of this research project contribute to our understanding of the complexity of drug-death bereavement, and we believe these results will be of interest to bereaved family members and their social networks, as well as professionals in health and welfare services. Hopefully, they will lead to improvements in how we communicate about and relate to DRDs. Show kindness and compassion is also one of five key messages identified from the UK-study by Valentine and colleagues which is described in the guideline *Bereaved through substance use: Guidelines for those whose work brings them into contact with adults bereaved after a drug or alcohol-related death* (Cartwright 2015; Valentine and Bauld 2018). The findings from our study hopefully also contribute to an increased awareness and adherence to guidelines that describe how to implement relief measures for drug-death bereaved (e.g. Cartwright 2015; Norwegian Directorate of Health 2016).

This study set out to explore drug-death bereaved parents' grief experiences and what help and support they received. The parents experienced a special death and described a special grief. The title of the paper, 'Sounds of Silence', refers to the Simon and Garfunkel song 'The Sound of Silence' (Simon 1964) and characterizes what drug-death bereaved parents go through. The song's lyrics demonstrate how silence can be perceived: 'People talking without speaking, People hearing without listening, People writing songs that voices never share, And no one dared, Disturb the sound of silence.' This silence is reflected in how the parents perceived a silence from helpers when their child was alive. When the child died, the silence from public services was described as deafening. They were not sought out, and the ones who got help had to seek out the services themselves. Self-stigma, which disturbed the dynamics in their communication with others, and the fact that people in the network were perceived as insecure also represented a type of silence. We argue that one of the main findings of this study is that such silence may have the potential to trigger intense suffering, and perhaps even complications in the grieving process, consequences that may be prevented or risks at least lessened, if the words of the bereaved parents expressed in this investigation are heard.

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How Do Drug-Death-Bereaved Parents Adjust to Life Without the Deceased? A Qualitative Study

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Abstract

Knowledge about how bereaved persons grieve can enhance quality in providing the support and potential services that they need. We aimed to identify ways in which drug-death-bereaved Norwegian parents go on with their lives and what inhibits or promotes adaptation during their grieving. Reflexive thematic analysis was used to analyze 14 semistructured in-depth interviews. We generated three themes: (I) processing grief emotions, (II) proactive coping, and (III) giving and receiving support and assistance. Processing guilt rumination, reflections on blame and a burden of grief emotions characterized grieving early on. Using cognitive strategies and functional-support-giving were found to be the most frequently used strategies. Oscillation between processing stressors and reorientation to the world promoted adjustment to ongoing life. We discuss characteristics of parents who struggle to reorient and outline important implications for policy and practice.

Keywords

grief, drug-death bereavement, parents, coping strategies, oscillation

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The way a person copes with the loss of a next of kin has been shown to impact on adaptation to bereavement (Nolen-Hoeksema et al., 2013, p. 17). Although grief is not a disease, and bereavement can be viewed as a normal experience, there is a risk of developing psychological and physical health problems after a loss of a loved one, especially after sudden, unnatural deaths (K. Dyregrov, 2003; Stroebe et al., 2007; Stroebe, Stroebe, et al., 2017). Drug-related deaths (DRDs) are unnatural deaths, ones that have reached epidemic proportions in the United States (21.7 per 100,000) (Centers for Disease Control and Prevention, 2019). They also present a major public health challenge across Europe (European Monitoring Centre for Drugs and Drug Addiction, 2019, p. 80). Clearly then, there is need for particular attention to the situation of bereaved family members left behind after DRDs as their unique difficulties have been identified in the scientific literature (see later).

The ability to identify grief reactions and to understand ways of coping are important, both for the bereaved and for professionals in the health and welfare services, as such knowledge can be used to enhance the bereaved person's ability to adjust to life and to improve the services when these are needed (Crunk et al., 2019; Stroebe, Schut, et al., 2017). In this context, we think of coping as processes, strategies, or styles of managing the bereavement and define coping as the "changing thoughts and acts that an individual uses to manage the external or internal demands of stressful situations" (Folkman, 2001, p. 565). Grief reactions such as grief rumination and repetitive thinking about the causes and consequences of the loss and loss-related emotions can have negative impact on adjusting to life after a loss (Eisma & Stroebe, 2017). Such rumination is associated with depression, posttraumatic stress, and complicated grief (van der Houwen et al., 2010) and is a strong predictor of complicated grief (Eisma et al., 2013). By contrast, the construction of meaning has been identified as an important part of how people adapt to a traumatic death (Bonanno, 2013). The process of *meaning-making* may facilitate coping with the loss of a family member through a complex reorientation to the world (Neimeyer, 2019). Prior to using coping strategies, people might use proactive coping strategies that are "processes through which people anticipate or detect potential stressors" (i.e., what the bereaved have to deal with) "and act in advance to prevent them or to mute their impact (proactive coping)" (Aspinwall & Taylor, 1997, p. 417). Finally, social support has been identified as a major factor in coping. The extent to which parents experience support may relate to the degree that they adapt after the death (Greeff et al., 2011). K. Dyregrov and Dyregrov (2008, p. 50) found that bereaved ask for support from both their social network (e.g., family, friends, colleagues) and from other bereaved (peer support), in addition to professional help, as help and support from these sources address different types of needs. However, the time frame, amount, and needs of these different types will differ among grieving individuals and families (K. Dyregrov & Dyregrov, 2008). Bonanno and Burton (2013) also drew attention to the need for flexibility, emphasizing the importance of various strategies for ultimate adaptation. Such a concept would seem especially relevant in the case of DRD bereavement, given the range and complexity of associated stressors (cf. Templeton et al., 2017).

Several different theoretical models have been developed to help understand coping with bereavement (Stroebe, Schut, et al., 2017). One that explicitly captures flexibility in the coping process is Stroebe and Schut's (1999) *Dual Process Model of coping with bereavement (DPM)*. According to this model, to cope effectively, a bereaved person must oscillate between *loss-orientation* and *restoration-orientation*. The former refers to coping processes that focus directly on the stress of the loss itself, including symptoms of grief, loss, and sadness, while the latter includes the processes one uses to cope with the secondary stressors (e.g., having lost one's caregiving identity) that accompany one's new status as a bereaved person (perhaps including symptoms relating to these changes, such as exhaustion and anxiety). Two additional features of the DPM, elaborated on more recently, are particularly relevant in the current context: (a) overload, "the bereaved person's perception of having more than s/he feels able to deal with," can affect the ability to oscillate (Stroebe & Schut, 2016, p. 100) and (b) family dynamics are understood to affect personal grief and vice versa (Stroebe & Schut, 2015).

Despite indications of its importance, given earlier, a systematic review by Titlestad, Lindeman, Lund, and Dyregrov (2019) showed that there has been hardly any investigation of ways that parents cope after DRDs. Yet, losing a person who used drugs is associated with stigma, complicated grief reactions, and unacknowledged grief (Titlestad et al., 2019; Valentine et al., 2016). Research evidence comes mainly from a qualitative substudy of 32 next of kin in England and Scotland (Templeton et al., 2017) and a quantitative study of 48 parents in United States (Feigelman et al., 2011). Templeton et al. (2017) described the stigma relating to DRDs, feelings of guilt, self-blame, and unworthiness to grieve. Feigelman et al. (2011) found a consistent pattern, whereby drug-death bereaved were consistently more troubled by grief and mental health difficulties than those bereaved after accidents or natural deaths. Adding to these, a qualitative study by Feigelman et al. (2018; $n = 11$) reported how bereaved adjusted to life. Their findings showed that as time goes by, drug-death-bereaved parents "were able to arrive at a 'new normal' and reflect on their own posttraumatic growth (Feigelman et al., 2018, p. 17)." Taken together, the evidence so far suggests special difficulties and special needs among DRD-bereaved persons and a need to further explore how they cope and adapt to their loss and changed lives.

A large Norwegian study was launched in spring 2017. The purpose of the main project was to contribute to knowledge on bereaved family members and close friends after DRD. The main study was a mixed-method one, collecting quantitative data through a survey and qualitative data through interviews

(ResearchGate, 2019). Definitions of DRD vary (Robertson, Bird, & McAuley, 2019). In this study we defined DRDs as deaths caused by the intake of substances classed as narcotics and deaths among people who use narcotics, where the cause of death is violence, accidents, infectious disease, and other health disorders, which in different ways may be linked to drug use. A distinction was made between drug- and alcohol-related deaths, and we focused only on drug death bereavement. Reactions to these two types of death likely differ. Using drugs is an illegal activity and, as Corrigan, Schomerus, and Smelson (2017) point out, the addiction stigma is likely to be worsened by criminalization, since drug use is conflated with felonious conduct. Moreover, people who die from an overdose are more likely to be male and young and to suffer a death that occurs early in the path of addiction (Templeton et al., 2017).

This article is one of two articles that explore drug-death bereaved Norwegian parents' grief. In the paper "Sounds of Silence" we reported how parents described a special death and how the silence from helpers, self-stigma and complicated interactions within the social network can contribute to a special grief (Titlestad, Mellingen, Stroebe, & Dyregrov, 2020).

The aim of the current article was to explore ways in which drug-death-bereaved parents go on with their lives after losing their child to drug use. Thus, the research question is as follows: "How do drug-death-bereaved parents adjust to life without the deceased and what seems to inhibit or promote adaptation during their grieving process?"

Methods

To generate a phenomenological, hermeneutic understanding of how parents experience DRD, we used reflexive thematic analysis as described by Braun and Clarke (2019). We searched specifically for a variety of coping processes and strategies that are unique to drug-death bereavement. Semistructured in-depth interviews were carried out, and NVivo 12, qualitative data analysis software (QSR International Pty Ltd, 2018), was used in the data analysis process. This article was guided by "Standards for Reporting Qualitative Research: A Synthesis of Recommendations" by O'Brien et al. (2014).

Recruitment and Sample Size

In the period from March 2018 until the end of December 2018, the main project enrolled drug-death-bereaved family members and friends by inviting them to fill in a questionnaire on paper or digitally. A flyer that described the project was sent to all Norwegian municipalities' public email addresses. We also contacted personnel who were engaged in the Norwegian Directorate of Health project to reduce drug overdoses, involving 28 municipalities at that time. Recruitment was also facilitated through nongovernmental organizations working with drug use, treatment centers, the Norwegian Labor and Welfare Administration, and crisis teams (either by mail or by handing out flyers). We disseminated information about the project through participation at conferences and various media such as television, radio, and social media (Facebook and Twitter). *Snowball recruitment* by participants and by collaborators in other research networks or professionals in clinical practice was another important recruitment strategy employed.

The interview sample in this substudy was drawn from a total sample of parents. Ninety-five parents participated in the survey, and 75 parents agreed to be interviewed. Inclusion criteria were that the participants (a) had participated in the END-project survey, (b) spoke fluent Norwegian, and (c) had lost a child to DRD at least 3 months prior to recruitment. No other restrictions were set for the time since death. Because many more parents ($n = 75$) agreed to be interviewed than could actually be included, the sample to be analyzed in this article was selected according to background variables such as gender, age, place of residency (city/village and northern/central/western/southern/eastern geographical part of Norway) of the parents, the time since death, and the age and gender of the deceased. Malterud et al. (2016) have proposed a set of considerations about different dimensions that influence the sample size such as the study's aim, sample specificity, theoretical background, dialogue quality, and strategy for analysis. To ensure the adequacy of the final sample, we looked to Malterud et al. (2016) for their guidance on *information power*. After interviewing seven fathers and six mothers, we decided to equalize the sample according to gender, in case the descriptions specific to gender became relevant to our discussion. Another mother was therefore invited to participate. After interviewing her, and given that the contribution of new knowledge was limited, we concluded that we had reached a satisfactory level of information power.

Semistructured In-Depth Interviews

A semistructured interview guide, built on the questions in the survey that we wanted to explore in detail, was developed for the interviews. The guide consisted of five themes: (a) the time before the death; (b) the loss; (c) stigma from the environment and self-stigma; (d) help, support, and coping; and (e) posttraumatic growth. In the preparation phase, the interviewing authors discussed subthemes that could possibly be relevant as follow-up questions in the interviews. During the interviews, we encouraged the participants to tell us about the deceased, their relationship to the deceased, the deceased's living habits, the circumstances surrounding the death, their grief reactions and how the death affected their health, working situation, and leisure time. In relation to stigma, we talked about attitudes emanating from their surroundings (family, friends, work colleges, etc.) and how they and others in their network communicated about the loss. We encouraged the parents to reflect on support from family, friends, colleagues, social networks, and support groups and help from health and social services, the police, ambulance personnel, priests, crisis teams, and so forth. We also asked the participants to share their thoughts about potential barriers to support and what help and support they needed, in addition to barriers or facilitators of own coping and meaning-making. However, first and foremost, the interview method required the researchers to pursue the thoughts and reflections of the interviewees. The interviews were carried out in the period August 27 to December 4, 2018. To synchronize the interview method and pilot test the interview guide, the last author conducted a trial interview with a bereaved parent, with the first and second authors (interviewers) present. The interview was discussed with the bereaved and the research interviewers. The interview guide was adjusted according to discussions after the trial interview and prior to other in-depth interviews.

Following completion of the informed consent process, the first author conducted six, the last conducted five, and the psychologist three in-person interviews in a private setting selected by the participant (home = 9, work office = 4, a hotel [sheltered space] =1). The interviews were audiotaped and transcribed verbatim by a research assistant. In addition, all interviewers noted their general impressions immediately after each interview. The length of the interviews ranged from 1 hour and 20 minutes to 3 hours and 10 minutes, including required or desired breaks. Altogether, the transcripts consisted of 431 single-spaced pages (range 20–39).

Sample

The sample consisted of 14 parents: 7 women and 7 men, who were parents to 14 deceased persons in total. One mother withdrew for personal reasons and one of the recruited participants failed to attend the planned interview. We were unable to reach out to the latter individual, either during or after the interview time, and no explanation was given as to why the potential participant decided not to keep the preplanned appointment.

One parent represented two deceased people, and a divorced couple represented one deceased person. All the parents were aware of the drug use, and none of the deceased had died after first-time use. Ten of the parents had lost a son, and four parents had lost a daughter. The time since death ranged from 3 to 126 months ($M = 38$), and all parents reported (on a 5-point Likert scale) to have been close to the deceased (12 reported to have been very close). The age of the deceased varied between 19 and 45 years ($M = 27.36$), and the age of the parents ranged between 45 and 75 years ($M = 58.29$). The participants reported to have experienced, on average, three demanding life loads. They came from all parts of Norway (north, $n = 2$; central, $n = 2$; west, $n = 5$; south, $n = 2$; and east, $n = 3$), with eight living in a village and six in a town. Twelve of the parents were married/cohabitants, while one had a boyfriend, and one was divorced. Only

2 of the 14 participants were still married to the other parent of the deceased. The parents were well educated (79% had received higher education beyond 12 years). Annual household gross income was in the range from 28,500 to more than 143,000 dollars, and 42.9% had an annual household gross income of 85,500 to 114,500 dollars. The income level in Norway is high, and the participants' income was high compared with the average annual household gross income.

Reflexive Thematic Analysis of Interviews

Braun and Clarke (2019) describe a six-phase process for reflexive thematic analysis: (a) familiarization with the data, (b) coding, (c) generating initial themes, (d) reviewing themes, (e) defining and naming themes, and (f) writing up. The phases are sequential, each build on the previous one, and the analysis is therefore a recursive process. We analyzed the interviews as recommended by Braun and Clarke (2019), conducting a reflexive thematic analysis with movement back and forth between different phases.

After reading and rereading all the interviews to become immersed and intimately familiar with their content and coding the entire data set in NVivo, we examined the codes and collated data to identify significantly broader patterns of meaning (potential themes). Themes, defined as patterns of shared meaning underpinned by a central concept or idea (Braun & Clarke, 2019), were then defined. Moving back and forth between the phases, clustering of themes was generated. We worked out the scope and focus of each theme, deciding on an informative name. A table of the codes and themes was then produced.

The analyses were conducted by the first author (a social educator) in collaboration with the last author (a sociologist) and then altered in accordance with consensus discussions with the second author (a psychologists). Trustworthiness of the findings was enhanced by thorough discussions among the authors. All authors agreed upon the coding framework, the interpretation of the data, and the confirmation of codes and themes.

Ethical Considerations

All procedures were conducted in accordance with the Declaration of Helsinki (The World Medical Association, 2018). This study was approved in February 2018 by the Norwegian Regional Committees for Medical and Health Research Ethics (reference number 2017/2486/REK vest).

All participants signed a written informed consent form that described the purpose, method, and procedure of the study, and the participants were informed that the data would be published in a nonidentifiable manner. Care was provided to the participants during the entire interview process according to K. Dyregrov's (2004) recommendations concerning research on vulnerable

Figure 1. Three Interconnected Themes Describe How Drug-Death-Bereaved Parents Adjust to Life Without the Deceased.

populations. The parents were assured of anonymity, confidentiality, and the option to withdraw from the study at any time. The interview data were treated confidentially. All identifying information concerning transcripts and recordings was de-identified and stored in the research server at the university.

Results

The mothers and fathers each told their own story, sharing their individual experience and personal perspective. How they adjusted and adapted to life without the deceased were influenced by both intrapersonal and interpersonal management strategies, as well as by internal and external circumstances. Even though they had adjusted to life in varying degrees and in varying ways, there were three interconnected themes that were identified from the data: (I) *processing grief emotions*, (II) *proactive coping*, and (III) *giving and receiving support and assistance* (Figure 1).

As would be expected, losing a child triggered many negative emotions. Repetitive and recurrent thinking regarding guilt was the most striking negative emotion reported by the parents. This processing of grief emotions was connected to three codes: (a) ruminating about guilt, (b) reflections on blaming others, and (c) adaption to external triggers.

Processing Grief Emotions

As would be expected, losing a child triggered many negative emotions. Repetitive and recurrent thinking regarding guilt was the most striking negative emotion reported by the parents. This processing of grief emotions was connected to three codes: (a) ruminating about guilt, (b) reflections on blaming others, and (c) adaption to external triggers.

Ruminating About Guilt. Many of the bereaved had ruminating thoughts before the death. They felt guilt for not making the right parental decisions early in their child's life and blamed themselves for the predicament their child had been in. When the child died, and all hope was gone, rumination associated with guilt escalated. The bereaved ruminated about why they had failed to prevent their child from using narcotics, hanging around with *the wrong* friends, and for working away from home. They ruminated about whether they should have used more punishing strategies, yet at the same time, they were convinced that putting their child *in chains* would not have solved anything. A mother who had lost her son 18 months previously ruminated as follows: "Why? Why, why couldn't we? Why couldn't we stop him, and should we have done something different? Should we have punished him, been stricter? These thoughts arise, were we stupid, blind?" (ID 15)

For many of the parents, guilt rumination decreased, but the extent and persistence over time after the loss differed from parent to parent. The parents described how they had become reconciled to the fact that they had done their best to help their child and to prevent the death, as expressed by one mother:

> So I have no guilt today, because I know I've done everything I could. I couldn't do any more. I might have done things differently, some of it, but no, I really couldn't. Well, he always knew that I was there for him and that he could always call me. (ID 7)

Although the parents explained that they had learned to live with the guilt, some also pointed out that guilt rumination was seething in the back of their mind and that guilt and negative thoughts could arise when they least expected it.

Reflections on Blaming Others. The bereaved reported that they had many questions about whether the death was an accident, suicide, or if their child was killed. They wanted answers about what part others played in their child's addiction to narcotics and why the child did not get the help she or he needed. This father reflected that bitterness could easily be the outcome of ruminating over who was responsible:

> After the loss, I could very well have gone into a state of bitterness (mhm), and of course at times, there were lots of questions and critical issues. I never got straight answers, though when you are in this situation, right after the loss, you try to get answers to a lot of things, but I do not think there were clear answers. Still, the bitterness - nothing good comes from it. (ID 26)

The parents often blamed the deceased's friends. As for this father, a coping strategy for many of the bereaved was that they accepted that nothing good came out of blaming others. That many of the deceased prior to their death had encouraged them to stop blaming others and helped them put aside this rumination. After some time with rumination about who to blame, many reported that they acknowledged that their child's friends struggled just as much as their child. All the parents, except one, said that the loss had changed their way of thinking. Some said they had changed perspective regarding what was important in life, they were softer and tougher at the same time, while others said that they were more tolerant toward other people's challenges.

The parents also blamed those working in public services, health services in particular. It was harder for the parents to comprehend and accept that services did not provide appropriate health services that could have kept the child alive or that general practitioners (GPs) prescribed drugs that, in their opinion, their children were not in need of.

Adaption to External Triggers. Many of the parents experienced grief emotions that were triggered by external circumstances. Overwhelming sorrow, such as bursting into tears or experiencing anxiety, could be triggered by places they associated with the deceased or through watching a movie that brought back memories. Holidays and memorials also brought on grief reactions with unexpected waves of emotions. Like this father, several bereaved described listening to music to be a trigger:

> Yeah, well, it didn't take much to trigger me for quite some time, though I simply thought of it as a relief. And that I got proof for myself of how much I cared, so it was, (that is good to hear), it was actually a good, a decent feeling in a way. (ID 26)

This father also described that he used music therapeutically in the grief process. Over time, most of the parents experienced that the impact of triggers of complex emotions decreased or triggered different emotions. Most of the parents reported that the reactions got easier to cope with, and as time went by, the emotions were not so overwhelming. Some triggers changed from initiating grief reactions to acting as a coping mechanism. Listening to music could eventually calm the father mentioned previously, and a mother experienced that after some time, it calmed her down when sleeping in her daughter's bed at their family cottage, contrary to the distress she experienced when visiting the cottage right after the loss. On the other hand, some parents actively avoided some triggers, especially locations they knew that would trigger reactions, such as places they associated with the deceased.

Proactive Coping

As time goes by, most of the parents adjusted gradually to life without the deceased. Four codes reflect active sets of strategies: (a) cognitive strategies,

(b) communication strategies, (c) craving knowledge, and (d) back to day-to-day activities.

Cognitive Strategies. All parents described that they worked with their *mindsets* by using cognitive strategies to deal with complex emotions and reactions. Many parents described this as hard work that required great will, reflection, and pragmatism. They had to change their way of thinking. For example, those who experienced existential thoughts stated that taking control of their mindsets was vital. One father called it a mental defense wall and explained how he took control by talking to himself, that he gave himself instructions on how to react and behave. In this way, many of the parents decided to make room for grief. This mother's strategy was to acknowledge that she had bad days and to allow herself time-outs for grieving:

> I am very good at allowing myself to have bad days and feel the loss, and they come less frequently now, but they came much more often before. And then I thought, then it was just like, it is of no use to try today, today is just one of those days . . . use strategies I found are good for me . . . not hold back, . . . So you lock yourself inside on Friday and go back out again on Monday morning, because you just have to disconnect from the whole world and everything, right. . . . I've done that very consciously; I've worked hard to move on. (ID 125)

In addition to deciding when to grieve, several of the parents also decided to put aside grief. A father described the oscillation like this:

> I had to . . . really listen to my feelings, to the extent that I felt it and endured it. And tolerating the grief, eh, doing what I felt I could manage, no more, stay still, but also be active . . . . I can't be grieving all the time, so I think that has worked for me, sort of switching between sadness and a totally, totally OK feeling. Not jumping for joy, but like I'm fine and I can enjoy things too. (ID 57)

However, some experienced that putting emotions aside also had serious consequences. Strategies that at one point felt like a coping strategy turned into an avoidance mechanism, and over time putting emotions aside made it all worse. Most parents experienced that they were better able to bear their grief as time went by, though many described that, despite trying hard to control their emotions, a wave of grief emotions could overwhelm them, without any warning.

Communication Strategies. Almost all the parents were open to others about why their child had died. This category of communication strategies reflects how parents actively chose with whom they wanted to communicate about the loss. Again, the bereaved preferences differed, but all experienced that talking was therapeutic, a coping strategy used to aid acceptance of the loss, and that they often repeated themselves, even to the same listener. A mother described how she also used taking about the loss to cope with self-perceived stigma:

> It is probably more like you are looking for it, that is, you feel it so strongly, that everyone thinks it is your fault. If you had managed to take better care of your daughter, then this would not have happened, everyone thinks so. So you see it in people's body language, their eyes, or hear it in things they may not even say. Eh, so for me, I had to be proactive, it became sort of important to me not to, I would rather be open about it.... "Yes, she died of an overdose, yes, she died of intoxication, no, she did not have it easy and I have done my best." (ID 62)

For many of the parents, it was also important to talk about the deceased to honor the person's memory, fearing that others would forget him or her. As they felt that communicating about the child was not that easy for all in their network, the bereaved had preferences toward whom they preferred to talk to, more often close family members or a few close friends.

Craving Knowledge. Some of the deceased persons had trouble adapting to the expectations from, for example, the school system, and some had mental health problems. Growing up, most of the deceased had experienced challenging life events such as sexual abuse. The parents described that they ruminated about the extent to which genetic factors or certain life events caused their child's addiction to narcotics. Several of the parents called on skilled personnel to learn more about drug addiction and/or sought out professionals who had treated their child. Like others, new knowledge helped this father to cope with and accept the loss:

> Reason, I'm probably never going to find the whole reason, but just to understand in a way what happened to him [the deceased]? Getting a better understanding of what happened would have been nice, what happened to him [the deceased], that's really my grief process. I've come a long way, and I will never quite see the end of this, these questions, but I have to understand a little more about the effects of drugs and drug use and, yes, just hear people talk about similar cases and say that this is completely normal. ... Well, it would be like, settling my mind. (ID 42)

Even though all the parents feared losing their child, it is a devastating shock to many of them when death occurs. Many ruminated about what happened during the time leading up to the death, and the parents wanted to know who was involved or present at the time of the death. The parents therefore sought out to police, health-care professionals, and GPs who had been in contact with their child. The parents, who used this information to make a time line for the death event, described that this knowledge reduced their rumination, even though not all their questions were answered.

Back to Day-to-Day Activities. Many of the bereaved used their energy after the loss to deal with practical tasks necessary after a death. A plan for the day, and going through with this plan, kept many parents on their feet in the time immediately after the death. Returning to work was described as a very important action to adjust to life without the deceased. For many, as this father described, going back to work was the most important action after the loss:

> . . . the most important thing I have done to move on after the death was that I was able to go back to work, in light of returning to the community you are supposed to be in, or daily routine in a way, getting the machinery running again. (ID 96)

Flexible and concerned employers and colleagues were important to stay in work. The parents praised their GPs especially, for using graded sick leaves and making a back-to-work plan. Bereaved, who did not have an employer or were not part of a positive work environment, stated that they struggled more, both with finding meaning with work and with life. Other activities that were described as important managing strategies were hiking, jogging, knitting, and meditation.

Giving and Receiving Support and Assistance

This theme reflects on external circumstances that parents experienced which strengthened their ability to adjust to life, as well as covering descriptions of reactions to lack of help. Four codes were identified: (a) to be needed by others, (b) social network support, (c) professional assistance, and (d) peer support.

To be Needed by Others. The parents described how they pulled themselves together after the loss in consideration for the deceased's sibling(s) or child (ren). Most of the parents cared for, and some took over the parental responsibility for, the bereaved grandchild(ren). Even though some said being the main care provider at times was difficult, taking care of others helped parents cope. Functional-support-giving prevented this father from collapsing:

> But moving on is a must, I definitely have to do that, and I have to be, I must also be, strong and ready for my daughter [the deceased's sister] who needs a father who is there for her, and who can support her, so I can't break down. (ID 42)

Some parents describe being needed by others as the most important factor for getting back on their feet and that caring for others was the main motivation for going on with their lives. Their children were also a bright spot in the bereaved parents' lives, and the parents found strength in fighting to prevent that the sibling or the deceased's child from walking in the same footsteps as the deceased. Nevertheless, parental responsibility also limited their grief; they did not allow themselves to show their child(ren) how the loss affected them. Being responsible for other children or grandchildren also strengthened cohesion in these families. A mother described how sharing this experience seemed to reinforce positive family dynamics and reduced and relieved their own pain (ID 15).

Parents who had lost their only child or did not have other children who depended on them struggled more to adjust to life. After several years, with the child who continuously needed help and care, one father described that not to be needed was like being hit by a meteorite strike; the landscape had completely changed, and all the reference points were gone. "It is very difficult to find something to take a compass course, because you have nothing to put it on," he said (ID 39).

Social Network Support. Two of the 14 bereaved parents were still married to the childs other parent when the child died; five parents described ongoing conflicts with their former spouses, while others described a good collaboration. Experiencing the loss did, in most cases, strengthen the ties between family members, but those who were already in tough conflict prior to the loss experienced that the death worsened the conflict.

Many bereaved described supports by family members, friends, and extended network immediately after the death, and parents found comfort in an unexpected support from the child's friends. This mother was clearly affected when she described how much the support meant to her:

> (her voice cracking with emotions) The days were hectic, but I actually experience a lot of support, there are people here all the time. I don't really know how to relate to all the people, but I actually think it's okay that they are here. Then some leave, some stay, and some come and go again, and I receive flowers and cards and it keeps on coming. ... And at the funeral the friends could come in first. ... I sat out of sight. I couldn't bear their grief. But there is something about adolescents that differ from the adults who are more enclosed and (sigh) afraid to say something wrong. These youths, they were crying, and they were asking, and they were talking, and they were hugging each other and hugging me and wanted me to sit with them (voice cracking with emotions). So we were kind of together, and I remember that like... (crying). (ID 62)

They described how people in their network fulfilled different needs. Family members were their most important support in grieving over the loss, while close friends were important in the way they provided free space that they needed to put their minds on other things. Some of the bereaved pointed out the importance of telling others what you need, as it is difficult for others to understand and know. Importantly, parents described close networks as the most helpful in the process of adjusting to life. However, over time their networks narrowed down to a few very close family members and friends, as some bereaved found it difficult to communicate with people in their social network, especially those who lacked knowledge about addiction. Some also felt that others did not seem to handle bearing their grief and therefore did not talk about the deceased or ask how the bereaved was doing. Many bereaved coped with this behavior by excusing these people, saying that they themselves before the loss could have expressed ignorant statements about addiction and that they probably would not have known how to give support.

Professional Assistance. All parents expressed a need for professional help after the loss, and yet only 1 of the 14 interviewed parents was contacted by a local crisis team. Most of them described that they had to take the initiative and reach out to get the help they needed from public services, and even when they reached out, some felt neglected/ignored. Several of the parents received help from the deceased child's therapists, but most parents said that they reached out to a GP who referred the bereaved to a specialist (e.g., a psychologist, grief therapist) or to a grief group.

Eventually most of the parents got help, though some experienced that their GPs requests (e.g., for them to receive therapy) were rejected. Those who received help expressed that the assistance was of good use. They learned strategies to cope both with the emotional burden and self-perceived guilt, as well as coping strategies for day-to-day living. This mother described how she also got help to understand her grief reactions:

> So the best thing about that psychologist (light laughter in her voice), he was absolutely fantastic at explaining to me how the brain works and he could explain to me why I reacted the way I did. Because I, I didn't know, I never thought I could be depressed (no), it was far beyond my thoughts. Of course, when I think back, I reflect on why haven't you been depressed long ago? (laughter) (yes). But at that time, it was not even in my mind, but now I am careful not to relapse. So, just as I approach the edge, then I know I must do something, and that is what he has taught me. (ID 7)

Peer Support. The few parents who were referred to a support group described that the threshold for taking in the group was low and that there was a basic understanding about what it is like to lose a child. Talking to people who had the same experiences helped, though some parents needed breaks from the group like this father:

> And that has helped me many times, that I have been able to talk to others, or listen to others. Maybe comforted others when I have come a little further .... And there are often friends and others who motivate me or ask me to talk to others.

> Then for a while it was a bit too much. Although, it somehow became something you can give back, that helps me move on. (ID 125)

For the parents, it was important that the other bereaved in their support group had experienced DRD. They argued that it is impossible to fully understand drug-death bereavement if you have not experienced it yourself. Those who participated in grief groups with bereaved after other causes of death also argued that support groups for drug-death bereaved would be more beneficial.

Discussion

The themes (I) *processing grief emotions*, (II) *proactive coping*, and (III) *giving and receiving support and assistance* describe how drug-death-bereaved parents adjust to life without their child. The three themes are intertwined and were shown to influence each other; together, they helped to describe what inhibits or promotes adjustment to life after DRD loss. Also, the themes aid understanding of coping with bereavement as a personal as well as an interactional pathway. The codes (IIa) *cognitive strategies* and (IIIa) *to be needed by others* comprise the main findings promoting adaption, while (Ia), *Ruminating about guilt*, dominated the parents' descriptions of reactions that had a negative impact on adjusting to life after the death. Adjusting to life was mainly described through oscillating between stressors, functional-support-giving, and proactive coping. Challenging communication was reported to be a

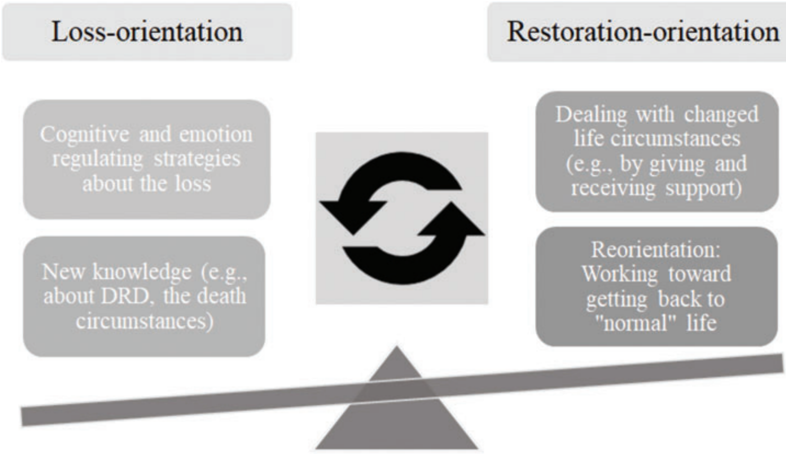

Figure 2. Illustration of How the Parents Oscillated Between LO and RO Strategies as They Adjusted to Life.
DRD = drug-related death.

hindrance, and the bereaved parents called for help from services and support, and from peers.

Adjusting Through Oscillating Between Stressors, Functional-Support-Giving, and Proactive Coping

The findings of our study illustrate certain parameters of the DPM, placing our results in theoretical context. Loss-orientation coping, such as rumination and using cognitive and emotion regulating strategies, characterized the first time period after the loss (Figure 2). Restoration-orientation coping that actually increased the sense of the loss was also found in this study; changed roles in relation to the deceased child(ren) was the most striking finding. The participants reported oscillating between processes such as actively grieving (loss-orientation) and going back to day-to-day activities, such as, in some cases, returning to work (restoration-orientation). These findings of alternation between stressors and other activities illustrate the oscillation process as an integral part of the process of coping with grief and grieving. The results resonate with those of a parental bereavement study by Albuquerque et al. (2017), which highlighted the importance of being flexible. In line with Bonanno and Burton (2013), these findings show the importance of coping and emotional regulation as flexible adaptation, stressing that responses are rarely static. There are reasons to argue, then, that, on a personal level, flexible adaptation and oscillation between loss-orientation and restoration-orientation processes promotes adjustment to life for many of our grieving parents.

Our study showed how important the restoration-orientation strategy incorporating distraction from the loss itself was, notably, by taking care of the other children; those who had lost their only child and/or did not have other children who depended on them struggle more to adjust. In our view, these results illustrate that restoration-orientation stressors are important to deal with (e.g., finding a new role represents a needed reorientation to the world). We also conclude that functional-support-giving was also an important part of the meaning-making process that facilitated coping with the loss. In the DPM-Revised, Stroebe and Schut (2015) recognized how family dynamics can impact individual adjustment in either positive or negative ways. We argue that the family-level stressor of being needed by others actually promoted adjustment, while ongoing conflicts with former spouses inhibited the bereaved person's grieving process.

Extensive rumination, combined with the generally more adaptive *working through* grief (cf. Stroebe, Schut, et al., 2017), was one of the most striking results in our study. Most parents described how it helped them not only to ruminate about their loss but also to process grief emotions, especially self-perceived guilt and blaming others. Oscillating between maladaptive rumination and eventually more and more adaptive cognitive processing helped many parents set aside guilt and the blaming of others. Stroebe and Schut (2016) argued that coping with bereavement according to the DPM is a complex regulatory process of confrontation and avoidance. Our study's findings suggest that avoidance as well as confrontation was an important coping mechanism; for example, for longer term adjustment, it seemed to be necessary to oscillate between loss-orientation and restoration-orientation (as well as take time off from coping) to avoid a resurgence of grief.

The stressors, particularly those relating to guilt rumination, were at times difficult to deal with and at times too much for the bereaved to handle. According to Stroebe and Schut (2016), overload can hinder the bereaved person's ability to oscillate *effectively* between loss-orientation stressors on one hand and restoration-orientation ones on the other hand. The finding in our study is consistent with this; the parents who described an extensive overload after the loss were the ones who had most difficulties with flexible adaption and oscillation. These parents also described a need to put the overload aside to ignore the stressful things that needed to be coped with, which in the long run made reorienting even more difficult.

The parents' descriptions of grief following DRD is reported in Sounds of Silence. The Special Grief of Drug-death Bereaved Parents (Titlestad et al., 2020). In that article we discuss how the time before death imposed a considerable emotional and practical burden on these parents, one that causes a special grief. Folkman (2001, p. 564) pointed out that coping may sometimes have less influence on adjustment compared to factors such as the timing and nature of the death, history and personality. Therefore, we argue that the drug-death bereaved parents' history, as well as the nature of the child's death, must be taken into consideration when DRD bereaved parents need assistance and support.

Many parents described that they used proactive coping strategies, and cognitive strategies were the most frequently used of these. For example, deciding to go back to work, making room for grief, and ceasing to blame others probably also helped to reduce overload. Deciding at times simply not to confront one's grief also served to bring some respite. The bereaved participants reported not only that avoidance inhibited adjustment but also that alternating between *making room* for grief and taking time off grief was an important coping strategy. Furthermore, proactively avoiding some of the triggers, such as places they associated with the deceased, was always described as an adaptive strategy.

Challenging Communication and Call for Peer-Support Groups

This study shows that the parents who seemed to have the best interactions were the ones who were proactive, who clearly stated how and when they wanted to communicate about the loss. Even though the parents used *ventilating* as a strategy to cope, as described by K. Dyregrov and Dyregrov (2008, pp. 38, 47), the parents undercommunicated their grief because they experienced that other people seemed helpless with regard to talking to them about the DRD loss. The term *social ineptitude* has been used to explain the withdrawal of network members, unsuccessful contact, and communication problems as experienced by traumatically bereaved (K. Dyregrov, 2006). Openness, an assertion of personal needs, involves educating others as to how to support them (K. Dyregrov & Dyregrov, 2008, p. 118) and can help the bereaved deal with the overload (Stroebe & Schut, 2016). In line with other studies of unnatural deaths (K. Dyregrov & Dyregrov, 2008; K. Dyregrov et al., 2018; Feigelman et al., 2018), there are good reasons to argue here that proactive bereaved persons can help people in their social networks to take the perhaps difficult step to talk about DRD. Social networks therefore need to be informed of their potential role through listening with respect and through empathy.

Our findings showed that families with good dynamics before the loss shared their grief and were brought closer together. The loss of a close family member has been shown to affect family interaction (Stroebe et al., 2013) and also create a need for reorganizing the family structure (A. Dyregrov & Dyregrov, 2015; Stroebe & Schut, 2015). A. Dyregrov and Dyregrov (2015) studied bereaved parents' perceptions of their relationship following the loss of a child. Our study supports their findings that talking together and communicating thoughts and feelings aid adjustment on a family level. Many divorced parents in our study were in conflict before the death; lack of mutual understanding and respect between former partners seems likely to hinder adjustment and complicate their relationships after the loss.

However, only a few of the participants in our study were offered participation in support groups. The parents stated that talking to other bereaved who had experienced DRD could be an important coping strategy and called for efforts to organize support groups specifically for drug-death bereaved. Bartone et al. (2019) synthesized studies regarding benefits of peer-support services for bereaved of sudden or unexpected deaths. These authors showed that peer support is beneficial in reducing grief symptoms and increasing well-being and personal growth. Peer support appears to be especially valuable for bereaved following suicide loss, a result that may be related to stigma. In addition, the study by Feigelman et al. (2018) of drug-death-bereaved parents, helping others by facilitating support was described as an important meaning-making strategy. Whether or how drug-death-bereaved parents benefit from facilitating and/or participate in peer-support groups is therefore an important topic for further investigation.

Methodological Issues

To improve methodological rigor, we have restoration-orientation a transparent and clear description of the research process from the initial outline through the development of the methods and the reporting of the findings. Reflexive journals were written after each in-depth interview, containing information about our subjective responses to the setting and the participants. In addition, the results section contains key, illustrative, verbatim extracts from the interviews. Describing reflexivity is important to enhance a study's validity. As recommended in standards for reporting qualitative research (Malterud, 2001; O'Brien et al., 2014), we described the characteristics and the role of the researchers in the article. We argue that the checklist for reporting standards strengthens the transparency of this study and enhances the transferability of its findings to other contexts.

One strength of this study is the wide use of different recruitment strategies. Nevertheless, despite our efforts to recruit bereaved parents from all classes in society, the risk of sampling bias is present, particularly given that people from lower social classes are underrepresented. On the other hand, the size of our study sample has sufficient information power, in accordance with Malterud et al. (2016) descriptions.

Conclusion and Implications for Practice and Policy

The aim of the present research was to examine how drug-death-bereaved parents adjusted to life without their deceased child and what seemed to inhibit or promote adaptation during their grieving process. The parents essentially helped themselves using proactive coping strategies, and the family stressor of being needed by others was described as the most important factor in the meaning-making process. They oscillated between loss-orientation and restoration-orientation strategies, and flexibility between different strategies seemed to promote adaption. There were parents in this study who still struggled with reorientation to the new life circumstances. There is a need to pay special attention to the parents who experience an enduring overload before and after the death, to those who ruminate persistently about their own guilt, and finally, to those who describe their grief process as one of being stuck in either rumination or avoidance.

There is call for attention to dissemination of better knowledge about DRD, to reduce perceived stigma and facilitate peer-support groups for drug-death bereaved. The bereaved themselves need increased knowledge about addiction to narcotics to help them understand what happened to their child. All the parents, except one, had to ask for help, and some were even not given it. Those who got help emphasized that individual therapy promoted coping with the loss. In therapy, they learned how to understand grief reactions and strategies to cope with the emotional burden, self-perceived guilt as well as coping strategies for day-to-day living. The Norwegian white paper *The Psychosocial Interventions in the event of Crisis, Accidents and Disasters* recommends action plans for follow-up in the municipalities after a sudden and potentially traumatic death (Norwegian Directorate of Health, 2016, pp. 31–35). The main features of the plans are early and active outreach, broad spectra and adapted help for all family members, and help over time. Help from health and social services based on existing guidelines needs to be readily available to avoid intense grief reactions and promote adaptive coping strategies.

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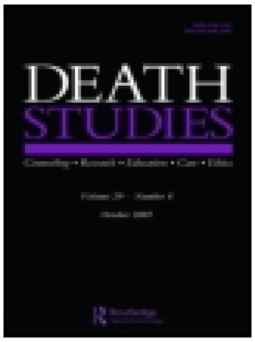
Author Biographies

Kristine B. Titlestad, PhD student, is a social educator who has continuing education in supervision and clinical milieu therapy and a master in evidence-based practice in health care. She is a mother and has a sister with moderate intellectual disability who has severe need for help to activities of daily living. Her father was dying when she was doing the interviews with the bereaved parents, and she lost her father in the period she was writing this article. She is a member of the project group Drug-Death-Related Bereavement and Recovery (in Norwegian called the END-project). This article is one of the two articles describing parents' experiences after drug-related death in her PhD thesis.

Margaret Stroebe, professor, PhD, has long research experience in the bereavement field and has written several articles about the dual process model of coping with bereavement (Stroebe & Schut, 1999, 2010, 2016). She is a member of the advisory board in the END-project.

Kari Dyregrov, professor, PhD, has long research experience in the bereavement field, both theoretical and empirical, and has developed a theoretical model for how to understand drug death (K. Dyregrov et al., 2019). She has interviewed parents and siblings bereaved after drug-related death. She is the project leader of the END-project.

IV



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Prevalence and predictors of prolonged grief symptoms among those bereaved from a drug-related death in a convenience sample of Norwegian parents: A cross-sectional study

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ABSTRACT

Drug-death bereaved parents are at risk of high levels of prolonged grief (PG) symptoms. We included 93 Norwegian drug-death bereaved parents in a cross-sectional survey and aimed to explain PG symptoms. High levels of PG symptoms ($M = 30.69$) were identified. Low level of self-efficacy and withdrawal from others were the most strongly associated with high levels of grief symptoms ($p < .001$). However, contrary to our expectations, social support, gender, employment, demanding life situations, and perceived proximity did not correlate significantly to PG symptoms. Our findings can enhance individual follow-up of drug-death bereaved parents.

Throughout life, many people will experience traumatic events like the unexpected loss of a next of kin. Traumatic loss may cause grief symptoms that severely affect those bereaved for long periods of time, but most people will deal with and adjust to life after such an experience (Bonanno et al., 2002; Galatzer-Levy et al., 2018; Stroebe et al., 2017). Dr. George Bonanno defines a stable path of healthy functioning after a highly challenging event as "resilience" (Southwick et al., 2014). Some people can move on with their lives and eventually maintain their levels of functioning, whereas others struggle to a greater extent. This is due to the ability to combine several coping strategies when unexpected challenges occur, namely the so-called regulatory flexibility (Bonanno, 2013; Mancini & Bonanno, 2009). In this context, we think of coping as strategies, but also as processes or styles of managing the bereavement. We define coping as the "changing thoughts and acts that an individual uses to manage the external or internal demands of stressful situations" (Folkman, 2001, p. 565).

Bonanno and Burton (2013) described three sequential components of regulatory flexibility: sensitivity toward demands and opportunities in the situational context; an available repertoire of regulatory strategies; and the ability to monitor and modify feedback (adjusting, maintaining, or ceasing strategy). Self-efficacy can contain many of the elements described as components of regulatory flexibility. Bandura (1982) describes self-efficacy as the perception that a person has on their capability to react effectively and functionally to environmental demands. Thus, self-efficacy and resilience can be considered personality resources that can influence how a person copes with a loss. To our knowledge, self-efficacy and resilience have not been systematically investigated in bereavement studies in recent years. Nevertheless, a study of healthy students' coping styles by Konaszewski et al. (2019) showed that resilience and self-efficacy were strongly and positively connected with problem-focused coping and that resilience can be a significant predictor in terms of seeking contact with others.

As mentioned, bereavement can have complications. The bereaved who experience grief, characterized by yearning and longing, persistent preoccupations, symptoms of intense emotional pain, and significant psychosocial impairment for a minimum of six months beyond the expected sociocultural norms, meet the criteria of Prolonged Grief Disorder (PGD) (WHO, 2020). PGD is regarded as a new mental health disorder in the 11th edition of the International Classification of Diseases (ICD-11) and presupposes severe functional disability. Several

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limitations are discussed about PGD prevalence studies, response bias (e.g., self-reported questionnaire data collected through a clinical tool), different criteria for PGD between tools, and sampling/selection bias due to small sample sizes and random recruitment procedures (Djelantik et al., 2020). We argue that with the lack of consensus relating to a diagnostic instrument and a cutoff score it is complicated to estimate the prevalence of PGD, and therefore, we state how many parents who filled the criteria for PGD but choose to examine the prevalence of prolonged grief (PG) symptoms.

Drug-Related Deaths (DRDs) are unnatural deaths (i.e., sudden unexpected death (Li et al., 2003). Considering the Norwegian Directorate of Health (2014), we defined DRDs as deaths caused by the intake of substances, classed as narcotics and deaths among people who use narcotics where the cause of death is violence, an accident, infectious disease, or other health disorders, which may be linked to drug use in various ways. In the US, 67,367 people died of an overdose in 2018 (20.7 per 100,000) (Centers for Disease Control and Prevention, 2020) and Norway, has one of the highest reported prevalence rates of DRDs in Europe (5.4 per 100,000 in 2018) (Norwegian Directorate of Health, 2019, p. 5; The Norwegian Institute of Public Health, 2019). Despite the high rates of DRDs, the only systematic review published about drug-death bereavement shows that the topic is scarcely investigated (Titlestad et al., 2019). The systematic review identified one quantitative and eight qualitative studies of good methodological quality. It showed that those bereaved from DRDs perceived a massive emotional impact, increased stigma, and a lack of help and understanding.

The heightened interest in studying the correlations between potential risk or protective factors of PGD has resulted in several systematic reviews of bereavement following other unnatural deaths (Djelantik et al., 2020; Heeke et al., 2019). Heeke et al. (2019) found small associations between PG symptoms and socio-demographic characteristics, such as female gender, a low standard of education, unemployment, the loss of an only child in addition to multiple losses, religious beliefs, and somatic/physical symptoms. Traumatic events, attachment anxiety, and the relationship to the deceased showed medium-sized associations, while large associations were found in the case of comorbid psychopathology and rumination. Heeke et al. (2019) did not find that time since the loss was significantly associated with PGD symptoms, while the systematic review of Djelantik et al. (2020) showed that a long time since the loss was associated with a lower prevalence of PGD. Djelantik et al. (2020) maintained that the death of an only child and violent killings were significant predictors of a higher prevalence of PGD, and social support was reported to be a protective factor after a traumatic event.

Recently two qualitative studies about drug-death bereaved parents have been published (Titlestad, Mellingen, et al., 2020; Titlestad, Stroebe, et al., 2020). Norwegian parents described their grief and how they adjusted to life after their loss in a series of interviews.

Table 1. Demographic characteristics for the included parents.

Variables	Total ($n = 93$)
Men/woman ($n = 93$), n (%)	17 (18.3)/76 (81.7)
Level of education ($n = 93$), n (%)	
Primary school	10 (10.8)
High school	29 (31.2)
College/university	45 (48.4)
Other	9 (9.7)
Employment ($n = 93$), n (%)	
Full-time job	31 (33.3)
Part-time job	13 (14.0)
On sick leave	4 (4.3)
Retired	23 (24.7)
Studying	1 (1.1)
Other	22 (22.6)
Sick leave before death ($n = 92$), n (%)	34 (36.6)
Sick leave after death ($n = 92$), n (%)	69 (74.2)
The closeness of kinship with the deceased ($n = 91$), n (%)	
Very close	79 (84.9)
Close	8 (8.6)
Somewhat close	3 (3.2)

	M	SD	Md	range
Age (years) ($n = 90$)	59.36	7.12	59	45-80
Demanding life loads ($n = 93$)	4.73	6.31	3	0-50
Number of loss due to DRD ($n = 93$)	1.17	0.48	1	1-4
Months since loss ($n = 92$)	79.53	80.44	59	3-420

Before the loss, the parents experienced public stigma and a constant fear of death, and after death, the self-induced stigma was the most challenging reaction. They also described complex and ambivalent emotions such as anger, guilt, and shock after their loss and complicated relationships with public services and their social networks (Titlestad, Mellingen, et al., 2020). Titlestad, Stroebe, et al. (2020) suggested the need to pay special attention to parents who experience an enduring overload before and after the death, who ruminate persistently about their guilt and describe their grief process of being stuck in rumination or avoidance. The parents adjusted to life by oscillating between stressors like being needed by other family members and proactive coping. The parents reported challenges regarding communication with networks and services and called for peer-support groups.

Dyregrov et al. (2003) found that self-isolation was the strongest predictor of psychosocial distress in parents bereaved by unnatural deaths. Losing a child can be more intense and prolonged than other losses, and bereaved parents are at risk of developing PGD (Kersting et al., 2011). Coping with grief following a child's death can negatively impact the parents' health significantly and is associated with increased mortality risks (Albuquerque et al., 2016; Song et al., 2019). A recent registry study from Norway support increased risk of mortality also for parents bereaved by DRDs when compared with nonbereaved parents or parents bereaved by other causes of death (Christiansen et al., 2020). This study also indicates that bereavement by DRDs is associated with adverse negative health outcomes that may be more severe than general bereavement due to the cause of death. Clearly, there is a need to acknowledge the situation of bereaved parents left behind after DRDs. More research is needed so the bereaved who are at risk of PGD can be identified. Particularly quantitative research can enhance knowledge of grief symptoms associated with DRD bereavement and illuminate the predictors for such symptoms.

The purpose of this study was to investigate whether Norwegian parents bereaved from DRDs suffer PG symptoms as measured by PG-13 and, if so, which predictors are key to explaining their high levels of PG symptoms. There are two primary aims: (1) to map the prevalence of PG symptoms in a convenience sample of parents bereaved from a DRD, (2) to examine which predictors are most important in explaining parents' high levels of PG symptoms in relation to self-efficacy, perceived support and other moderators and mediators identified in previous studies of unnatural deaths. Based on previous literature relating to those bereaved following an unnatural death and qualitative research on parents bereaved by DRDs, we hypothesized that socio-demographic characteristics, such as female gender, a low standard of education, unemployment, demanding life loads, a short time since death, and a close relationship, would result in high levels PG symptoms. Furthermore, we hypothesized that low scores in terms of self-efficacy and social support predicted a high score on PG-13.

Method

Design

This study has a cross-sectional, descriptive, correlational design, based on data from a nationwide Norwegian study obtained from the drug-death related bereavement and recovery project (in Norwegian, "The END-project").

Setting

Context. The END-project was launched in the spring of 2017 at the Western Norway University of Applied Sciences. The END-project's primary purpose was to contribute to a greater understanding of the consequences and the care needs of drug-death bereaved. The project was approved in February 2018 by the Norwegian Regional Committees for Medical and Health Research Ethics (reference number 2017/2486/REK vest) and applied mixed methods through a parallel collection of quantitative data, using a survey and qualitative data by conducting semi-structured interviews (ResearchGate, 2020).

Procedure

From March 2018 until the end of December 2018, we invited drug-death bereaved family members and friends to participate in the main project. A flyer detailing the project was sent to all Norwegian municipalities' public e-mail addresses, and we contacted governmental and non-governmental personnel associated with organizations working with those affected by drug use. We disseminated information about the project through municipal medical officers and crisis responders all over the country, using research networks and professionals in clinical practice, participation in conferences, various media channels, such as television, radio and social media (Facebook and Twitter) as well as via "Snowball recruitment". The participants were invited to fill in a questionnaire, either on paper via post or digitally via e-mail. The participants received an e-mail reminder after 14 days. All participants signed a written, informed consent form that described the study's purpose, method, and procedure, and we informed the participants that published data would be non-identifiable.

Participants

The inclusion criteria for this study stipulated that the participant had lost a child due to a DRD at least three months before recruitment. No other restrictions were set for the time since death.

A total sample of parents (*N* = 95) was enrolled. We excluded two participants who had more than 25% of missing responses in relation to PG-13. The 93 included parents had lost either a daughter (*n* = 21, 22.6%) or a son (*n* = 72, 77.4%). The average age of the deceased was 26.86 (SD = 6.431, range 18–45). The demographic characteristics of the parents are summarized in Table 1.

Measurements

The END-project survey has 22 background variables and 79 variables from different questionnaires (standardized and open questions). The results from the systematic reviews about unnatural deaths and the two qualitative studies involving parents bereaved from a DRD (Titlestad, Mellingen, et al., 2020; Titlestad, Stroebe, et al., 2020) formed the backdrop for our choice of variables.

The background variables included were gender, time since loss, level of education, employment, sick leave before and after death, number of DRDs, demanding life stresses, and relational closeness. Variables like relational closeness were rated on a 5-point Likert scale, scoring 1–5 (e.g., "Not at all close" to "Very close").

Prolonged grief. The Prolonged Grief Disorder-13 (PG-13, Prigerson & Maciejewski, n.d.) is a criterion-based diagnostic tool developed by Prigerson et al. (2009) that assesses the symptoms of PG. The instrument consists of 13 items and is scored as a continuous measure by summing the 11 symptom items (cognitive, behavioral, and emotional), i.e., the dichotomous time- and functional criteria are not included in the sum-score but must be fulfilled for the PGD diagnosis. The items are rated on a 5-point Likert scale, scoring 1–5. Four items range from "Not at all" to "Several times a day," while the next seven items are rated on an intensity scale ranging from "Not at all" to "Overwhelmingly" (Prigerson & Maciejewski, n.d.). The total score ranges from 11 to 55, with higher scores indicating more severe grief symptoms. There is no official cut-off score, but a Swedish research group, including one of the developers of PG-13, Holly G. Prigerson, suggested a preliminary cutoff score of 35 or more, which meets the diagnostic criteria for PGD (Pohlkamp et al., 2018). Internal consistency for PG-13 in the current study was good, Cronbach's alpha (α) .893.

Self-efficacy. The General Self-Efficacy Scale-SF (GSE-SF, Schwarzer & Jerusalem, 1995) measures self-efficacy and was applied to explore whether low levels of self-efficacy are a predictor of high levels of PG symptoms. GSE was developed to measure optimistic self-beliefs in relation to coping with a variety of challenging demands in life. The Norwegian short form (SF) version is validated by Tambs and Røysamb (2014) and consists of five questions, scoring 1–4, from "Not at all true" to "Exactly true," with higher scores indicating high levels of self-efficacy. Internal consistency for GSE-SF in the current study was good, α .851.

Grief experiences. The Special Grief Questions (SGQ, Dyregrov et al., 2020) explore various experiences after losing a next of kin as a result of a DRD. SGQ is not a scale with a sum score or a cutoff score. The 16 single items measure aspects of anxiety/fear of death, anticipated grief, self-condemnation/stigma/guilt/shame, ambivalence (relief/guilt for feeling relieved), and disenfranchized grief. This study included items that explore fear of death, stigma, complex emotions such as guilt, anger, relief, blame and shame, and open and closed communication items. The items are rated on a 5-point Likert scale ranging from "Almost never" to "Almost always," scoring 1–5, with higher scores in each item indicating high levels of grief symptoms.

Crisis support. The Crisis Support Scale (CSS, Elklit et al., 2001) measures informal networks' social support after a crisis. We wanted to investigate whether low levels of support constitute a predictor of high levels of PG symptoms. CSS consists of seven items with a rating scale from "Never" to "Always," scoring 1–7. All items are summed for a total mean score; a higher total score indicates more support received. Internal consistency for CSS was acceptable, α .709.

Bereavement assistance. The Assistance Questionnaire (AQ, Dyregrov, 2002) has previously been used to research people bereaved from unnatural

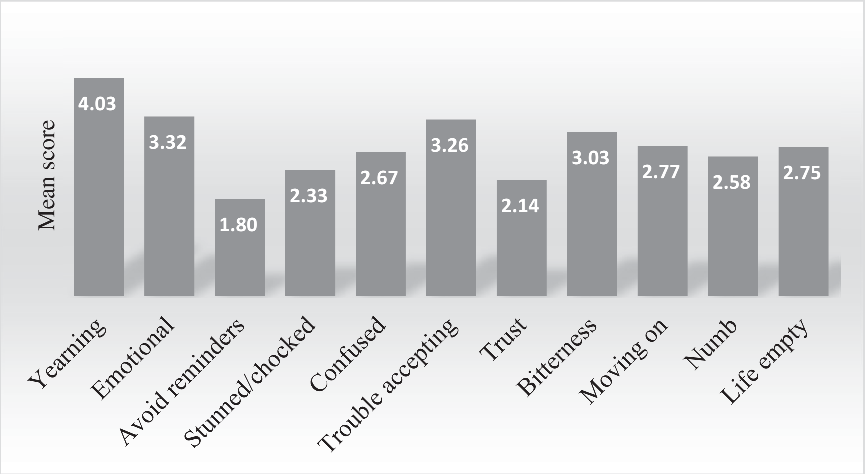

Figure 1. Mean score for PG-13 items rated on a 5-point Likert scale scoring 1 (low) to 5 (high).

deaths. This instrument contains 22 questions assessing how the bereaved report their experiences and their need for help and support. AQ is not treated as a scale with a sum score or a cutoff score. We analyzed two items; "I have experienced that others have withdrawn," and "I have withdrawn more from others." The items are rated on a 5-point Likert scale ranging from "Not at all" to "To a great extent," scoring 1–5.

Statistical analysis

Statistical analyses were performed using *IBM SPSS Statistics* version 26 (IBM Corp, 2019). Continuous variables were described by means (M), standard deviations (SD), medians (Mdn) and range, whereas frequencies and percentages described categorical variables. PG-13 sum-score was chosen as the dependent variable since the prevalence of PG symptoms and predictors for high levels of symptoms constitute the primary outcome of our analyses. At least 75% of the items in PG-13 had to be completed in order for participants to be included in the study. Missing scores were imputed by replacing with the individuals' mean for all items completed, (for PG-13, $n = 3$ [one missing], $n = 1$ [two missing]; for GSE-SF, $n = 1$ [one missing] and excluded for analysis including GSE-SF $n = 1$ [more than 25% missing] and for CSS, $n = 4$ [one missing]). No replacement was provided for background variables, SGQ, and AQ items.

We compared the same child's biological parents' data through cluster analyses to evaluate dependency in the data, as bereaved parents of the same child participated (i.e., seven pairs [$n = 14$]). The analysis indicated that the parents had responded independently.

We conducted descriptive analyses on the sample's demographic characteristics and mean sum scores for the PG-13 scale. Scatterplots, Spearman's correlation coefficient rho for categorical variables, and Pearson's *r* for continuous variables were created to screen for associations between PG-13 and the potential explanatory variables (covariates). The plots did not reveal any outliers or extreme scores. We applied a three-step procedure to identify the strongest associations between a covariate and the outcome variable, PG-13. Step 1 was to perform univariate linear regression analyses. Step 2 was to perform a multivariate linear regression, called Model 1, including only statistically significant variables at a 0.2 significance level in the univariate regression analyses. To retain the most important covariates and increase the precision of the estimated regression coefficients, Step 3 was carried out, including only variables from Step 2 that were significant at a 0.05 level (Model 2). Standardized regression coefficients (β) with corresponding p-values are presented for all regression analyses. For Model 1 and 2, we also present unstandardized regression coefficients (B) with 95% confidence intervals (CI).

Results

The parents' average PG-13 sum score was 30.69 ($SD = 8.89$); the score ranged from 15–49. The mean sum score for the mothers was 31.06 ($SD = 8.34$) and for the fathers, 29.02 ($SD = 11.18$), while the mean item score for the scale was 2.79 ($SD = 0.81$). Twenty-six (28%) of the individuals had scores equal to 35 or higher, and 20 (22%) reported symptoms daily for at least six months. The mean score for each item is shown in Figure 1 and shows that on a group level, the participants scored highest on the item assessing

Table 2. Predictors associated with PG-13 as estimated with linear regression.

		Univariate		Multivariate Model 1[a]				Multivariate Model 2[b]			
Variable	*n*	β	*p*	β	*B*	95% CI	*p*	β	*B*	95% CI	*p*
Age	90*	−.30	**.004**	−.05	−.06	[−.29, .17]	.596				
Gender	93	−.09	.397								
Level of education	93	−.17	**.107**	−.18	−1.97	[−3.89, .05]	**.044**	−.17	−1.81	[−3.55, −.07]	**.042**
Employment	93	.13	.234								
Demanding life loads	93	−.11	.312								
Number of loss due to DRD	93	−.14	**.181**	−.10	−1.81	[−4.86, 1.23]	.239				
Months since loss	92*	−.27	**.009**	−.28	−.03	[−.05, −.01]	**.003**	−.23	−.03	[−.04, −.01]	**.005**
Close kinship	93	.03	.773								
Sick leave before death	92*	.08	.435								
Sick leave after death	92*	.15	**.164**	.07	1.42	[−2.16, 5.00]	.431				
General Self-Efficacy Scale-SF	92*	−.52	**<.001**	−.27	−.90	[−1.52, −.28]	**.005**	−.37	−1.23	[−1.80, −.66]	**<.001**
The Crisis Support Scale	93	−.24	**.022**	−.11	−.12	[−.36, .11]	.298				
Fear disturbed night sleep ([c]SGQ)	92*	.28	**.006**	.11	.69	[−.45, 1.81]	.231				
Relieved ([c]SGQ)	89*	−.26	**.016**	−.04	−.25	[−1.31, .81]	.642				
Blame myself ([c]SGQ)	92*	.29	**.005**	.16	1.02	[−.15, 2.18]	.086				
Ashamed to talk openly ([c]SGQ)	92*	.21	**.041**	−.05	−.37	[−1.67, .94]	.579				
Others talk about me ([c]SGQ)	90*	.27	**.011**	.05	.37	[−1.39, 2.12]	.676				
Others have withdrawn ([d]AQ)	92*	.29	**.006**	.06	.48	[−1.12, 2.07]	.553				
I have withdrawn ([d]AQ)	92*	.50	**<.001**	.27	2.13	[.70, 3.56]	**.004**	.35	2.73	[1.41, 4.04]	**<.001**

β: standardized estimated regression coefficient; *B:* estimated regression coefficient.
[a] Model 1 included variables statistically significant at a 0.2 level in univariate analyses.
[b] Model 2 included variables statistically significant at a 0.05 level in Model 1.
[c] Single item from Special Grief Questions (SGQ).
[d] Single item from The Assistance Questionnaire (AQ).
*Sample size smaller due to missing items.
Univariate analyses: Bold values indicate results at a 0.2 level. Model 1: Bold values indicate results at a 0.05 level.

longing or yearning for the person they lost ("Yearning") and second-highest on the item loading intense feelings of emotional pain, sorrow or pangs of grief related to the loss ("Emotional"). The lowest score was associated with trying to avoid reminders that the person you lost is gone ("Avoiding reminders"), and the second-lowest score related to whether the bereaved had found it difficult to trust others since the loss of their loved one ("Trust").

Six of the SGQ items correlated positively with PG-13. Two of the six items explored relief, and due to the many variables for Modell analyses, the variable with the lowest β was excluded (Excluded "I feel guilty for feeling relief with regard to the death" $M = 2.28$, $SD = 1.43$; the following was included, "I feel relieved that he/she escaped from a difficult life" $M = 2.69$, $SD = 1.46$). Associations between symptoms of PG and selected contributing variables are shown in Table 2. Correlation analyses were used to screen for associations, and since a correlation and linear univariate regression analysis is the same when there is only one dependent variable, we present only β-values in the table. The R Square for Model 1 was .550, denoting that the model explains 55% of PG symptoms variance. The model was statistically significant, $p < .001$ ($F = 6.276$). Four variables were included in Model 2: level of education; months since loss; General Self-Efficacy Scale-SF; I have withdrawn (all significant at a .05 level). Model 2 explained 45.3% (statistic significant $p < .001$, $F = 17.823$) of the total variance of the dependent variable sum PG-13. The strongest association was found between a high score on PG-13 and low levels of self-efficacy and the experience of having withdrawn from others.

Discussion

The current study aimed to investigate the prevalence of Prolonged Grief (PG) symptoms and identify predictors of symptoms among Norwegian parents who had experienced DRDs. As measured by the sum-scores of PG-13, high levels of PG symptoms ($M = 30.69$, $SD = 8.89$), were found. Contrary to our expectations, socio-demographic characteristics like gender, employment, number of demanding life situations, and perceived proximity to the deceased did not correlate significantly to the level of PG symptoms. Another unanticipated finding was that the lack of social support was not a statistically significant predictor in explaining high levels of PG. As expected, a short time since death, low levels of self-efficacy, and withdrawal from others were associated with a high level of PG symptoms.

The fact that men and women grieve differently is well documented in bereavement literature (Doka & Martin, 2002), studies about unnatural deaths (Feigelman et al., 2011) and after losing a child (Dyregrov & Dyregrov, 2015). Mothers tend to grief more intense and have a more pronounced need to talk about the loss, while the men might block thoughts by doing practical tasks and trying to distract themselves when unpleasant thoughts or feelings appear (Dyregrov & Dyregrov, 2015). In our study, mothers reported somewhat higher levels of PG symptoms than fathers. Though the regression analysis did not support that gender is associated with the level of grief symptoms. Women were overrepresented in our study (81.7%). The fact that women are predominantly represented in the literature is in accordance with previous studies on this population (Feigelman et al., 2011). The results from a gender comparison could have helped identify whether drug-death bereaved mothers and fathers grieve differently, but with such a skewed selection, a comparison would have led to sample bias. Thus, it is difficult to conclude from the results whether mothers or fathers grieve differently.

We identified withdrawal from others and low self-efficacy levels as important personality resources associated with high levels of PG symptoms. Our results reflect those of Dyregrov et al. (2003), who found that self-isolation was the strongest predictor of psychosocial distress in their study of parents bereaved by other unnatural deaths, and Konaszewski et al. (2019), who found a strong positive correlation between self-efficacy and problem-focused coping among university students. With this knowledge combined, there are reasons to argue that withdrawal and low self-efficacy are not compatible with an extensive repertoire of regulatory flexibility strategies and context-sensitivity in coping. Thus, our results might indicate that the parents with the highest PG symptoms also struggle with regulatory flexibility. Therefore, our results suggest that resilience may be of great importance for further study to understand what characterizes regulatory flexibility among parents bereaved from a DRD.

Moreover, the adaptive value of flexibility is also relevant to the question of meaning making (Bonanno, 2013). In previous studies, parents bereaved from a DRD have reported an ambivalent situation of feeling pain on the one hand and relief on the other hand when death occurs (da Silva et al., 2007; Feigelman et al., 2011). The mean score for the SGQ items that measure relief showed that most parents reported relief to some extent. However, a negative correlation was identified between PG symptoms and the feeling of relief, indicating that parents who struggle with high level of grief symptoms do not feel relief at all. Yearning is a symptom that loads highly on the grief factor and is a symptom that is described as crucial to uncover as yearning is an important marker that can help clinicians differentiate grief complications from depression (Prigerson et al., 2009). The PG-13 item with the highest mean score was “How often have you felt yourself longing or yearning for the person you lost,” which suggests that yearning for the deceased is a PG core symptom also in parents’ bereaved from a DRD. The examination of meaning making after the loss of a child, carried out by Lichtenthal et al. (2010) revealed that 45% of the parents could not make sense of the loss of their loved one and that these parents were four times more likely to suffer from PGD. Lichtenthal et al. (2010) suggest that screening for deficits in meaning making may help determine which parents would benefit from psychosocial services. As making sense of loss is difficult for the parents in our study, we wish to emphasize the importance of screening for yearning and the lack of relief to identify the parents who struggle most.

The concept of avoidance has certain aspects worthy of further study, in addition to avoiding the fact that the person is gone (i.e., PG-13 item). Avoidance has been suggested to be a weak marker of traumatic grief (Prigerson et al., 1999). In a study of bereaved spouses and children, Maccallum et al. (2017) explored the relationships between symptoms of PG and found that avoidance appeared relatively unconnected to other PG symptoms, as measured by PG-13. Our study supports these findings concerning the PG-13 item, with the lowest mean score in our study being the avoidance item (“tried to avoid reminders that a loved one is gone”). Titlestad, Stroebe, et al. (2020) described how avoidance inhibited and promoted life adjustment. Therefore, results from both interviews and this survey support the findings of Maccallum et al. (2017), who advocate the need to adopt a more nuanced approach to understanding avoidance in PG and investigate whether the item is capturing what is intended.

Our study’s finding is consistent with previous research summarized by Djelantik et al. (2020), which showed that grief symptoms naturally decrease over time. The negative association between higher PG symptoms and months since the loss indicates that most of those bereaved following a DRD eventually adjusted to the loss and returned to adaptive functioning.

Surprisingly, the results did not confirm our assumption of a relationship between high social support levels and low scores for PG-13. This outcome contradicts the findings in many previous studies in which the general assumption is that social support will be a protective factor for the bereaved following an unnatural death (Dyregrov & Dyregrov, 2015). Bartone et al. (2019) also reported that peer support reduces grief symptoms in their systematic review. With these studies' results in mind, our data must be interpreted with caution. We believe that data from qualitative interviews can help identify and describe the social interaction between the bereaved and their network. There are several factors and processes that may explain why social support is not significantly associated with PG symptoms in our study (other than the factors that we measured the level of support by CSS). In the qualitative studies by Titlestad, Mellingen, et al. (2020) and Titlestad, Stroebe, et al. (2020), parents bereaved from DRDs reported that relating to other people was difficult due to stigma, self-induced stigma, and challenging communication with the network. Positive associations were found in the univariate regression analyses between PG-13 and SGQ items such as "I blame myself for the death" and "Others talk about me." Thus, we ponder whether self-induced stigma of blaming oneself and perceived stigma can contribute to a challenging type of communication for both the bereaved and their network. Based on previous literature findings and the results from the qualitative interviews, we suggest that it may be fruitful to explore the potential benefits of tailored support groups for parents bereaved from a DRD.

Methodological issues

This present study is the first study investigating PG symptoms among parents bereaved from a DRD. Since we were researching an unstudied field, it was challenging to identify the most critical predictors to investigate. We argue that we, through our knowledge of bereavement and unnatural deaths, chose variables that were important to explore in relation to this population. However, we still acknowledge that several other aspects regarding drug-death bereavement must be investigated. Significantly, we recognize that the item mapping consequences of an only child's death should have been included, as such a death has been documented as a significant predictor in other studies of unnatural deaths (e.g. Dyregrov et al., 2003).

The cross-sectional design has its limits, as it may be challenging to determine whether the exposure or the outcome comes first. Therefore, when using the concept predictors resulting from regression analysis, we document associations and not causality of our findings (e.g., the finding of withdrawal from others as a predictor of possible PGD). We also highlight that the prevalence is derived from a convenience sample, depending on the recruitment method, thus limiting the findings' generalizability. As no data from the registry of bereaved parents were available, we sought to recruit widely by all possible means for one year, resulting in the world's largest sample of parents bereaved from a DRD. Although serious life events are often remembered with great clarity, recall bias might have occurred, as many parents lost their loved one a long time ago or the average time since the loss was high. PG-13 is a diagnostic tool used by clinicians in structured clinical interviews; however, we used it to collect self-reported data. Assumptions relating to meeting criteria for the disorders should, therefore, not be made. However, the fact that the present study has used a valid and well-known instrument is a strength, and the choice of variables, amongst others, builds on the qualitative interviews with the parents and the fact that we have used validated instruments such as PG-13, GSE, and CSS.

Conclusion and implications for practice

The results in this study show that those bereaved from DRDs in many ways share the same experiences as others bereaved by unnatural deaths, though the results in our study highlight associations that may be significant for those bereaved from DRDs. As self-efficacy is the strongest predictor of PG symptoms, we maintain that the belief in oneself could have been negatively affected after many years of living with a possible societal stigma and an enduring overload before and after the death. Even though we do not assume that particular strategies are consistently beneficial or maladaptive, high self-efficacy levels can be the most important personal resource in coping with DRDs and a critical regulatory flexibility component.

To prevent social marginalization, it is crucial to pay special attention to those bereaved from DRDs. Considering our findings, we believe that there is a need for psychotherapeutic measures to be provided to individuals so that the bereaved can increase their self-efficacy, hinder withdrawal from others, and thus inhibit prolonged grief complications. As time since the loss is associated with a reduction in PG symptoms, there is a need for research that explores the trajectories of the loss of a loved one to a DRD, its effect on the bereaved, and the period required for most bereaved parents to adjust to the loss eventually. That would be a helpful tool in offering the necessary help and understanding, preventing the development of more prolonged and comprehensive grief symptoms, and reducing the risk of developing PGD.

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The authors declare no conflict of interest.

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Appendix I

TEMAGUIDE FOR INTERVJU (FAMILIE)

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?

Appendix II

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

Appendix III

Høgskulen
på Vestlandet

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

ETTERLATTE VED NARKOTIKARELATERT DØD (END)
- 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 sosialvitskap 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, mars 2018

Kari Dyregrov

Professor Kari Dyregrov
Prosjektleder

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

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

☐ Jeg ønsker tilsendt papirversjon av spørreskjema. Adressen er:_______________________________________

☐ Jeg ønsker tilsendt link til elektronisk spørreskjema. Mailadresse er:_________________________________

Sted og dato Deltakers signatur

Deltakers navn med trykte bokstaver

JEG ER <u>OGSÅ</u> 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 IV

Høgskulen
på Vestlandet

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET
ETTERLATTE VED NARKOTIKARELATERT DØD
- DYBDEINTERVJU

Dette er en henvendelse til deg som har mistet noen i narkotikarelatert død om å delta i et forskningsprosjekt. Du har svart på et spørreskjema i forskningsprosjektet og skriftlig samtykket til at vi kan ta kontakt for et intervju. Vi spør deg om å delta fordi du er et nært familiemedlem.

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 sosialvitskap og ledes av professor Kari Dyregrov.

HVA INNEBÆRER DELTAGELSE I PROSJEKTET?

Du deltar i forskningsprosjektet ved å delta i et dybdeintervju. Tilstede ved intervjuet vil det være forskere i prosjektet som har erfaring med slike intervju. Spørsmålene kartlegger din opplevelse av hvordan det er å ha mistet nærstående ved narkotikarelatert død. 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. Intervjuet vil foregå på et rolig avskjermet sted som vi blir enige om og intervjuet vil vare i to til tre timer inklusive pauser. Alle intervju vil tas opp på lydfiler, skrevet ordrett ut for å bli analysert, og oppbevart trygt på avlåst sted i henhold til HVL sine forskningsetiske retningslinjer.

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.

De fleste opplever det som meningsfullt å delta i personlige intervju. For noen kan også det å svare på spørsmål 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. Dette samtykkeskjemaet med underskrift tar du med til intervjuet.

HVA SKJER MED INFORMASJONEN OM DEG?

Opplysninger og data fra intervju, vil bli oppbevart i henhold til HVL sine forskningsetiske retningslinjer. Dette innebærer at lydfiler fra intervju og utskrevne intervju 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, samt lydopptak 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

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET VED Å DELTA PÅ INTERVJU

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver