Journal of grief and responses to death

# Bereavement support after a drugrelated death in Norway: Professional perspectives

#### Monika Alvestada Reime

Faculty of Health and Social Sciences, Western Norway University of Applied Sciences, Bergen, Norway Monika.alvestad.reime@hvl.no

#### **Birthe Møgster**

Faculty of Health and Social Sciences, Western Norway University of Applied Sciences, Bergen, Norway

#### Kjersti Halvorsen

Faculty of Economy and Social Sciences. Western Norway University of Applied Sciences, Bergen, Norway

**Keywords:** bereavement support, professional help, drug-related death, grief, 'special death'

#### Implications for practice

- Among health and welfare professionals, more awareness is needed to identify bereaved clients in need of support and to support them and/or refer them for appropriate treatment.
- Professionals in health and welfare services need more general knowledge about grief, including grief after a 'special death', and about the symptoms of complicated bereavement processes.
- Professionals in substance use services are likely to encounter many clients with experiences of loss and grief and thus need the competence and confidence to address these issues in their daily practice.
- More research is needed into the content and effects of bereavement support and how to best support and equip those professionals encountering the bereaved after a drugrelated death.

#### **Abstract**

After a drug-related death, the bereaved are at risk of severe social and health consequences, but their need for professional support in their bereavement processes often falls under the radar. The bereaved themselves ask for continued support, and the research shows significant symptoms of prolonged grief for years after the loss. This article explores professionals' perspectives on providing bereavement support to bereaved clients after a drug-related death. The article builds on focus group interviews with professionals from different health and welfare services in Norway who are likely to encounter the bereaved in their client work. A total of six focus group interviews were conducted, involving 29 professionals from services such as mental health and drug services, residential care, low threshold services, and medical services. The results show that bereavement support for the drugdeath bereaved is perceived as demanding relational work that is not part of their primary work tasks. The work is highly individualised because formal organisational structures are lacking, which can impair bereaved peoples' access to bereavement support. The lack of training, knowledge, and clear responsibility may lead to professionals lacking confidence and withdrawing from support initiatives in order to avoid stress and burnout.

#### Introduction

Losing someone close is a challenging, although normal and expected, life experience. In most situations, family and social networks can provide the support a person needs in their bereavement process (Aoun et al, 2015). In some situations, however, people need professional help to deal with grief and the impact of the bereavement on, for example, their quality of life and daily functioning (Breen & Moullin, 2022). Bereavement support may include professional assistance such as grief support, grief counselling, and grief therapy and informal assistance such as network and peer group support (Breen & Moullin, 2022). Different models have been developed for the assessment of bereavement risk, the support needs of bereaved populations, and the identification of the kinds of support services and training needed by those providing support (Aoun et al, 2015, 2018; Killikelly et al, 2021).

In this article, we address bereavement support provided by professionals who encounter the bereaved after a drug-related death (DRD). Examples of such professionals can be found in local health and welfare services, substance use services, and medical services. DRD refers to deaths directly attributable to the use of illicit psychoactive drugs, and deaths caused by illness, accidents, suicide, and violence related to the intake of drugs.

Worldwide, millions of people die annually for drug-related reasons. In 2022, in the European Union (including Norway and Turkey), 6,436 persons died of overdose (European Monitoring Centre for Drugs and Drug Addiction [EMDCCA] 2022). In the USA, overdose has reached epidemic proportions, with 106,699 deaths in 2021 (Centers for Disease Control and Prevention [CDC], 2023). Additionally, there are deaths related to illegal drug use, such as through accident, violence, infectious disease, or other health disorders. It is estimated that every deceased person leaves behind at least ten close family members and friends who must adapt to the loss (Dyregrov et al, 2020). Thus, the number of people affected by a death will depend on various factors, such as subjective experience, loss resilience, and affect dynamics (Coifman et al, 2007).

Research shows that death that is sudden, unexpected, and unnatural increases the risk

of complicated bereavement processes, such as prolonged grief disorder (PGD), post-traumatic stress disorder (PTSD), and early death (Djelantik et al, 2020; Dyregrov et al, 2003; Kristensen et al, 2012; Li et al, 2003). The term 'special death' is used for sudden and unnatural death that is particularly difficult for those left behind (Chapple et al, 2015; Guy & Holloway, 2007). Suicide, DRD, and death following HIV/AIDS are examples of special death. These deaths share certain features, such as often being perceived as self-inflicted and preventable. Additionally, the often traumatic circumstances of death may create more intrusive and negative memories that can affect the grieving process (Djelantik et al, 2020).

Special death following, for example, illegal drug use is often morally condemned in society and associated with deviant or morally reprehensible lifestyles (Corrigan et al, 2017; Guy, 2004). As such, stigma often follows such a death and can result in the death being devalued and disenfranchised within society. The concept of disenfranchised grief, developed by Doka (1999, p 37), 'recognizes that societies have sets of norms – in effect, grieving rules – that attempt to specify who, when, where, how, how long, and for whom people should grieve', which can lead to some types of grief not being recognised in society. Other researchers have contested this 'recognised-not recognised' binarity of grief and have discussed, for example, whether a hierarchical model of grief better captures the different norms regarding the legitimacy of grief in a society (Robson & Walter, 2013). However, both approaches agree that the powerful mechanisms of social norms result in some bereavement positions being more valued than others. Consequently, some groups of bereaved populations may be deprived of the assistance and support of family, friends, personal/social networks, and professionals and may be less likely to seek such support (Doka, 1999; Valentine et al, 2016).

## Discrepancy between support needs and support provision

People left bereaved after a DRD are at risk of severe health implications due to the trauma of the loss and the strain and stigmatisation both before and after the death (Bottomley *et al*, 2022; Christiansen *et al*, 2020; Titlestad, Mellingen *et al*,

2021; Titlestad & Dyregrov, 2022). For example, a Norwegian study found that parents left bereaved by a DRD (n=93) have a statistically significant high risk of prolonged grief symptoms (M=30.69) (Titlestad *et al*, 2022). Additionally, when family members are included (n=234), the analysis shows that many suffer from high levels of prolonged grief symptoms. Of these, 26% have scores equal to 35 or higher, which has been suggested as a preliminary cut-off score for the diagnosis of prolonged grief disorder (Titlestad & Dyregrov, 2022). In both studies, symptoms of prolonged grief were measured by Prolonged Grief Disorder-13 (PG-13), a criterion-based diagnostic tool (Prigerson & Maciejewski, n.d.).

The scarce research on bereaved people's experience of the professional support system indicates that those bereaved by DRD do not receive the support they need to deal with the bereavement process (Titlestad, Lindeman et al, 2021; Titlestad, Mellingen et al, 2021; Valentine et al, 2018). The bereaved themselves want help that is long-term, routinised, and competent (Fjær & Dyregrov, 2021), and they ask in particular for help from crisis teams and psychologists/psychiatrists and for help for the children in the family (Kalsås et al, 2022). Thus, there seems to be a discrepancy between the help needed and the help provided by the professional support system (Kalsås et al, 2022). Also, stigmatising attitudes can impede both the seeking and receiving of help (Dyregrov & Selseng, 2022; Titlestad, Mellingen et al, 2021). Based on interviews with 106 adults left bereaved by substance-related deaths (alcohol and drugrelated deaths) and six focus group interviews with practitioners in the UK, Valentine et al (2018) found that the bereaved generally experienced a lack of understanding in the support system (eg counselling services, police, funeral directors, treatment services). In the same study, they found that practitioners seemed unknowledgeable about the kinds of help the bereaved needed and had difficulty navigating the support system.

Research has also identified a general lack of knowledge about grief and bereavement processes among health professionals that may influence service provision (Breen, 2011; Breen *et al*, 2013; O'Connor & Breen, 2014). For example, professionals lack experience in bereavement support and associate the work with negative feelings such as discomfort, worry, helplessness, frustration, and guilt (Fan & Lin, 2022). These

factors can both limit support provision and interfere with the quality of bereavement support. In a survey of bereaved people's perception of different sources of bereavement support (n = 678), help from professionals was reported as the least used and had the highest proportions of perceived unhelpfulness (Aoun *et al*, 2018). The high levels of dissatisfaction may not only relate to the quality and availability of professional support but also result from bereaved people's expectations of the support system.

Knowledge about professionals' own experience helping individuals grieving a DRD and the resources they need to respond adequately is lacking (Reime et al, 2022). A recent Norwegian study of psycho-social follow-up immediately after DRD found that first responders often fail to include the DRD bereaved in the provision of services (Løseth et al, 2022). Titlestad and Dyregrov (2022) showed that symptoms of complicated grief were highest among those who had lost someone one to two years earlier, underscoring the importance of long-term help provision and the importance of professionals being aware of the symptoms of complicated grief over a longer time span. Thus, there is a need for more knowledge about the different groups of professionals who encounter bereaved clients and can provide both acute bereavement support and support over the longer term. The present article aims to address this knowledge gap by exploring health and welfare professionals' perspectives on bereavement support after a DRD and discussing some key conditions for help provision over the longer term.

#### Methods

This article is based on data from a large Norwegian study of those bereaved after DRD: the Drug-death Related Bereavement and Recovery Project (the END Project). Qualitative data from six focus group interviews with professionals likely to encounter the bereaved after a DRD in the municipalities was analysed for this article. The present study is anchored in a social-constructivist tradition. Given the lack of prior research, the study has an explorative design and empirically driven analysis.

#### Research participants

Participants were recruited from six Norwegian municipalities with relatively high DRD levels.

These municipalities varied in size (from about 40,000 to about 600,000 inhabitants) and were geographically spread. A contact person in the municipality was asked to recruit individuals from the different services likely to encounter the bereaved after a DRD. Additional participants were recruited through network and snowball methods. In total, 105 helpers were recruited from public, private, and non-profit organisations (NGOs). Four focus group interviews were conducted in each of the six municipalities between September 2019 and January 2020 (one group of first response helpers, one group of helpers from NGOs, one group of professional helpers who might encounter bereaved clients in the municipalities, one group of managers) for a total of 24 focus group interviews. The six focus group interviews included in the current study were conducted with 29 professionals from different workplaces (see Table 1). All of these participants were employed by public services, apart from one working for an NGO delivering residential care services. Focus group size varied as follows: four participants (one group), five participants (two groups), six participants (one group), and seven participants (one group). Additionally, one interview was conducted with two participants.

Table 1: Overview of	participant's workplace
Table 1. Overview of	participant 3 workplace

rable 1. Overview of participant's workplace		
Workplace	Number of participants	
Social services	3	
Grief therapy	1	
Health services (general practitioner)	1	
Local mental health and drug services	8	
Residential care services	5	
Low threshold services for people using drugs. For example: housing, care, and follow-up in the local community	6	
Services for next of kin	2	
Services for children, youth, and families	2	
Specialised services for drug addiction and rehabilitation	1	
	29	

#### Focus group interviews

The focus group interviews were piloted and based on a thematic guide. Themes related to:

- **1.** Participants' experiences of bereavement support after DRD
- 2. Challenges and examples of good practice
- **3.** Experiences of collaboration
- **4.** Their support needs.

A team of six researchers conducted the focus group interviews. Each interview was led by two researchers (moderator and assistant). The first author (MAR) was involved in conducting six of the focus group interviews. The project group developed a joint procedure for conducting focus group interviews to ensure all focus group participants were given the same information and to guide interview structure and facilitation. Focus group interviews took place in a meeting room at either a participant workplace or a nearby site convenient for participants and with the necessary facilities. Focus group interviews lasted about two and a half hours and were audiorecorded and transcribed verbatim. Before the interviews, participants were informed of their rights as research participants and completed a consent form.

#### **Analysis**

The analysis was inspired by reflexive thematic analysis (Braun & Clarke, 2006). First, the authors read the material several times to form an overview of the content. In the next step, data was grouped by initial codes based on patterns identified that characterised bereavement support from the professionals' perspectives. The first and third authors conducted the initial analysis separately; then the two authors discussed and modified the codes as the basis for the next step in the analysis. In the final step, the initial codes were modified to form two overarching themes with related codes illustrating patterns in the data on the professionals' perspectives on bereavement support to DRD bereaved clients and key conditions for help provision.

#### **Ethics**

The study was approved in February 2018 by the Norwegian Regional Ethical Committees for Medical and Health Research Ethics (2017/2486/REK vest). The study follows ethical standards from the Helsinki Declaration. Data is managed and stored according to the Norwegian General Data Protection Regulation, instructions of

the Regional Ethical Committee, and internal regulations of Western Norway University of Applied Sciences (HVL). The study has a sensitive and emotional theme, and in the design of the overall project, the data collection, and the analysis it has been important that the researchers involved have both broad experience as grief researchers and clinical experience from working in the substance use field. The first and second authors of the present article have been involved in grief research for several years and their professional background includes work with people with substance use problems. The second author also has related experience as a next of kin.

#### **Results**

Two themes were identified: 'demanding relational work' and 'in the margins of professional work'. The second theme refers to professionals having other primary tasks but being likely to encounter the DRD bereaved as part of their daily work. The themes and subordinate codes are presented in Table 2. The themes are described and illustrated with excerpts below. To ensure the anonymity of all the professionals, they have been given fictitious names.

Table 2: Overview of themes and codes		
Demanding relational work	In the margins of relational work	
Restoring trust in the support system	Professionals who lack confidence	
Taboo and stigma around death	Lack of routines and formalisation	
	Fragmented support system	

#### Demanding relational work

The results show that one important characteristic of bereavement support from the professionals' perspective is the demanding relational work involved when the professionals encounter the DRD bereaved.

#### Restoring trust in the support system

Some of the professionals in this study found the bereaved very angry with the support system because they were dissatisfied with the help the deceased received when still alive. This work context can make it difficult for professionals to establish a supportive helping relationship and be recognised as legitimate helpers. Trude, a general practitioner, described it as follows:

It is the next of kin that have felt stress and grief for years, and they are tired. And they experienced their child not getting the assistance from the support system that was wanted, and then it ended in death. And then the municipal health system comes and is supposed to serve the bereaved in their grief process. At least that was what I experienced when I worked at the hospital: 'Now you are coming, now you want to talk.' Right? [...] It is difficult, and you need competence in that to manage to get into a helping position.'

Trude emphasised that the DRD bereaved differ from other groups of the bereaved because they have often struggled for many years before the death. The rumination about what could have been done to save the deceased often includes blaming the support system. The anger towards the support system that some professionals have been subject to, can affect their ability to establish a good helping relationship and make these professionals less confident about providing bereavement support. Grete, a public health nurse, also described being accused by the bereaved:

'And then, oftentimes, we [the professionals] are the ones who must take it [...] when they are in grief and shock. I have often been insulted on the basis that I killed their child, that I didn't watch out well enough. So, you must endure that, but if you have a relationship from the beginning, then you will not have that reaction. So, it is about trust and, yes, relationships.'

Grete also emphasises that blame and anger can be modified if the professionals are known to the bereaved. A general pattern in the professionals' descriptions of successful help provision is that it occurs in a context of a pre-existing relationship. If the bereaved are known to the professionals, the professionals' threshold for initiating contact is lowered and they are more likely to be perceived as legitimate helpers. In the above quote, Grete emphasises that the establishment of a trusting relationship is a key condition for help provision, but one that is particularly challenging in the context of DRD bereavement. The professionals' experiences indicate a form of de-personalisation: the professionals are seen as

representing the support system in general and are therefore targeted by the bereaved, who are frustrated with not having received help before. As such, the professionals' work in this context often has two stages, with their ability to provide bereavement support being dependent upon their restoration of trust in the support system and correction of misconceptions about their roles and responsibilities.

#### Taboo and stigma around death

Taboo and stigma, which are frequently mentioned in connection with bereavement support following a DRD, make relational work demanding and can affect help provision. For example, Vilde, who was from a low threshold service for people with substance use problems, found that some bereaved persons hide the cause of death:

I have found that the public explanation was that their heart stopped, and that was true, right, their heart stopped because of an amphetamine overdose [...]. They [the bereaved] stick to a truth, but we know that it is something else. And maybe the bereaved are in need of another type of talk than in ordinary grief support groups? But how dare we as helpers go into that? And I think we are afraid of that, I think it is difficult.'

Vilde asked, 'How dare we [...] go into that?' and intimated that this helping context demands approaches other than those usually provided to the bereaved, such as grief groups. The professionals indicated that the DRD bereaved often have feelings that can be hard to talk about, such as blaming themselves for the death, the deceased's way of life when they were alive, or feeling relieved by the death. Such feelings can also be difficult for professionals to address and can hinder open communication. Trond, who was from the local welfare services, found it important to openly recognise the bereaved's feelings:

If I talk with a friend, a mother, it is about giving support and recognising the bereaved's feelings. I think maybe the person of concern is relieved by the death. I know how it is, there have been so many concerns, there has been so much fear related to the deceased's way of life, enough to support them with "Yes, it is ok to experience the feelings you have now, relief over everything, maybe your close one is now better off in another place."

Many of the professionals in this study emphasised the importance of talking about the deceased in a respectful and recognisable way to help the bereaved renegotiate their memories of the deceased and restore a sense of dignity. In addition, some of the professionals that knew the deceased before death found that they could perform an important role by providing the bereaved with information and narratives about the deceased. Often the bereaved had little contact with the deceased before their death, and information about how the deceased was living before their death can be important to the bereaved's meaning-making processes. Ane, who was from a local residential care unit for older people with substance use problems, described this as follows:

'To tell them [the bereaved] about the person behind the drugs. Because I think, or I know, that the bereaved find it very good to talk with someone who sees the person and not merely the 'drug abuser'. I think it is very good for the bereaved to hear that, despite the violence, they [the deceased] were also a very good person, they were nice and kind, and they helped their friends, they were supportive of their friends, and yes, the small things in life that were positive.'

Here, Ane was referring to the importance of narrating a story about the deceased that emphasises the deceased's qualities as a human being. This way of communicating with the bereaved illustrates how bereavement support can also be important for counteracting the aforementioned taboo and stigma around the death.

## Bereavement support in the margins of professional work

A general pattern in the data shows bereavement support occurring mainly in the margins of professionals' daily work in the municipality. This context is important in terms of identifying bereaved persons who need professional grief support and counselling and distinguishing between clients' bereavement needs and referring clients in need of grief therapy to specialised services.

#### Professionals who lack confidence

The results of this study show that many professionals (including experienced

professionals) did not feel confident about providing bereavement support. For example, those who worked with clients with substance use problems in residential care wanted to know more about bereavement in general, as many of their clients were bereaved, and DRD was a frequent occurrence in their units. Kristin, who was from a residential care unit, expressed particular concern about being bereaved while also having substance use problems:

'Related to those who have a substance use problem themselves, it is a great challenge, so you might need special competence to go through with the conversation. It is as if you are going to help a person with the same deadly disease, you can die at any point in time, it is a great challenge [...]. I think that we need specific professional programmes on how to approach that. When you start with that type of follow-up, you open up to so much, and in fact you can sit there and you can feel, I have no knowledge about this, here I need more help, and then it can take too long to establish that help [...]. So, there I could have wished for supplementary training. I think we can do it very well, but it is a very neglected group.'

The professionals were ambivalent about how or whether to approach the bereaved with their own substance use problems. On the one hand, they acknowledged the need for openness and communication; on the other hand, they highlighted the proximity of death and the bereaved's own risk of dying as factors that can make openness harmful if it triggers fear in the bereaved. Even in cases where professionals said they had a good helping relationship, they mentioned lacking confidence in bereavement topics. For example, they found it difficult to know when and whether clients were ready to talk about the loss and what it might bring about. Furthermore, professionals said they are afraid to summon feelings that cannot be handled and may lead to increased drug use or a relapse. Thus, in the above quote, Kristin did not view referral to other services as appropriate ('It can take too long'). Instead, she asked for more training to handle this in the residential care unit where she worked. Vilde, who was from a low threshold service for people with substance use problems, elaborated further on this lack of confidence:

'How confident are you about going into it [bereavement support] when you do not know who you will meet? And to give condolences at the

funeral, or to call [...]. We have so little training [...]. And we might be afraid of being rejected and do not know quite what to say.'

Vilde referred to activities that can be generally challenging to anyone facing bereavement and grief and questions about how to relate to the bereaved, what to say, and how to act appropriately. However, she also referred to a fear of being rejected, which can lead to avoidance and obstruct bereavement support outreach. From Vilde's perspective, more frequent experience of these situations can help reduce stress and lack of confidence among professionals. The professionals also experienced that bereaved persons with substance use problems often avoid contact and make themselves unavailable for bereavement support, as shown in this quote from Kristin, who was from a local residential care unit:

'They will often try to bottle up feelings and say, "It is no problem. No, I do not want to talk about it."' They become angry and turn us down [...]. And they [the persons with substance use problems] experience DRD time after time.'

Because bereavement support is on the margins of the professionals' daily work tasks, many of the professionals in this study did not have much experience of DRD and bereavement. They highlighted the importance of experience in terms of not only numbers but also routines and training, as in this quote from Odin, who was from the local welfare services:

I am not sure that we provided good assistance if faced with such a death [...]. Really, we have never experienced that problem. In that way we are lucky. But in relation to routines and training, that is minimal, right?'

Odin was concerned about the quality of the bereavement support because of the lack of relevant training. Several of the professionals in this study described not being confident in performing this part of the work. Again, this relates to a lack of knowledge about grief and bereavement and a lack of training.

#### Lack of routine and formalisation

There are routines in Norway for bereavement support in the immediate aftermath of a sudden and unnatural death (Norwegian Directorate of Health, 2016), but the results from this study

show that, after the first acute phase, formal work descriptions for bereavement support are lacking. As bereavement support is located in the margins of many different professional services, the initiative for bereavement support is individualised and depends on the different services' focus and priority, and certain professionals' awareness of the deceased and their next of kin. When the professionals in this study gave examples of situations where they had provided helpful bereavement support, the follow-up was characterised by compassion and motivated by the professionals' former relationship with the deceased and their family. The professionals described a field where bereavement support occurs more by chance, as this quote from Andreas, who works with next of kin, shows:

'When it comes to follow-up after the acute crisis, there is a need for more systematic work [such as] how to terminate services, how to continue work with the bereaved? When are municipalities supposed to terminate services and refer the bereaved? That is a challenge that we need to address more clearly.'

What Andreas describes is a common theme in the data relating to the professionals' uncertainty over their roles and responsibilities in bereavement support. He is referring to the division in the Norwegian health and welfare system, where specialised services are a state responsibility and the municipality offers other services at the lowest possible level. When tasks have not been formalised and assigned to specific services, as is the case with bereavement support after the acute crisis, the responsibilities get blurred, as illustrated by this statement by Else, who worked with grief support in specialised care:

'We are preoccupied with whether there is a clear mandate, what our tasks are, what is expected from us, and what we should do, what are the boundaries or frames of the work. When I do not know about the boundaries, then I must know my own limitations. Also, we are engaged in taking care of ourselves as helpers, as we call it, to prevent care fatigue. We have to pay a lot of attention to that.'

Else is describing bereavement support as a demanding professional task and emphasised the importance of clear expectations and formal work descriptions. From her perspective, this is important to prevent burnout, which she refers to as 'care fatigue'. Else points to the tension between the goal of good-quality service provision and protecting professionals' health and well-being. This study shows that the professionals tended to ask for more formalisation, for example with regard to what was expected of them and when it was legitimate to terminate the intervention or refer the bereaved to other services for further follow-up.

#### A fragmented support system

The professionals also emphasised the importance of formal routines as a precondition for collaboration between relevant services for bereavement support. The professionals said they did not know which services (public, private, NGO) existed and were relevant for the bereaved. They asked for better routines for communicating with other services, both for exchanging relevant information (such as giving the bereaved details about the cause of death or the deceased's final days) and making referrals to other services for grief support, counselling, or therapy. Support for the DRD bereaved was described as a fragmented system with a web of helpers who could potentially become involved. Usually, the deceased received help from services such as low threshold services, mental health and drug services, residential care services, medical services, and welfare services. When someone with substance use problems died, many of those services could be relevant in terms of approaching and supporting the bereaved.

However, the professionals found no clear division of roles and responsibilities, and the services often lacked information about the other services involved, as exemplified in this statement by Odd, who was from a low threshold service for people with substance use problems:

I have also reflected upon our role because the ones [the bereaved] we encounter, they often have many helpers [...]. If our role is obvious, and we think that in this case we are close, then it is implicit that we make contact [with the bereaved]. But in some cases, our role is not obvious. I have felt a need to know [whether] the bereaved received the information they needed, and eventually from whom? Because, when there are many helpers, who does what? Who is it that can inform the bereaved about our services?'

When many helpers are involved, there is a risk of disavowal of responsibility. Additionally, the results show this web of helpers can inhibit the bereaved's access to relevant information, such as whom they can contact if they need information or bereavement support.

#### **Discussion**

This study shows that bereavement support after a DRD occurs in a demanding relational context where professional legitimacy is contested and support initiatives are challenged by the taboo and stigma connected to the cause of death. The work occurs 'on the margins' of professionals' daily work, and professionals lack the training and knowledge to confidently provide bereavement support. Additionally, the lack of organisational routine leaves responsibilities unclear and increases the risk of the bereaved being omitted from professionals' awareness and priorities. This study's key findings highlight certain micro-political and organisational conditions of relevance for reducing inequalities in access to bereavement services and understanding how to better the services provided to the DRD bereaved from a longer-term perspective.

# Bereavement support relies on individualised relationships and professional awareness

The study results show that pre-existing relationships with the bereaved persons concerned are perceived as an important condition for the provision of help and for professionals' helping initiatives being accepted. This study's findings differ from those of Løseth et al (2022), who explore the experiences of first responders encountering the DRD bereaved in Norway and finds that relationships established before death can obstruct help provision. These divergent findings can probably be explained by the multiple and conflicting positions of help and control (eg of child welfare worker and crisis team member) occupied by some of the first responders in the study by Løseth et al (2022). The municipal helpers in the present study had a more distinct helping function and, as such, their role was less ambiguous. The importance of having a pre-existing relationship also corresponds with the findings of other studies that document the importance of continuing support from health

care providers who were involved before the death, such as in studies of the parental experience following the loss of a child (Berrett-Abebe *et al*, 2017; Darbyshire *et al*, 2013).

In cases where one had not met the bereaved person before their loss, the starting point for professional helping initiatives was perceived as considerably more complex. In the absence of a pre-existing relationship with the bereaved family or friends, there was, according to some professionals, a greater likelihood of a negative response to their helping initiatives and, as a result, they had to work harder to be perceived as legitimate helpers and to form a therapeutic relationship. For example, some participants in this study were accused of causing the death and served as a personified scapegoat for an anonymous helping system that was unable to prevent the death. Rumination about guilt and whether someone is to blame for the death is a typical reaction in a DRD bereavement (Da Silva et al, 2007; Templeton et al, 2017; Titlestad, Mellingen et al, 2021). Titlestad, Mellingen et al (2021) found that parents' anger was directed mainly towards the support system for not providing their children with the services they expected from the welfare state. First responders are also often exposed to anger and resentment when encountering family members in cases of sudden and unexpected death (Løseth et al, 2022; Nelson et al, 2020).

The concept of rectification work refers to professional efforts to rebuild trust after hospital incidents that have insulted or threatened the patient's composure (Strauss et al, 1982). The concept is relevant to situations in the present study where professionals discussed having often dealt with bereaved persons who were dissatisfied with their earlier encounters with professionals. Central aspects of rectification work, such as providing patients with apologetic support and stoic responses to aggression or accusations (Strauss et al, 1982), were also shown by professionals in this study as important for rebuilding the bereaved's trust in a support system that some held accountable for the death. The work is time-consuming and involves relational work to restore trust and confidence, but it also stands out as a precondition for further support provision.

Despite their long careers in the welfare services, most of the participants in this study,

including professionals working with persons with substance use problems, had limited experience of providing support to be eaved family or friends in the aftermath of this special kind of death. Their lack of experience can be explained by the small number of DRDs in the municipality, but it may also relate to a lack of awareness of clients' experience of grief and loss. Selseng et al (2023) found that when persons with substance use problems experience traumatic and devastating loss, they are deprived of both social and professional support and seen mainly as 'drug users' and not as 'grievers'. Research has also shown that people with substance use problems are at high risk of experiencing the DRD of those they are close to, overdosing themselves, and witnessing overdose deaths (Kenny et al, 2022). As such, it is reasonable to assume that most of the participants in this study who encountered clients with substance use problems also related to the DRD bereaved in their practice but without being aware of or attentive to the clients' experience of bereavement and loss.

The findings in the present study comprise examples of how bereavement support can be facilitated by exclusive, semi-personal, and semi-professional relationships involving an attentive professional and a bereaved individual or a small group of the bereaved. However, service provision that relies on individualised relationships and professionals' awareness can lead to unequal access to services. As such, this is the flip side of this micro-political prioritisation of bereavement support that takes place in the marginal zone of the professional's everyday work.

## Lack of organisational anchoring can lead to professional withdrawal

Many support services may be relevant in terms of supporting the DRD bereaved, but this study shows no organisational anchoring of bereavement support when the first responders have finished their work. The professionals in this study experienced a lack of confidence when approaching the bereaved after a DRD, in connection with, for example, how to bring up the topic of grief or whether they should talk openly about the cause of death. The professionals also said they encountered bereaved persons who did not want to disclose the cause of death or did not want to talk about the death or the deceased. The taboo on death is interpreted

as related to the stigma associated with DRD (Dyregrov *et al*, 2020; Dyregrov & Selseng, 2022; Titlestad, Mellingen *et al*, 2021), which is at risk of being reinforced if the professionals do not have the confidence to address the death and its causes. In the absence of formal descriptions of bereavement support after the acute phase, there can be no guiding principles that can prevent stigma and taboo from affecting helping initiatives.

The professionals in this study wanted in particular to become more knowledgeable about grief and bereavement. As such, it shows that being an experienced professional in a field does not necessary make one more prepared to provide bereavement support. Additional support and training seem to be necessary to improve professionals' ability to provide bereavement support. In general, professionals' lack of knowledge about bereavement care has been reported in studies of professionals, such as general practitioners and professionals working in palliative care, encountering the bereaved after other types of death as well (Fan & Lin, 2022; Jensen *et al*, 2017; O'Connor & Breen, 2014). Lack of knowledge (eg about recent developments in grief theory) can influence not only the choice of grief intervention but also the professionals' ability to identify and differentiate between clients with high levels of need for bereavement support and those with lesser needs (Breen et al, 2013). The results of the present study show that, in case of special deaths such as DRD, the stigma that follows death can further impede professionals' perception of self-efficacy when they encounter the bereaved.

More training and knowledge are needed to improve professionals' sense of self-efficacy in bereavement support and, as such, to strengthen the provision of bereavement care (Fan & Lin, 2022). The results from this study point towards the risk of professional withdrawal when professionals who lack confidence work in contexts without formal structures for bereavement support or collaboration between services relevant to the provision of bereavement support. The problem of 'many hands' is frequently addressed in organisational studies and describes the challenges of addressing responsibilities in organisations, particularly in situations when something goes wrong (Dixon-Woods & Pronovost, 2016; Thompson, 1980). When the support system is fragmented, roles

are unclear, and many helpers are involved, the process of assigning responsibility is more difficult. In the worst case, this can lead to withdrawal and impede service provision. This study confirms the findings of a study on substance-related deaths in the UK pointing to complex systems that are difficult to navigate for professionals and the bereaved. The lack of communication and collaboration between different inter-organisational services was emphasised in particular (Valentine et al, 2018). The present study also adds to the findings of the Løseth *et al* (2022) study of first responders encountering the DRD bereaved, wherein they documented some first responders associating the DRD bereaved with the deceased's drug use and thereby determining that they were better assisted by the drug services than by the bereavement support services.

The present study shows that professionals fear becoming burnt out if they overly involve themselves in this type of work. The descriptions by the professionals in this study of the burdens of bereavement support are also documented in studies of professional support after other types of death, which, for example, point to negative emotions associated with bereavement support (Fan & Lin, 2022; Jensen *et al*, 2017). One form of burnout may be compassion fatigue, first defined by Figley (1995, p7) as 'the formal caregiver's reduced capacity or interest in being empathic or "bearing the suffering of clients" and is "the natural consequent behaviors and emotions resulting from knowing about a traumatizing event experienced or suffered by a person".

Hochschild's (1983) concept of emotional labour, which describes professionals encountering demanding emotional situations and simultaneously being expected to manage both their own and their clients' emotions, also resonates with the findings of this study. In the absence of formal descriptions framing professional's responsibilities for bereavement support, the professionals must set limits to manage the emotional work, the result of which may be withdrawal or less emotional involvement in order to cope with the intense emotional situation. These mechanisms may have powerful implications for both the bereaved persons and the professionals. The bereaved in need of formal bereavement support may be omitted from services, or receive support services of reduced quality. Simultaneously, the professionals are at

risk of burnout or other negative social and/or health-related consequences if not adequately trained and equipped with resources to deliver bereavement support.

#### Conclusion

This study shows that DRD bereavement support over the longer term is mostly individualised. Support services depend on the respective professional's initiative and whether they feel responsible for providing bereavement support and have the resources, competencies, and strengths to provide adequate support. This can lead to unequal access to bereavement services. Unclear roles, a lack of knowledge and practical training, a fragmented support system, fear of burnout, and challenging emotional work are all conditions within the work context that have influenced professionals' capabilities to initiate bereavement support.

Results from this study point to a general lack of knowledge about grief and bereavement among the participating professionals that poses an obstacle to initiating help. We recommend that professionals who are likely to encounter bereaved persons as part of their daily work be provided with opportunities to increase their competency in relation to grief and bereavement processes following death in general and special death in particular. There is a need for competent professionals who can identify bereaved persons in need of bereavement support, who know the system, and who feel confident about openly communicating about the loss and managing the severe emotions that can be aroused. Although this study is limited to exploring professionals' perspectives on bereavement support after a DRD, the research on bereavement after other types of death also emphasises the need for more knowledge. As such, the study results are applicable to health and welfare professionals encountering bereaved clients after death from other causes, but some distinct features of DRD need particular attention.

Finally, the study indicates a lack of organisational anchoring of bereavement over the longer term. There is a need to develop routines and clarify responsibilities to prevent professional withdrawal and unequal access to support and to counteract the stigma that interferes with the delivery and receipt of support. There is a need for further research on

not only the content and effect of bereavement support for the bereaved after a sudden and unnatural loss such as a DRD, but also on how best to support and equip those encountering the bereaved as part of their work.

#### **Acknowledgements**

We are very grateful to all the professionals who contributed to the focus group interviews and openly shared their experience of encountering those left bereaved after a DRD.

#### References

Aoun SM, Breen LJ, Howting DA, Rumbold B, McNamara B & Hegney D (2015) Who needs bereavement support? A population based survey of bereavement risk and support need. *PloS One*, *10*(*3*), e0121101. https://doi.org/10.1371/journal.pone.0121101

Aoun SM, Breen LJ, White I, Rumbold B & Kellehear A (2018) What sources of bereavement support are perceived helpful by bereaved people and why? Empirical evidence for the compassionate communities approach. *Palliative Medicine*, 32(8), 1378-1388. https://doi.org/10.1177/0269216318774995

Berrett-Abebe J, Levin-Russman E, Gioiella ME & Adams JM (2017) Parental experiences with a hospital-based bereavement program following the loss of a child to cancer. *Palliative & Supportive Care*, 15(3), 348-358. https://doi.org/10.1017/s1478951516000821

Bottomley JS, Feigelman WT & Rheingold AA (2022) Exploring the mental health correlates of overdose loss. *Stress and Health*, 38(2) 350-363. https://doi.org/10.1002/smi.3092

Braun V & Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2) 77-101. https://doi.org/10.1191/1478088706qp063oa

Breen LJ (2011) Professionals' experiences of grief counseling: implications for bridging the gap between research and practice. *OMEGA* - *Journal of Death and Dying*, 62(3) 285-303. https://doi.org/10.2190/om.62.3.e

Breen LJ, Fernandez M, O'Connor M & Pember A-J (2013) The preparation of graduate health professionals for working with bereaved clients: An Australian perspective. *OMEGA* - *Journal of Death and Dying*, 66(4) 313-332. https://doi.org/10.2190/om.66.4.c

Breen LJ & Moullin JC (2022) The value of implementation science in bridging the evidence gap

in bereavement care. *Death Studies*, 46(3) 639-647. https://doi.org/10.1080/07481187.2020.1747572

Centers for Disease Control and Prevention (2023) Drug overdose deaths in the United States, 2001-2021 [online]. Available at: https://www.cdc.gov/nchs/products/databriefs/db457.htm.

Chapple A, Ziebland S & Hawton K (2015) Taboo and the different death? Perceptions of those bereaved by suicide or other traumatic death. *Sociology of Health & Illness*, 37(4) 610-625. https://doi.org/10.1111/1467-9566.12224

Christiansen SG, Reneflot A, Stene-Larsen K & Johan Hauge L (2020) Parental mortality following the loss of a child to a drug-related death. *European Journal of Public Health*. https://doi.org/10.1093/eurpub/ckaa094

Coifman KG, Bonanno GA & Rafaeli E (2007) Affect dynamics, bereavement and resilience to loss. *Journal of Happiness Studies*, 8(3), 371-392. https://doi.org/10.1007/s10902-006-9014-5

Corrigan P, Schomerus G & Smelson D (2017) Are some of the stigmas of addictions culturally sanctioned? *The British Journal of Psychiatry*, 210(3) 180-181. https://doi.org/10.1192/bjp.bp.116.185421

Darbyshire P, Cleghorn A, Downes M, Elford J, Gannoni A, McCullagh C & Shute R (2013) Supporting bereaved parents: a phenomenological study of a telephone intervention programme in a paediatric oncology unit. *Journal of Clinical Nursing*, 22(3-4), 540-549. https://doi.org/10.1111/j.1365-2702.2012.04266.x

Da Silva EA, Noto AR & Formigoni, MLOS (2007) Death by drug overdose: impact on families. *Journal of Psychoactive Drugs*, 39(3) 301-306. https://doi.org/http://dx.doi.org/10.1080/02791072.2007.10400618

Dixon-Woods M & Pronovost PJ (2016) Patient safety and the problem of many hands. *BMJ Quality & Safety*, 25(7) 485-488. https://doi.org/10.1136/bmjqs-2016-005232

Djelantik AMJ, Smid GE, Mroz A, Kleber RJ & Boelen PA (2020) The prevalence of prolonged grief disorder in bereaved individuals following unnatural losses: systematic review and meta regression analysis. *Journal of Affective Disorders*, 265 146-156. https://doi.org/10.1016/j.jad.2020.01.034

Doka KJ (1999) Disenfranchised grief. *Bereavement Care*, 18(3) 37-39. https://doi.org/10.1080/02682629908657467

Dyregrov K, Møgster B, Løseth H-M, Lorås L & Titlestad KB (2020) The special grief following drug related deaths. *Addiction Research & Theory*, 28(5) 415-424. https://doi.org/10.1080/16066359.2019.1679122

Dyregrov K, Nordanger D & Dyregrov A (2003) Predictors of psychosocial distress after suicide, SIDS and accidents. *Death Studies*, 27(2) 143-165. https://doi.org/10.1080/07481180302892

Dyregrov K & Selseng LB (2022) "Nothing to mourn, He was just a drug addict" - stigma towards people bereaved by drug-related death. *Addiction Research & Theory*, 30(1) 5-15. https://doi.org/10.1080/16066359.2021.1912327

European Monitoring Centre for Drugs and Drug Addiction (2022) European drug report. Trends and development [online]. Available at: https://www.emcdda.europa.eu/publications/edr/trends-developments/2022\_en

Fan S-Y & Lin W-C (2022) An educational bereavement program to decrease clinical staff's barriers and improve self-efficacy of providing bereavement care. *Supportive Care in Cancer*, 30(1) 835-841. https://doi.org/10.1007/s00520-021-06497-y

Figley CR (1995) Compassion fatigue as secondary traumatic stress disorder: an overview. In CR Figley (ed.), Compassion fatigue: coping with secondary traumatic stress disorder in those who treat the traumatized, 1-20. Routledge.

Fjær S & Dyregrov K (2021) Advice to policy-makers for improving services to the drug-death bereaved. *Nordic Studies on Alcohol and Drugs*, 38(6) 615-630. https://doi.org/10.1177/14550725211018333

Guy P (2004) Bereavement through drug use: messages from research. Practice, 16(1) 43-54. https://doi.org/10.1080/0950315042000254956

Guy P & Holloway M (2007) Drug-related deaths and the 'special deaths' of late modernity. *Sociology*, 41(1) 83-96. https://doi.org/10.1177/0038038507074717

Hochschild AR (1983) *The managed heart:* commercialization of human feeling. University of California Press.

Jensen J, Weng C & Spraker-Perlman HL (2017) A provider-based survey to assess bereavement care knowledge, attitudes, and practices in pediatric oncologists. *Journal of Palliative Medicine*, 20(3) 266-272. https://doi.org/10.1089/jpm.2015.0430

Kalsås ØR, Titlestad KB, Dyregrov K & Fadnes LT (2022) Needs for help and received help for those bereaved by a drug-related death: a cross-sectional study. *Nordic Studies on Alcohol and Drugs*. 14550725221125378

Kenny KS, Kolla G, Firestone M, Bannerman M, Greig S, Flores B et al (2022). Frequency of fatal and non-fatal overdoses and response to grief and loss among people who inject drugs:

an unexplored dimension of the opioid overdose crisis. *Drug and Alcohol Dependence*, 237 109539. https://doi.org/10.1016/j.drugalcdep.2022.109539

Killikelly C, Smid G, Wagner B & Boelen P (2021) Responding to the new International Classification of Diseases-Il prolonged grief disorder during the COVID-19 pandemic: a new bereavement network and three-tiered model of care. *Public Health*, 191, 85-90. https://doi.org/10.1016/j.puhe.2020.10.034

Kristensen P, Weisæth L & Heir T (2012) Bereavement and mental health after sudden and violent losses: a review. *Psychiatry: Interpersonal & Biological Processes*, 75(1) 76-97. https://doi.org/10.1521/psyc.2012.75.1.76

Li J, Precht DH, Mortensen PB & Olsen J (2003) Mortality in parents after death of a child in Denmark: a nationwide follow-up study. *The Lancet*, 361(9355) 363-367. https://doi.org/10.1016/s0140-6736(03)12387-2

Løseth H-M, Selseng LB, Dyregrov K & Mellingen S (2022) How do professionals in municipal health and welfare relate to be eaved persons during the acute phase of a drug-related death? A qualitative study. *Global Qualitative Nursing Research*, 9. https://doi.org/10.1177/23333936221085035

Nelson PA, Cordingley L, Kapur N, Chew-Graham CA, Shaw J, Smith S et al (2020) 'We're the first port of call' - Perspectives of ambulance staff on responding to deaths by suicide: a qualitative study. *Frontiers in Psychology*, 722. https://doi.org/10.3389/fpsyg.2020.00722

Norwegian Directorate of Health (2016) Mestring, samhørighet og håp. Veileder for psykososiale tiltak ved kriser, ulykker og katastrofer [Coping, companionship and hope: psychosocial interventions in the event of crisis, accidents and disasters] (IS-2428). https://helsedirektoratet.no/retningslinjer/mestring-samhorighet-og-hap-veileder-for-psykososiale-tiltak-ved-kriser-ulykker-og-katastrofer

O'Connor M & Breen LJ (2014) General practitioners' experiences of bereavement care and their educational support needs: a qualitative study. *BMC Medical Education*, 14 1-10. https://doi.org/10.1186/1472-6920-14-59

Prigerson, HG & Maciejewski PK (n.d.) *Prolonged grief disorder (PG – 13)*©. Center for Research on End of Life Care at Weill Cornell Medical College. Retrieved 29 Aug 2023 from: https://endoflife.weill.cornell.edu/sites/default/files/pg-13.pdf

Reime, MA, Løseth HM, Lindeman SK, Titlestad KB, Dyregrov K & Selseng LB (2022) Professional helpers' experiences of assisting the bereaved after drug-related deaths: a knowledge gap.

*Nordic Studies on Alcohol and Drugs*, 39(4) 453-465. https://doi.org/10.1177/14550725221085345

Robson P & Walter T (2013) Hierarchies of loss: a critique of disenfranchised grief. *OMEGA*- *Journal of Death and Dying*, 66(2), 97-119. https://doi.org/10.2190/om.66.2.a

Selseng LB, Reime MA & Lindeman SK (2023) Help and support for bereaved persons who use drugs: a qualitative study. *European Journal of Social Work*, 1-13. https://doi.org/10.1080/13691457.2023.2188146

Strauss A, Fagerhaugh S, Suczek B & Wiener C (1982) Sentimental work in the technologized hospital. *Sociology of Health & Illness*, 4(3) 254-278. https://doi.org/10.1111/1467-9566.ep10487954

Templeton L, Valentine C, McKell J, Ford A, Velleman R, Walter T et al (2017) Bereavement following a fatal overdose: The experiences of adults in England and Scotland [Review]. *Drugs: Education, Prevention and Policy*, 24(1) 58-66. https://doi.org/10.3109/09687637.2015.1127328

Thompson DF (1980) Moral responsibility of public officials: The problem of many hands. *American Political Science Review*, 74(4) 905-916. https://doi.org/10.4324/9781315246567-12

Titlestad KB & Dyregrov K (2022) Does 'time heal all wounds?'The prevalence and predictors of prolonged grief among drug-death bereaved family members:

A cross-sectional study. *OMEGA - Journal of Death and Dying*. https://doi.org/10.1177/00302228221098584

Titlestad KB, Lindeman SK, Lund H & Dyregrov K (2021) How do family members experience drug death bereavement? A systematic review of the literature. Death Studies, 45(7) 508-521. https://doi.org/10.1080/07481187.2019.1649085

Titlestad KB, Mellingen S, Stroebe M & Dyregrov K (2021) Sounds of silence. The "special grief" of drug-death bereaved parents: a qualitative study. *Addiction Research & Theory*, 29(2) 155-165. https://doi.org/10.1080/16066359.2020.1751827

Titlestad KB, Schmid MT & Dyregrov K (2022) 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*, 46(6) 1354-1363. https://doi.org/10.1080/07481187.2020.1867255

Valentine C, Bauld L & Walter T (2016) Bereavement following substance misuse: A disenfranchised grief. *OMEGA - Journal of Death and Dying*, 72(4) 283-301. https://doi.org/10.1177/0030222815625174

Valentine C, McKell J & Ford A (2018) Service failures and challenges in responding to people bereaved through drugs and alcohol: An interprofessional analysis. *Journal of Interprofessional Care*, 32(3) 295-303. https://doi.org/10.1080/13561820.2017.1415312. ■