

# Advice to policy-makers for improving services to the drug-death bereaved

Nordic Studies on Alcohol and Drugs

1–16

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DOI: 10.1177/14550725211018333

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## Abstract

**Aims:** The objective of this study is to contribute to an improvement of bereavement services and experiences for the bereaved after drug-related deaths (DRDs) by investigating their expressed opinions on what would constitute improvements. **Methods:** As part of a larger survey questionnaire, we asked people bereaved by DRDs what advice they would give to politicians to improve bereavement services. Out of 255 respondents, we received 196 written statements of advice, 83 focusing on the time after death. Two-thirds of these respondents were either parents or siblings, the other third were other family members or close friends. A thematic analysis was conducted to examine the written statements. **Results:** We found four central themes: broad-spectrum help, routinised help, respectful help and competent help. The advice represents a long list of psychosocial support to ideally be offered on a regular and long-term basis. Furthermore, the bereaved also discussed the cognitive and normative side of the services by including considerations about stigma and respect, and the need for more research- and experience-based knowledge about their experiences both before and after DRDs. **Conclusions:** Many of the services sought by the bereaved are already in place and described in national guidelines for follow-up strategies after sudden unexpected deaths. DRDs, however, has not been included as a task for the services and are not explicitly mentioned in these guidelines. The scope of research and policymaking on drug problems and DRDs should be broadened to include families and social networks in order to make the group more visible and strengthen their influence on policy.

Submitted: 21 December 2020; accepted: 29 April 2021

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## Keywords

drug-related bereavement, policymaking, psychosocial follow-up, welfare services

People who have lost close ones to drug-related deaths (DRDs) are a quiet stakeholder group, invisible in the heated long-lasting drug policy debates. This article presents an analysis of how the bereaved themselves articulate advice to the politicians about their own needs when they struggle to go on with life after losing a child, a family member, or a close friend. Research about next-of-kin co-habiting with severe substance users has thoroughly documented ways in which family members are subjected to increased stress and burden, poor health, and reduced quality of life (Di Sarno et al., 2021; Richert et al., 2018). When it comes to life after drug-related death, the research is scarce. A recent systematic review of the literature included only ten studies (seven with unclear/high risk of bias), indicating that people bereaved by DRD experience a significant emotional and existential post-loss burden. Grief reactions and lack of understanding and help from support systems, stigmatisation from society, as well as self-inflicted stigmatisation, influenced the bereavement process (Titlestad et al., 2019). The scarce research on this group supports an assumption that the grief of bereaved after DRD is disenfranchised grief, that the cause of death results in less social support and openness around the grieving process (Doka, 2002; Titlestad, Mellingen, et al., 2020). The Norwegian Drug death related bereavement and recovery project (END) is devoted to the study of several aspects of DRD bereavement and recovery, e.g., how the DRD-bereaved experience grief and stigma and are supported by health and social care services (Dyregrov et al., 2020; Dyregrov & Selseng, 2021; Løberg et al., 2019; Titlestad, Mellingen, et al., 2020; Titlestad, Stroebe, & Dyregrov, 2020). A major rationale of the project is to communicate advice to service providers and

policymakers in order to reduce stigma and improve the quality of life of the bereaved.

The lack of voice, or being “discounted” in the words of Goffman (1963), indicates an experience of stigmatisation by those who are bereaved through DRD. The prevention of stigmatisation and drug-related harm is high on the agenda in the drug policy debates generally. Even more so, the fight against stigmatisation is lifted as a central argument for the decriminalisation of drug use and possession of drugs for personal use in the proposal for drug policy reform as currently presented in Norway. Neither the White Paper (NOU, 2019:26, 27-28) nor the proposition to the Storting (Prop. 92 L 2020-2021) include the vast group of next of kin and bereaved persons as affected by the same stigmatisation into the discussion.

It should be noted, however, that important steps have been taken in recent years to prevent overdoses and in the follow-up of groups of the traumatic bereaved. Following a first period of attention from 2014–2019, the second National Strategy for Overdose Prevention 2019–2022 (Norwegian Directory of Health (NDH), 2019) stated the importance of the END project and the need to focus on the welfare of the DRD-bereaved. There has been a recent professionalisation and systematisation of the follow-up of those bereaved after unexpected deaths, such as deaths from suicide, accidents and acts of terror (NDH, 2016). Recommendations include the need for municipalities to respectfully offer early and need-related assistance measures, contrary to previous expectations that a person in crisis will seek support themselves. The recommendations provide clear definitions of key concepts, auxiliary principles and different affected groups, highlighting the importance of providing different measures of support for different groups of people after certain modes of death. Those bereaved by suicide,

accidents, terror and sudden infant death syndrome (SIDS) are highlighted, but those bereaved by DRDs are not mentioned. Therefore, both in formal guidelines and in practice, the DRD-bereaved seemed to have been forgotten (Reime & Dyregrov, 2021).

Despite the body of knowledge about the challenges facing next of kin living with persons with addiction problems and the negative health effects of disenfranchised grief on an individual level (Doka, 2002), those bereaved after DRD have been discounted in the policy debates on drug policy and the services offered to other bereaved people after sudden and unexpected deaths. This article furthers knowledge on their experience-based views on the service provision. The research question is “What advice do those bereaved by DRD give to politicians to improve the situation for those who lose a close person to this kind of death?”

## Methods

### *Context and recruitment*

This article emanates from the nationwide cross-sectional END research project. The END project’s main objectives are to explore how those bereaved following a DRD experience grief and stigma, how they are being supported by health and social care services, and how the municipalities help and support these bereaved people (ResearchGate, 2020). An important goal is that advice on follow-up should be given to the authorities based on the results. The project consists of four mixed-methods studies with separate research questions and data collections (Study 1–3: bereaved; Study 4: helpers). Data were collected during 2018–2019 and consisted of a large survey with standardised and open questions and qualitative interviews. The total sample of bereaved (Study 1–3) consisted of 255 persons who had lost a child, parent, sibling, partner, other family members (a few step-parents, uncles, aunts, grandparents, cousins) or close friend to a DRD. Also, 103 health and welfare professionals from Norwegian

municipalities filled in questionnaires and participated in focus group interviews for Study 4 of the END project. The participants were recruited through public email addresses of all Norwegian municipalities, governmental and non-governmental personnel working with drug users through municipal medical officers and crisis responders nationwide. Thus, the researchers sent letters to various officials who were then asked to pass on information about the survey to people affected by the drug-related death of a relative and helpers working with the bereaved after DRD. We also contacted research networks and professionals in clinical practice, participants at addiction conferences, used various media such as television, radio and social media (Facebook and Twitter) and used snowball recruitment via existing participants.

Participants were invited to complete a questionnaire, either on paper or digitally. All participants received written information about the purpose, method and procedure of the END project and were informed that the data would be published in a non-identifiable manner. All participants provided written consent. The END project was approved by the Norwegian Regional Committees for Medical and Health Research Ethics in 2018 (reference number 2017/2486/REK vest). For more details, see the END project on the END ([www.hvl.no/end](http://www.hvl.no/end)) or the ResearchGate webpage (<https://bit.ly/39aoLmf>).

### *Data*

The data in the present article consist of written answers from an open question in the survey questionnaire used in Study 1 and Study 2: “Is there any advice that you want to give to politicians? (yes/no) If so, please describe”. This question was placed at the end of the survey that mapped the psychological, physical and social situation of the bereaved and their perceived needs for help. In total, 196 (77%) respondents from the total sample of 255 gave written advice and 59 (23%) answered “no” or

**Table 1.** Characteristics of drug-death bereaved giving advice to politicians ( $N = 83$ ).

Characteristics	
Male/Female (%)	16 / 84
Years of age ( $M$ , ( $SD$ ), range)	48 (13.288), 23–71
Relationship to deceased (%)	
Parent	39
Sibling	31
Child	6
Partner	2
Other family members	12
Close friends	9
Months since the loss ( $M$ , ( $SD$ ), range)	93 (78.604), 3–273

did not complete the question. All the respondents highlighted between one and ten sentences containing advice for politicians, yielding an informative data set (altogether 4208 words). The question about “advice to politicians” was contextualised after 21 questions relating to assistance, and the 83 written answers from the homogenous group of bereaved by DRD were rich, punctuated, and saturated. Thus, in line with Malterud’s concept of information power of qualitative data (Malterud et al., 2016), the data are considered to yield credible information. The written statements were identified with an ID corresponding to background information of the respondents and imported to an Excel matrix for analysis. After an initial reading of the material, we observed that, whereas some of the bereaved would give advice concerning the time before the loss, others pointed out what should have been done for the bereaved after death of a loved person. The present article explores the written statements of the 83 participants who provided advice concerning the time after death and had less than 273 months since their loss.

### Sample

The main characteristics of the sample of bereaved are described in Table 1.

In total, 53% had college or university education and 51% were in paid labour (37% full time). The vast majority (90%) reported that at time of death, they had felt “very close” to the deceased and 96% knew about the deceased’s drug use before their death. Concerning help and support, 51% had received help after the DRD, 5% were contacted by the community helpers, and 45% of those being helped were satisfied with it. Only 20% had been in contact with non-governmental organisations.

Among the deceased, 25% were women ( $N = 21$ ) and 75% were men ( $N = 62$ ), aged between 18 and 68 years at time of death, with a mean age of 31 years ( $SD = 9.638$ ). Their substance abuse had lasted on average 13 years, with a minimum of three months and maximum of 38 years ( $M = 13$ ) ( $SD = 8.227$ ).

### Analysis

Thematic analysis (Braun & Clarke, 2006) was used for identifying and analysing logical content patterns (themes) in the material. It is a flexible approach that can be used across a range of epistemologies and research questions and is compatible with both essentialist and constructionist paradigms within social sciences. In this study, it was used as a “contextualised” method, sitting between the two poles of essentialism and constructionism, characterised by theories such as critical realism (for example, Willig, 1999). This position acknowledges the ways individuals make meaning of their experience and, in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material and other limits of “reality”. Themes or patterns within the data are identified in an inductive or “bottom-up” way, meaning that they are strongly grounded in and linked to the data. As such, the themes are patterns across data sets that are important to the description of a phenomenon and are associated to a specific research question.

Braun and Clarke (2006) described a six-phase process for thematic analysis: (1) familiarisation

with the data; (2) coding; (3) generating initial themes; (4) reviewing themes; (5) defining and naming themes; (6) writing up. The phases are sequential; each builds on the previous one and the analysis is therefore a recursive process. As authors, we started reading and re-reading all the written pieces of text in order to become intimately familiar with their content. Then we coded the entire data set in Excel, examined the codes and collated data to identify significantly broader patterns of meaning (potential themes). Thereafter, initial themes defined as patterns of shared meanings underpinned by a central concept or ideas were generated. Moving back and forth between the phases, themes were reviewed and decided upon and given informative names. A table of codes and themes was then produced to be discussed and decided upon by the authors.

The analysis was conducted by the first author (PhD drug policy) and second author (PhD bereavement) separately and then refined in accordance with consensus discussions between both authors. Thereafter, both authors agreed upon the coding framework, the interpretation of the data and the decisions of codes and themes.

## Results

Parents and siblings are the largest groups of our sample for this analysis. When we searched for their advice, we got a clear notion of their quest to find help on a long-term basis after their loss. This is a sample of people who have had a long time to reflect on and understand their needs (maximum of 273 months since the loss, with an average of 93 months). We briefly contextualise the answers to the research question as the respondents also did this.

### *Descriptions of personal situations*

Although the question sought participants' advice to politicians, we also found that some responses contained detailed descriptions of their difficult situations. This quotation from a parent described several dimensions of the life

crisis of losing a close person which was typical of many of the answers:

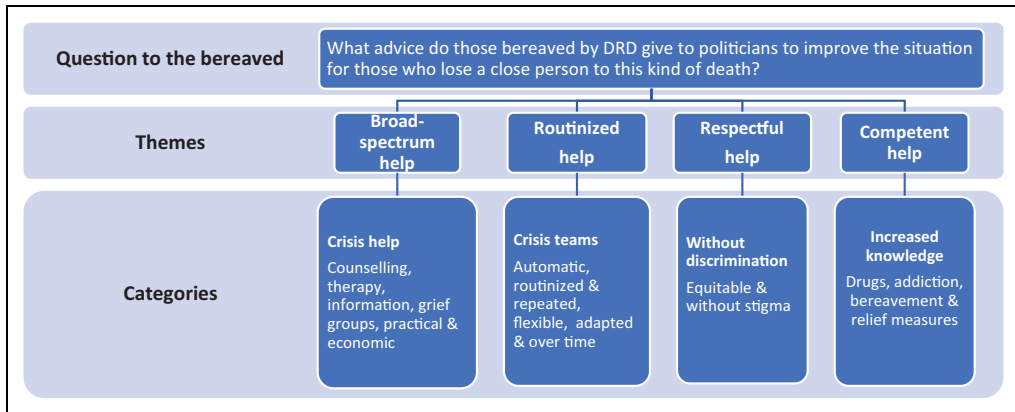
DRD has an enormous stigma. I have a notion that we as parents get a kind of label. The truth is that it is an enormous extra load . . . Then it happens that you lose [your child] in a tragic manner and all the effort you invested in your child over many years becomes in vain. Incredibly meaningless. (ID 39)

A mother who was also a grief group leader claimed that:

As a grief group leader in the XX organisation, I know that most of the mothers who come to us are suicidal after their children die. They also struggle a lot with sleep problems and nightmares, memory problems and lack of concentration, and these problems last for many years after death. Most people need at least three to five years to find a way to live with the loss. Others need much longer. Some of the bereaved might have had a better life, and probably returned to work with adequate and correct help. (ID 77)

Although help was called for by all groups of family members and close friends, parents asked for help more often than other groups. Some, like this mother, had given up seeking answers and put her experiences of meaninglessness and hopelessness into words: "Then the world collapsed again when he finally was found dead in his own bed. We will probably never know more about the circumstances around this and we just have to try go on living with it" (ID 83). A lack of help was connected to DRD, as illustrated by this sister who lost a sibling two years ago: "The feeling of being understood in our grief has not been present, as he was just a drug addict" (ID 10). Siblings strongly called for help and pointed out that the whole family needs help both before and after the death of a sister or brother with drug-related challenges. A sister stated:

I remember my mother getting mentally ill from living with a drug addict and I was afraid she



**Figure 1.** Advice to politicians to improve the situation of drug-death bereaved.

would take her own life. After the death, she laid on the couch for two years. My father worked a lot. My little brother was just a child. I was young . . . In my family it was not talked about. I wish I had got help earlier. Fifteen years after the death I took the initiative to get help. Substance abuse not only harms the substance abuser but everyone in the family in different ways, both before and after death. It can lead to neglect of the other children in the family because the focus on the drug addict is so great. (ID 112)

### *Advice to politicians*

The analysis of the advice to politicians, regarding what bereaved people in the same situation need, generated four interconnected main themes about psychosocial follow-up: (1) broad-spectrum help, (2) routinised help, (3) respectful help and (4) competent help. Each theme contained two or three categories (Figure 1) that will be exemplified through quotations in the presentation of the findings.

**Broad-spectrum help.** The reflections in this category communicated respondents' struggles in several life domains. They wanted to inform politicians about the need for various forms of help, including counselling, therapy, grief groups/peer support, information, practical and economic help. Many participants wrote that

the DRD-bereaved would need a broad spectrum of "crisis help" or "crisis teams" with the type of health and welfare professionals that are provided by public health authorities in Norwegian communities after other types of unnatural death. They expressed the view that health professionals should have a duty to assess the needs of the bereaved following DRDs to find out what specific forms of help are needed, "in the same way as they did after the Norwegian terror killings in 2011" (ID 118). Many people who were not specific about the various forms of help endorsed adequate and correct help that should be varied.

Many participants highlighted the importance of a focus on family, with special attention to and time for the closest bereaved, i.e., parents, siblings and children of the deceased. Another recommendation was that they should be offered "some kind of psychological help" and that mental health care should be strengthened for those left behind after DRDs. A sister wrote "for my part, it will be easier to talk about difficult things with a professional, because not everyone in your circle of friends and family wants to discuss dark things. For me it will be too close" (ID 254). Others who asked for counselling and grief therapy wrote that they have struggled with great grief for many years before the person's death. Waiting times of half a

year to a year to get an appointment with a psychologist were deemed inappropriate crisis help (ID 262).

Respondents stated that because people are run down, few will actively seek psychological help. Several pointed to the need for support with stigma, guilt and trauma after the loss. For some, the time before the death may be so straining and traumatising, because of the violence of the drug abuser, that they may need help to deal with anxiety and other effects after death. One mother explained how the whole family were helped and why she thought this had contributed to the wellbeing of the family five years post-loss:

I want the bereaved to receive help in the form of family therapy, hours with a substance abuse therapist or priest, etc. after the loss, but also and especially as soon as an imminent substance abuse problem/illness becomes stressful and lasting. I think I have done so well because I contacted the Department for Substance Use and Addiction and got hours in family therapy every month during the three years when the drug/disease problem (psychosis) for my son was at its worst. After the death, the family was helped by a crisis team once a month for one year, and I also sought out a priest for two years. My daughter and ex-husband went to grief groups for two years, led by a priest. All the family members, three siblings and my ex-husband are currently living a full life. To politicians, I would like to say that I believe it is important to give relatives and the bereaved the opportunity to get as much appropriate help as possible, adapted to each individual and their situation – and automatically offered. (ID 108)

Participants felt that they wanted information about the cause of death from the police, including being supported to review the autopsy report, as stated by a young daughter: “the autopsy report should be accessible [to relatives] even if it is ordered by the police. If the cause of death is unknown, we should be invited to the hospital for an explanation of what it means” (ID 249).

Another request was to organise a menu with various service offers that one can choose from and an overview that is easily available, both in terms of online provision and via physical attendance (ID 206). Some respondents claimed that practical and economic assistance would be needed because of the extraordinary situation, as this sister wrote: “When you experience such grief, and your head cannot keep up, such things require very much of you and small things can feel like you have a huge mountain to climb” (ID 103). Others pointed out that the National Welfare Service (NAV) does not function optimally and that the bereaved need help to get back to a work–life balance more easily.

On a general level there was a focus on advice for help from the health and social services, but the importance of peer support, e.g., in the form of grief groups, was also promoted. Participants thought that other bereaved people have a special understanding that is very much needed and wanted when experiencing the crisis of DRD losses. In the words of a mother: “The most important thing for someone who has lost someone in this way is to talk to others who have experienced the same thing. They are the ONLY ones who really understand what it’s all about” (ID 278). Therefore, “politicians and the Government were urged to support the development of an organisation for the drug-death bereaved, to get a meeting place – a place to belong” (ID 21).

**Routinised help.** The second theme pertained more explicitly to the organisation of the help. Respondents asked for outreach services that are tailor-made and offered regularly on a long-term basis. The politicians were urged to provide routinised help that is organised by crisis teams, but at the same time being flexible and adapted to the individual and the family. Help should be given automatically by the services and continue over time. The justification for this was that many bereaved people do not know what help they need, only that they need help. They do not know where to find adequate resources, nor do they have the energy to make

contact if they know what they need. Finally, they expressed that they do not know what rights they have as drug-death bereaved.

Respondents asked that local crisis teams be part of “the regular emergency preparedness in Norway” (ID 46) to secure systematic help. Recommendations were that there should be crisis teams available after all DRDs, and that treatment and contact with professionals should be easily accessible for the bereaved, when they are “ready for it” (ID 51). Many of the bereaved participants were aware of the Norwegian health policy which undertakes assistance for those bereaved by, or who have survived, crisis and catastrophes, and asked for the same follow-up system. Standardised and equal principles of help “should be offered on an equal basis after unnatural deaths and there should be no difference due to cause of death” (ID 52).

As stated by many participants, it is very difficult to know what help is needed when people are in crisis and people around do not see and understand what help and support is needed. A sibling claimed that there are many reasons for this that must be solved by a systematic, automatic and continuous system for psychosocial follow-up:

When a family member is in active drug use, it is followed by a fear and anxiety for the close family that no one else can imagine... Although in many ways we were prepared for this day to come, it was a shock that we should have help to process... of course, we should have had help to deal with this. So, my advice is probably simple and straightforward, that the family members of a deceased drug addict MUST be followed up. There should be an offer of continuous follow-up, not just a notice in the newspaper that there are groups for those who want them. The threshold for seeking out such a group can be high for many. A team in each municipality should ensure this, someone in addition to “only” the GP who understands. (ID 20)

These messages and advice were repeated in many ways by several participants who pointed

out how difficult it is to know what one needs when in grief and not having the energy to seek the help yourself: “Give us active outreach help after DRD and repeat this offer after some time” (ID 34); “Offers of help should come early, and if you refuse, the offer should be repeated after four to six months” (ID 134). The bereaved reported that they are in a mental and physical state that makes it hard to seek necessary help themselves due to shock and grief. The message of repeated contact to offer help was made by bereaved people who felt that many may refuse to accept help close after the loss but may experience a need when the shock has subsided.

Bereaved children and young people should be attended to and given a special focus independent of parents’ needs. “Children in the family should be asked directly if they need help and that should not be the decision of the parents – they can answer for themselves”, a bereaved sister stated (ID 112). Some children might have been exposed to neglect since the focus has long been on the drug addict. A young woman who lost her mother wrote:

There should be a better support system around children of drug addicts in general, but preferably especially after a death. Don’t just be placed in a foster home and forgotten there. I know with myself that even in the darkest times of my mother’s drug abuse, I still lived in hope, and I had something to fight for. When the death was a fact, the whole ground was torn away beneath me, and I had nothing to stand on. I’ve staggered ever since. It was probably in my case reinforced by the fact that mother died in a treatment programme, and we had for about two years lived in the belief that we were done and out of danger. Our shoulders were lowered, we made plans, only to end up feeling that life itself and the universe have held you for a huge fool. The immediate support of family and friends was enough in the beginning and at that time I probably would not have agreed to any help from outside. But when the dust has settled half a year later, and everyone else has moved on and



expects it to be over, then it would have been nice if some knowledgeable person would have extended a hand. (ID 142)

Due to serious burdens before death and long-lasting aftereffects of the loss, participants urged support providers to take a long-term perspective on psychosocial help: "Most bereaved need between three to five years of follow-up", wrote one mother (ID 77).

The great insecurity of the bereaved, and their need to be seen and understood, led some participants to advise politicians to give very clear and unambiguous guidelines for follow-up. Bereaved parents, children and siblings were mentioned as groups that specifically should be attended to.

**Respectful help.** In the third theme, the bereaved asked for equitable and respectful help. They wanted to be met in the crisis without stigma, in the same way as other bereaved people after unnatural deaths/accidents. Many respondents observed that they had been treated differently than other groups of suddenly bereaved in the country. Support for the bereaved was felt to be comprehensive after the terror killings in 2011, accidents or suicide; it was hard for participants to witness the different approaches to follow-up that were offered to these people compared to themselves. A mother stated that,

... today, there is no priest, social worker, etc. who provides a meeting place for the drug-death bereaved, seeks out and contributes to help in the acute phase. This is a big difference compared to the response to traffic accidents and homicides. (ID 116)

Another mother wrote:

Unexpected death, especially when you lose a child, is a traumatic experience. If the death is caused by overdose, suicide, or an accident, there should be equality when it comes to help through the crisis, irrespective of which municipality you live in. (ID 262)

A close family member also pointed out the injustice when considering the long period of anticipatory grief that the drug-death bereaved have experienced:

There is great attention and help for families who experience children dying in major accidents and disasters. There is no sure help for those who are faced with death as a possible outcome every single day, 365 days a year, for years. (ID 60)

The differential treatment was linked to the stigma that was experienced by the bereaved, as shown in these statements from close family members: "The feeling of being understood in grief has not been present because he was just a drug addict" (ID 10); "We experienced zero understanding. He was worth nothing because he was in a drug environment" (ID 159); "The stigma associated with intoxication is also noticeable when talking to the police. They gave the impression that this was just 'another drug addict' who was dead" (ID 66).

A 39-year-old man who lost his close friend 16 years ago expressed the need to be included into the group of next of kin:

Give health service personnel the duty to evaluate the next of kin's needs after a DRD. Remember that next of kin is not only families and earlier friends, it is also us that know the deceased from their life with addiction and from treatment. Perhaps we are even more ashamed because we are a part of the problem. (ID 79)

An important message to politicians was that the stigma against drug users must be combated because they are also human beings and should be treated with respect.

**Competent help.** The final theme encapsulated the need for competent help. The bereaved put a lack of knowledge about their situation into a context with stigma and lack of help. The advice to politicians clearly signalled that the bereaved did not feel understood by professional helpers, e.g., police, priests, crisis teams, NAV and others who they met after the loss. As

stated by this 26-year-old bereaved uncle, crisis teams should have the competencies of both addiction and bereavement to help and support drug-death bereaved:

Most relatives know how dangerous their (the deceased's) lifestyle is and that every single dose can be potentially fatal. Relatives may be aware that they are at high risk of dying, but one is never prepared when it first happens. Therefore, I believe that it should be a crisis team that has expertise in the problems and grief associated with this group. My family got a priest at the door who conveyed the message of death, but he had no expertise in addiction or drug abuse problems. (ID 66)

It was recommended that professional helpers should learn about crisis reactions after traumatic and unnatural deaths to understand the traumatic impacts (such as concentration problems, nightmares, and sleep problems) of such deaths. The bereaved pointed out the importance of connecting such reactions to knowledge about the deceased being a drug user. A young sister who was bereaved three months before participating in the research pointed to the importance of helpers understanding the connectedness between the time before and after death to understand and help the bereaved:

They should study the concept of "co-dependence". That situation does not disappear by itself, even if the person dies. One has a strong notion of guilt after the death because one lost a struggle which was impossible to win from the start . . . This is as traumatic as losing someone in an accident as it happens equally suddenly. (ID 85)

Participants were also of the view that professionals should learn from other professionals with competencies in the fields of both addiction and bereavement, and these fields should be more interconnected. In addition, knowledge about what help should be offered and when, and the importance of including bereaved children and the family, should be improved.

Importantly, as stated by several participants, other bereaved people should be asked for input to increase the user knowledge in this field. A mother who had lost her son in an overdose advised politicians to "introduce quality indicators on offers to the bereaved of both overdoses and suicides and earmark funds for initiative development and knowledge development in the field" (ID 116).

## Discussion

The respondents' advice to politicians entails various personal experiences, needs, and suggestions for solutions. In our material these materialised in four central themes: the need for receiving broad-spectrum help; the need for authorities to organise the help in good routines, as well as the need to provide respectful and competent help. The participants saw their own life situations as hard to handle on their own. Their answers also revealed experiences of being excluded and not treated equally to others who had lost someone close in unnatural or unexpected death cases. Thus, we find an apparent experience of being discounted, which is a central characteristic in stigmatisation and marginalisation processes.

Our exploration of open written answers aims to improve support services available to the bereaved after DRD and help support the inclusion of their voices to the political debate to make their advice matter to policymakers. Notably, more than two-thirds of the advice stemmed from parents and siblings, i.e., those who may have been closest to the deceased, which lends their advice credibility. They assert that there is a need for a greater understanding of the reasons for the seeming exclusion of this group of bereaved people from services that are provided for other groups of bereaved people. In the further discussion, we elaborate on how institutional, epistemological, and normative dimensions historically have framed both policy debates and the development of services in the drug area (Thelen & Steinmo, 1992). In this discussion, we find possible explanations for

the bereaved group's exclusion and invisibility and potential strategies to strengthen their influence and make their advice matter to policymakers.

The first dimension that we want to bring attention to is this group of people's right to become eligible for and included in support structures. Here we refer to the request for broad-spectrum and routinised help. The second dimension refers to the need for a knowledge base to make this group of bereaved people more visible and relevant in the policy processes, both in the general drug policy debate and also in the specific discussion of service provision. The requests for respectful and competent help are connected to this dimension. Thus, we can look to both organisational and more normative and epistemological dimensions that should be included to make the advice matter in the development of policy and services for this group.

### *Becoming eligible for welfare services*

It is obvious that the situation of this group is defined by their closeness to the area of the drug problem and drug policy. Historically, the drug problem has been met by comprehensive measures in the Norwegian criminal justice system, together with a strong focus on social rehabilitation and treatment. During the period from the first White Paper in 1976 (Fjær, 2004) to the recent NOU on drug reform (NOU, 2019:26), there has been high political interest in the area and a broad-spectrum service system has been built. Historical studies of Nordic welfare policies on alcohol and drugs describe a process of gradual professionalisation, with a movement from a normative and value-based policy to rationally organised service provision based on professional principles (Edman & Stenius, 2007). In Norway, the Substance Treatment Reform (Rusreformen) of 2004 played a formative role in this professionalisation. In summary, it secured formal patient rights for people with drug addictions and improved treatment quality by moving the responsibility

for treatment from county level to specialist health care. However, one evaluation finding was the challenge of establishing continuity of care and communication between the different sectors and levels of governance (Nesvaag & Lie, 2010).

This historical development process also saw the introduction of harm-reduction strategies during the 1990s, and two separate action plans for the reduction of DRDs from 2014 to 2022. The focus of both action plans has been concentrated on the drug users, without inclusion of their families or social network. On the organisational side, we can argue that moving the responsibility to specialist health care and giving patient rights to the group represent an individualisation which made the families even more peripheral. DRD was handled partly by the police or by the specialist health care services, with the follow-up of bereaved parents, siblings and friends handled at municipal level. Thus, the organisation created a blind spot for this group of bereaved in the development of crises teams and grief support groups at the municipal level (NDH, 2016). Those bereaved by DRD were latecomers to eligibility for services from municipalities compared to other groups, e.g., those bereaved by suicide, for whom exclusive guidelines for psychosocial follow-up were developed in 2011 (NDH, 2011a).

Our analyses have shown that the DRD-bereaved themselves have, however, a wealth of advice grounded in experience, which emphasises the merits of using existing health and welfare services to provide better help. There were suggestions for how regulation and professionalisation within the framework of the existing system can provide a basis for better help. The legal regulation of right of information and access to information was central to many of the answers of the bereaved. This could take many forms, e.g., information to understand normal reactions to unnatural deaths, how to support one's own children and where to access help if it is not offered (Dyregrov & Dyregrov, 2008). All these elements are

important aspects in what we consider to be securing the quality of welfare services.

There were also several suggestions for broadening the spectrum of relations that should be viewed as next of kin, by including the wider family and close friends. In addition, many references to the life situation over many years prior to the person's death showed that most bereaved have health problems caused by long-term extreme life experiences in families as parents or siblings, or from their own addiction problems. We know that many are worn out when the DRD occurs (Richert et al., 2018) and, as with many other people after unnatural deaths, the DRD-bereaved lack the energy to contact support or make any claims for themselves (Dyregrov & Dyregrov, 2008). Many have had bad experiences with the "help-system" after many years of struggle for their child, sibling, partner or close friend with drug challenges (Dyregrov et al., 2020; Templeton et al., 2017).

The respondents also expressed a need for an institutional dimension in terms of making the support for this specific group an integrated part of welfare services. Generally, when respondents described experiences of requests for psychological treatment that were rejected, or information they were denied, it was caused by lack of formal rights, or the perspective that the group or situation is not defined as sufficiently serious to be entitled to help. Given the historical background of the lack of formal recognition of the DRD-bereaved, it is probably more relevant to think of this situation as a result of a lack of institutionalised attention to the needs of this group.

An excellent Norwegian example of how the bereaved might be attended to is represented by the large-scale follow-up after the Utøya Island terror attack of 22 July 2011 (NDH, 2011b). In line with the guidelines that were revised after the atrocities (NDH, 2016), all 69 bereaved families who lost their children were automatically contacted by an appointed family contact and offered adapted broad-spectrum psychosocial help for at least one year. The follow-up

model was based on principles of proactivity from helpers and showed a far greater user satisfaction than found in any other research with people bereaved by unnatural deaths in Norway (Dyregrov et al., 2015). None of the DRD-bereaved people in our sample reported that they experienced anything close to this kind of proactive follow-up.

### *Becoming visible and relevant to politics by building knowledge*

The request for respectful and competent help led us to the knowledge base of the provision of services to people bereaved after DRD. While many respondents expressed that they are less visible than other comparable groups, some of them pointed to the helpers' lack of knowledge about the effects of DRD bereavement. Some also accounted for experiences of stigma connected to drug use and drug death in general as documented in previous research (Curcio & Corboy, 2020; Richert et al., 2018). Reasons for the invisibility of the group in research and policymaking related to DRD may be hard to understand, particularly when the problem of drug addiction has received so much public and political attention since the late 1960s. It points in the direction of the group also being discounted in the priorities of research themes.

There is a large body of epidemiological studies on DRD both at national and international level (European Monitoring Centre for Drugs and Drug Addiction, 2019), which have concentrated on causes of death, partly in order to develop preventive strategies. Amundsen (2015) commented on the lack of insights in these studies into the heterogeneity of the group of deceased and found that the socio-economic situation prior to death was more heterogeneous than expected. Our respondents clearly described experiences of being associated with a rather one-dimensional conception of the drug problem when they needed help. There is a lot of knowledge about the general effect of high and increasing mortality rates in specific groups in society. Large-scale research has provided

convincing and disturbing evidence for the increased risk of negative health effects, including premature death, for the next of kin after unnatural deaths (Djelantik et al., 2020; European Monitoring Centre for Drugs and Drug Addiction, 2019; Li et al., 2003). For research on social problems to be relevant and receive funding, it seems necessary to have compatibility with central political goals. The aim of contribution from research in the handling of the drug problem has guided the reach priorities in most countries and has been very explicitly formulated in the Nordic countries (Fjær, 2010). The lack of research on the situation for people bereaved after DRD (Titlestad et al., 2019) follows as a consequence of research focusing on the handling of the drug problem, and paying less attention to the social cost of the problems, and even the cost of death.

Our participants supplied some interesting reflections on the causes of their invisibility, via a spectrum of emotions as regards the need to be understood, to be seen and respected. They also described the effects of trauma and stigma, and notions of shame and anxiety (Curcio & Corboy, 2020; Dyregrov & Selseng, 2021). Their advice to policymakers in respect to these experiences was directed towards re-establishing dignity for drug users and the bereaved, and to develop understanding by including experience-based knowledge in service development. Inclusion in the general help system provided for similar groups would be a powerful approach to addressing the self-stigmatisation that is strongly present among the DRD-bereaved (Corrigan & Watson, 2006; Løberg et al., 2019).

In line with some previous research (e.g., Di Sarno et al., 2021; Nordgren et al., 2019; Richert et al., 2018), our respondents highlighted the necessity to build knowledge and conduct research into the life situations of families before death. The distinction between the time before and the time after death lacks relevance for the life worlds of these persons. Further research should focus on the experiences of this group of bereaved as co-dependent, and

develop understandings of the specific life situations of families both pre and post loss. The term co-dependence appears in a number of answers and also has an ideological and normative basis that should be investigated further (Nordgren et al., 2019).

Finally, the importance of making this group relevant to participate in the policy process should be noted. Several respondents pointed to the necessity of getting organised, but the organising process requiring political recognition and support. User involvement is a larger trend in other areas and is especially important when it comes to groups that have been invisible in the public sphere.

### *Methodological issues*

There are several methodological aspects which highlight this article's quality. First, the two authors analysed the data separately and discussed the categories and themes to yield the most "credible" conceptual interpretation of data (credibility). Second, we ensured transparency by referring to IDs for typical citations of the bereaved which we saw that exemplified the themes. Third, the transferability of the findings beyond the project to similar populations is good, since the data are based on written experiences from a large and varied community of DRD-bereaved people. Finally, we consider the data analysis and theory generation to be reliable as it has been completed by two senior researchers representing the fields of both drug policy and bereavement. Also, the data combine methods, giving insights into both the distribution and the content of the research question on the world's largest DRD population so far.

### **Conclusion**

The analysis clearly illustrates that DRD-bereaved family members and friends are relative latecomers in receiving help and support compared to other bereaved groups. They express the experience of being discounted and

excluded from the service system. They are aware of the situation and contribute to possible explanations on unequal access to support services, as well as making suggestions to improve the services. Even if the DRD-bereaved have been included as a group eligible for help in the national guidelines for psychosocial help (NDH, 2016), they account for experiences of lack of follow-up, both short- and long-term.

The analysis provides some overall and clear advice for further development of support for this group, namely broad-spectrum help, routinised help, respectful help and competent help. These experience-based suggestions are both organisational and epistemological in their nature. Within the sphere of public health research, a common saying is that you cannot manage what you do not measure. Our participants pointed out a need for more research-based knowledge about the life situations of the next of kin, both before and after their loss, in order to provide good services. Furthermore, the analysis shows the necessity to make some welfare services more visible, as findings point to the structures and services that are already there, which should be accessible.

This study provides evidence of service development needs of both an organisational and an epistemological character. What is usually described as “the drug problem” is more than problems of consumption, addiction and criminality. The scope of policymaking should be similarly widened so that it includes families and social networks.


### Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The END project has financial support from the Research Council Norway, Western Norway University of Applied Sciences, the Municipality of Bergen, and The Norwegian Directorate of Health.

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