

Experiencing grief and trauma in the ongoing syndemic

A narrative review
and reflection from
people with lived/living
expertise of drug use
and their allies



Authors:

Matthew Bonn*^A, Samara Mayer*^{A,B,C}, Brandi Abele^A, Frank Crichlow^A, Kathy Pinheiro^A, Alex Sherstobitoff^A, Natasha Touesnard^A, Dean Wilson^{A,B}, Kelsey Speed^{A,B,C}, Kat Gallant^{A,B,C}, Jade Boyd^{A,B,C}, People With Lived/Living Expertise of Drug Use National Working Group

* Matthew Bonn and Samara Mayer contributed equally to this report, and share first authorship

Affiliations:

^A People With Lived/Living Expertise of Drug Use National Working Group, Canada

^B British Columbia Centre on Substance Use, British Columbia, Canada

^C University of British Columbia, Vancouver, Canada

Suggested citation:

Bonn M, Mayer S, Abele B, Crichlow F, Pinheiro K, Sherstobitoff A, Touesnard N, Wilson D, Speed K, Gallant K, Boyd J, People With Lived/Living Expertise of Drug Use National Working Group. (2024). Experiencing grief and trauma in the ongoing syndemic: A narrative review and reflection from people with lived/living expertise of drug use and their allies. Vancouver, Canada: Canadian Research Initiative in Substance use Matters (CRISM) People With Lived/Living Expertise of Drug Use National Working Group.

Design/Layout: Pulp & Pixel

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Acknowledgments

We acknowledge that the work of this document was done by people across the Indigenous lands of what is now referred to as Canada. But acknowledging territory is only a small part of cultivating strong relationships with the Indigenous Peoples of Canada, and should take place within the larger context of genuine and ongoing work to forge real understanding and challenge the legacies of colonialism. One small way we strive towards this is by working to include and empower Indigenous Peoples to take leadership roles in the work we do.

This report benefited from the contributions of other members of our People With Lived/Living Expertise of Drug Use National Working Group who are not on the authors list—only those who provided permission were named. We also thank Jennifer Stewart and Alex Betsos. This study was supported by the Canadian Institutes of Health Research (FRN 154824 and MM1 181119).

We highlight and acknowledge all of our community members who have lost their lives due to the ongoing overdose and drug poisoning crisis. We have lost members, and continue to lose members, due to drug-related harms such as HIV/AIDS, hepatitis C, and overdose. Rick Sproule, Loretta Brown, Karen Turner, and Alexandra de Kiewit—we miss you, and continue to work with

you in our hearts and remember what you have taught us as we move forward.

We want to highlight the contributions of one of these members in particular, Alexandra de Kiewit. Alexandra played a significant role in our working group and community, and we only just recently lost her. She was a very passionate and dedicated advocate who had expertise in HIV/AIDS, hepatitis C, sex work, harm reduction, and other drug policy-related issues. Alexandra was particularly passionate about this project, which could not have been done without her. This report is one way to acknowledge the work she has done.

*This report is
dedicated to you,
Alexandra.
We miss you!*

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Abstract

Background: People who use criminalized drugs are exposed to repeated losses of their loved ones. Despite persistent (numerous) experiences of grief, they often lack access to effective services to support them. While the devastating impact of this grief is pervasive among people who use drugs, there has been limited academic attention on this critical topic.

Objective: To centre the expertise of a national working group of frontline harm reduction workers with lived/living expertise of substance use by collaboratively reviewing, analyzing, and generating knowledge regarding grief as a central and underrecognized component of Canada's overdose epidemic.

Methods: From 2020 to 2022, the group (which has been meeting monthly since 2018) conducted a community-based narrative review on grief as it pertains to people who use drugs, and drew on member expertise to reflect and expand upon the existing literature. Findings emerged via monthly Zoom meetings facilitated by rotating members and through one-on-one correspondence, later analyzed thematically by members.

Results: Multiple types of grief and methods for processing grief as it relates to trauma were identified as relevant to members' experiences. Also identified were experiences of grief that were absent from the literature, including the compounding impact of loss amidst experiences of stigma and limited resources to address grief due to factors such as employment discrimination (e.g., via employment benefit programs such as counselling, paid leave). Creative means to attend to grief were discussed, including alternative memorials when prevented from attending funerals due to drug-related stigma.

Conclusion: Policy changes designed by/for people who use drugs are urgently needed to recognize and address cumulative grief, alongside upstream grief interventions and rapid, actionable alternatives to the toxic unregulated drug supply that is causing preventable deaths and perpetuated by prohibitionist drug policies.



Photo by Alex Sherstobitoff

Introduction

People who use criminalized drugs are experiencing profound grief and trauma stemming from an ongoing syndemic. Syndemics occur when multiple health and social issues intersect and interact to worsen or accelerate disease progression and social outcomes (Bonn et al., 2020; Singer et al., 2017; Tsai et al., 2017). Factors contributing to the current syndemic include alarming rates of accidental overdose (Belzak & Halzerson, 2018), HIV and hepatitis C virus infections, other injection-related infections, homelessness, extreme poverty, and now the COVID-19 pandemic (Ali et al., 2021; Collins et al., 2020; Russell et al., 2021). In Canada, this syndemic has led to the deaths of more than 20 people per day due to overdose (Government of Canada, 2023) and the crisis disproportionately and more severely impacts Indigenous Peoples and socio-economically marginalized people who use drugs (First Nations Health Authority, 2023).

Survivors of the syndemic have experienced extreme amounts of loss, related not only to the deaths of their friends and family members, but also to the loss of housing, secure income, child custody, social circles, health status, and social groups. This leads to complex and compounding expressions of grief, rendered further complex due to trauma such as intergenerational trauma, trauma

associated with responding to overdoses, and trauma stemming from medical violence (Roche et al., 2013). Experiences of grief and trauma among people who use drugs are diverse and ongoing, and survivors often do not have access to effective supports or resources to attend to the loss they have experienced. Unfortunately, despite a profound need, the emotional impact of grief and trauma in the context of the syndemic has not been sufficiently investigated in research, nor widely acknowledged and addressed in policy and programming. To address this important gap, this community-based report focuses on grief and trauma as experienced by people who use drugs in the context of the persistent syndemic.



Methodology

This report stems from the perspectives of our National Working Group of People With Lived/Living Expertise of Drug Use (herein referred to as “the working group”). The working group, which has been meeting monthly since 2018 and is composed of members from four regional nodes across Canada: British Columbia; the Prairies; Ontario; and Quebec/Atlantic regions, developed as a component of the national Canadian Research Initiative in Substance use Matters (CRISM, 2022). Members rotate facilitation of virtual monthly meetings to discuss and develop research projects, research priorities, knowledge translation, and mobilization ideas to address Canada’s overdose epidemic (e.g., People With Lived Expertise of Drug Use National Working Group et al., 2021), and to support one another.

We draw upon methodological approaches that are community-driven and involve collaboration, shared decision-making, and power sharing. Community-based research methods are particularly appropriate for shared efforts to address community-identified issues with the goal of social justice and/or societal transformation (M. R. Boyd 2020; S. Boyd, 2017; Souleymanov et al., 2016). This practice has proven to be especially effective in substance use-related research, the principles of which have been expanded upon by

members of our group (e.g., Boilevin et al., 2019; Touesnard et al., 2021), and has been essential for mobilizing equity-focused approaches to the unique challenges experienced by people who use criminalized drugs (Damon et al., 2017; Souleymanov et al., 2016).

From 2020 to 2022, the working group conducted a community-based narrative review on grief as it pertains to people who use drugs, and drew on member expertise to expand upon the existing literature. This topic was identified by the group because it had received little attention in the academic field despite its importance for members of the working group and affected communities. Further compounding the significance of this topic was the painful and unarticulated experience of losing four of our original 14 group members to drug-related deaths since we began to work together in this capacity. Our process involved three components: member-facilitated group discussion on grief and trauma, a review of thematically related manuscripts (Grant & Booth, 2009), and collective manuscript development. The narrative review aimed to centre the expertise of our national working group of frontline harm reduction workers with lived and living expertise of substance use by collaboratively reviewing, analyzing, and generating knowledge regarding grief and its intersection with

trauma as a central and underrecognized component of the syndemic.

Articles for this review were identified through a combination of search terms (e.g., overdose, grief) and referrals from working group members. All working group members then self-selected various academic and grey literature to review (31 readings in total). At meetings, each member reported summaries of and personal reflections on their readings. We then developed the main research question through discussions of the relevant literature: “How do people who use criminalized drugs experience grief and trauma in

the context of the syndemic?” Findings emerged via monthly Zoom meetings and through one-on-one correspondence, later analyzed thematically by members. Feedback was given both orally and in writing by members of the working group throughout all stages of the project. The initial report was co-drafted by MB (who has lived expertise of drug use) and SM (who is a health researcher) based on this narrative review. Working group members provided feedback and revisions via group discussions and email correspondence before approving the final report. Ethical approval was obtained from the Providence Health Care/University of British Columbia Research Ethics Board.

Narrative Review on Grief and Trauma

While grief and trauma have received interest in the academic field, there has not been an extensive examination of how these emotional states are experienced among people who use criminalized drugs living through persistent crises (Becker & Fiellin, 2020; Krausz et al., 2021). This section summarizes some relevant Western models and theoretical frameworks of grief and trauma that were described in the reviewed literature, with our personal perspectives and experiences of grief and trauma as a working group engaging with the above literature in the context of the syndemic explored in the *Reflections boxes* throughout.

The reviewed literature on grief spans many disciplines (e.g., sociology, psychology, anthropology), which conceptualize grief from varied viewpoints. For instance, sociological literature explores the impact of the social bond with the deceased, while anthropological literature investigates the cultural experiences of the mourning process (see, for example, Garcia, 2008; Jakoby, 2012; Rosaldo, 2014; Silverman et al., 2021). Within these disciplines, various concepts and theories specific to the grieving experiences of people who use drugs have been developed. We explore these models

cautiously, and resist the tendency to individualize and medicalize grief. Rather, we aim to draw attention to the broader social and structural contexts these models are situated within to highlight how intersecting factors such as drug prohibition, racism, and housing insecurity impact the way people who use drugs experience and process grief. Similarly, we are attentive to the fact that the invoking of trauma as a concept

can lead to a medicalized focus on the individual while obscuring the concrete mechanisms that cause, exacerbate, and sustain it (e.g., social and structural factors such as prohibitionist policies, racialized and gendered violence, and the legacies of slavery and continued colonialism) (Brave Heart et al., 1998), resulting in the ongoing erosion of networks, communities, and families (S. C. Boyd, 2004; Million, 2013).

Grief

The definition of grief is complex, as it is experienced both individually and collectively, and is embedded in one's social, cultural, and historical context (see *Reflections: Everyone Experiences Grief Differently*). As a starting point, we can think about grief as “the physical, emotional, mental, and spiritual responses within us stimulated by the fact of the loss—being bereaved” (Perreault, 2011, p. 31). Grief arises from all types of loss; in addition to the death of a friend or loved one, grief can also derive from the loss of a child through forced separation (e.g., to child protection services) (Kenny et al. 2022; Nixon et al. 2013), loss related to one's health (e.g., HIV diagnosis), or loss of a social role (e.g., as a partner or grandparent), among many other things (Perreault, 2011). Grief can generate all kinds of different emotions, including anger, denial, relief, shame, and guilt (Young et al., 2022). Given the varied experiences, expressions, and coping mechanisms of

grief, it cannot be approached through a singular lens, model, or intervention (Barney & Yoshimura, 2020). Grief is also a nonlinear process that is very complex, particularly when people experience sudden loss, multiple loss events, or loss from stigmatized activities (Barney & Yoshimura, 2020). Below are some models of grief relevant in the context of people who use drugs.

Special Grief

One model of grief developed by Dyregrov and colleagues (2020) is *special grief*. This model comes from the view that overdose death is a “special death”—an unintentional death that should not have happened so soon, yet receives both less attention and less empathy from society (Dyregrov et al., 2020; Lambert et al., 2021)—that is considered a threat to individual, familial, and societal ontological security (a sense of stability in life) (Dyregrov et al., 2020; Guy & Holloway, 2007).

Anticipatory Grief

Another concept, *anticipatory grief*, describes the experience of expecting a death or loss to happen imminently, which elicits grief from the bereaved before the death actually occurs (Valentine et al., 2016). For example, one research study explored how, among family members bereaved due to a substance use-related death, those with past knowledge of the deceased's substance use reported a pre-existing sense of loss before the death (Valentine et al., 2016).

Disenfranchised Grief

Related to these concepts, *disenfranchised grief* refers to grief that is not publicly mourned, openly acknowledged, or socially validated (i.e., lack of recognition of a person's right to grieve or social sympathy for the loss) (Selfridge et al. 2021; Valentine et al., 2016; Wojtkowiak et al., 2019). This type of grief is driven by stigma, which can come from many places, including family, friends, communities, and service providers (Valentine et al., 2016). As a result, people bereaved due to drug-related deaths may seek to hide or misrepresent the cause of death to avoid stigma or other negative responses from others (Valentine et al., 2016).

Cumulative Grief

Cumulative or compounded grief refers to when people experience multiple losses and/or are frequently in multiple loss situations (Giesbrecht et al., 2018;

Reflections: Everyone Experiences Grief Differently

People who use criminalized drugs are not homogenous and therefore one strategy to address grief and trauma will not work for everyone. We come from all sorts of backgrounds, with diverse ethnicities, genders, sexual orientations, abilities, nationalities, and life histories. The cultural aspect of our grieving should be central, and we should be allowed and encouraged to grieve in the ways that work best for us.

Kenny et al., 2022; Perreault et al., 2018). Multiple losses can result in a cumulative burden of grief, which can further complicate and present challenges for processing grief and loss (Perreault et al., 2018). A recent study found that of 244 research participants, 28.7% reported two or more personal overdoses, 70.9% witnessed two or more overdoses, and 28.3% experienced the overdose death of two or more significant persons in the previous six months (Kenny et al., 2022). Beyond more severe responses to grief and loss when experiencing or witnessing multiple overdoses, this study also found that cumulative exposure to different types of overdose events (i.e., experiencing, witnessing, or responding to an overdose or losing someone to an overdose) was associated with a higher proportion of other emotional responses, such as anger, blame, and guilt (Kenny et al., 2022).

Mourning Without End

Related to cumulative grief is the concept of mourning without end (Garcia, 2010),

which builds on the idea that the loss of a loved one remains persistently present and behaves like an open wound (Freud, 1995). Importantly, this work moves away from the tendency to pathologize melancholy and instead highlights how suffering is also embedded in and perpetuated by institutions (e.g., drug treatment centres, drug courts, Narcotics Anonymous meetings; see **Reflections: Endless Mourning**) (Garcia, 2010).

Generational Loss

Lastly, the concept of *generational loss* refers to a significant number of deaths impacting a whole community. This concept was developed during the HIV crisis, in which the significant number of HIV-related losses led to the disruption of security and stability

Reflections: Endless Mourning

As a working group, we have experienced this “mourning without end”—noting that without dramatic socio-structural changes, including ending drug criminalization and prohibition, access to safer drugs, and an end to economic, colonial, and gendered violence, preventable deaths and experiences of loss and grief will inevitably continue.

of entire communities (Perreault et al. 2018; Rofes, 2013). It is thought that another cycle of generational loss is currently being experienced, as our communities are dealing with a significant loss of people who use drugs due to the ongoing syndemic, resulting in profound individual and societal implications (see **Reflections: Lost Advocacy**) (Kenny et al., 2022).

Trauma

Grief and trauma are interrelated, as they are often experienced simultaneously when someone who uses drugs dies. Additionally, people who use drugs are also more likely to experience trauma compared to the general population, due to the exacerbation of harm associated with the criminalization of drug use and other intersecting axes of oppression and marginalization (Moustafa et al., 2021). These harms include, for example, experiencing, witnessing, or responding to an overdose; being

criminalized for drug use; living in poverty, experiencing housing precarity, or being unhoused; experiencing colonialism or systemic racism; and encountering heteronormativity or misogyny. When trauma is combined with grief, it can result in complex expressions and management. Trauma can be defined in many ways, but it is often considered a *psychological wound* (Perreault, 2011). Below are some models of trauma relevant in the context of people who use drugs.

Reflections: Lost Advocacy

The overdose crisis and related syndemic have resulted in the loss of active community members who tirelessly resisted the war on drugs through their advocacy and frontline work. These people had incredible knowledge of community needs, were strong leaders, and were trusted and respected members of the community. In our working group alone, we grieve the loss of several members who passed away in the course of our project. We mourn these absences; most notably, we mourn those who were marginalized, experienced barriers to participation, and were overextended and underresourced/supported.

Losing people who kept the history of what we have gone through and had visions of where we could go has had profound consequences on both an individual and societal level. The ongoing loss of people who have done this advocacy work and who worked on the front lines not only creates individual and community grief, but also creates increased strain as this work falls to others in the community who have to keep going. The escalating generational loss and the need to concentrate on survival means that it is hard to work on building resilience through community connection. For example, some of us have noticed that fewer drug user groups are forming because people are forced to focus on their immediate needs, living day-to-day.

We recognize that the generational loss created by the syndemic is experienced most acutely by Indigenous Peoples due to the legacy of colonialism (which informed early drug laws in Canada), intergenerational trauma, and white supremacy (S. C. Boyd, 2022; Lavalley et al., 2018). Factors that increase and perpetuate drug-related harm and generational loss for Indigenous Peoples include forced child separation (through the legacy of residential schools and racialized child apprehension practices); inadequate access to, and experiences of racism within education and health services; and racialized law enforcement practices resulting in heightened surveillance, policing, and overrepresentation in the criminal justice system (Allan & Smylie, 2015; Browne, 2017; Goodman et al., 2017; Lavalley et al., 2018; Marshall, 2013; Zinger 2023). This results in the profound loss of Indigenous knowledge in communities and impacts the capacity of Indigenous Peoples to contribute to drug-user-led advocacy.

Vicarious Traumatization

Vicarious traumatization describes a shift in worldview experienced by someone after being exposed to traumatic material through interactions with other people who directly experienced trauma. It is typically used to describe the experiences of employees who work with people who experience trauma regularly (e.g., supportive housing workers) (Perreault, 2018).

Traumatic Bereavement

Traumatic bereavement refers to the intersection of trauma and grief that results from responding to traumatic events, such as an overdose of a loved one. In these circumstances, survivors experience both bereavement and trauma, either simultaneously or alternatively, which can lead to overwhelming reactions through conflicting sets of thoughts, feelings, and psychological demands (Perreault, 2011).

Post-Traumatic Stress Disorder

Post-traumatic stress disorder

(PTSD) is a diagnosis ascribed to some people who have experienced a shocking, scary, or dangerous event (National Institute for Mental Health, 2019). However, its diagnostic use is contentious in its application to people who are experiencing ongoing trauma, violence, and social marginalization. For example, one study examining the relationship between PTSD symptoms and experiencing and witnessing overdoses among female sex workers in Baltimore, Maryland, had mixed results, given the population had experienced multiple and continual traumas in their lives (Schneider et al., 2021). When the study adjusted for socio-demographic characteristics and drug use, experiencing an overdose was associated with intrusive and cognition/

mood symptoms but did not remain associated with PTSD diagnosis.

Overall, this research points to the need for further inquiry into the normalization of overdose trauma among highly affected populations, including people who use drugs. While normalization of overdose can create a sense of comradery (that others are going through the same stress), it can also undermine and de-legitimize the trauma and material impact of witnessing or experiencing an overdose (Schneider et al., 2021). Moreover, we argue the normalization and medicalization of trauma stemming from overdose and other harms related to drug criminalization can draw attention away from the underlying systemic drivers of trauma and violence, including ongoing colonialism, racism, poverty, and drug prohibition.

Some Ways of Processing Grief and Trauma for People Who Use Drugs

Across the examined literature, there were various models of processing and addressing grief relevant to the experiences of people who use drugs. Overall, recent literature examining experiences of, and responses to, grief among people who use drugs has shifted from an individual and medicalized focus to situate grief within a broader social and structural context (Giesbrecht et al., 2023; Kenny et al., 2022; Schlosser

& Hoffer, 2022). This includes a consideration of how grief is experienced differently by people given their identity (e.g., gender, ethnicity) and socio-economic marginalization (e.g., poverty, racism, colonialism). It also includes how grief is impacted by and experienced in relation to broader institutions and policies such as prohibitionist drug policies and drug treatment programs.

The Dual Process Model

The Dual Process Model of coping with bereavement (DPM) describes how people both acknowledge and avoid death during the grieving process (Stroebe & Schut, 1999). This model suggests that people will focus on the past and what they have lost (loss-oriented), but at the same time will also focus on the future and what they must rebuild (restoration-oriented) (Perreault, 2011). The DPM asserts that people have to cope with the loss itself (e.g., grief, sadness, longing) as well as with secondary stressors that result from the death of a close person (e.g., changes to identity, having to perform new tasks the deceased used to do) (Stroebe & Schut, 1999). This model has been applied to research on grief experienced by people who use drugs (Scroggs et al., 2022; Selseng et al., 2023), where four types of stories were identified: (1) managing grief through the use of drugs, (2) silence, (3) guilt and responsibility, and (4) death as a transformative life event (Selseng et al., 2023).

Misplaced Internalized Guilt

We recognize the tendency of people who use drugs to internalize blame, guilt, and shame when processing grief, unintentionally individualizing the consequences of broader structural factors (e.g., prohibition leading to toxic drug supplies that result in preventable deaths) (McNeil et al., 2022).

Reflections: Relationships and Vicarious Grief

People lost to the current overdose crisis are members of our social networks, family (biological and chosen), intimate partners, community members, coworkers, bosses, and friends. Often one person provides multiple types of support for another (e.g., carer, advocate). Because of the many kinds of relationships we have with people we have lost, we have complex expressions of grief. From our perspective, working in drug policy and harm reduction allows us to know one another more intimately because we are working with people with shared experiences. Drug use continues to be stigmatized in society, so forming relationships with people who do not perpetuate this stigma strengthens the bond between people. The intimacy of these relationships therefore makes the loss that much harder and further complicates people's experiences of grief, and can lead to clusters of drug-related deaths among people in the same social network.

For example, Schlosser & Hoffer examined how people who use drugs grieve drug-related deaths in the US. They found that stigma, operating on intersecting individual, social, and structural levels, shaped people's experiences of bereavement (see **Reflections: Frontline Work, Grief, and Trauma**). In their study, participants received little to no grief support from formal health or social services, which they suggest reflects intentional structural stigma (Schlosser & Hoffer, 2022). Moreover, their research found that involvement with criminal and social service systems (e.g., incarceration, institutionalization) limited some participants' ability to attend funerals and access social and psychological support for grieving (Schlosser & Hoffer, 2022).

Reflections: Frontline Work, Grief, and Trauma

Many people who use drugs are working in overdose response and/or on the front lines advocating for policy change (Kolla & Strike, 2019), having created a new sector in the field of public health focused on the delivery of innovative lifesaving interventions (e.g., overdose prevention sites, safer supply programs). We are often employed because we have dual expertise, as an employee with knowledge of harm reduction and as a person who uses drugs with a connection to the community, resulting in a nuanced understanding of using drugs and of people who use drugs. Given that the clients we serve are sometimes part of our social networks and communities, this can lead to us being impacted more heavily than other employees when clients die (Giesbrecht et al., 2023; Olding et al., 2021; Winstanley, 2020). The grief and trauma that we continue to experience in our everyday lives can be exacerbated in frontline-care jobs when institutions fail to support the needs of people who use drugs.

This issue is magnified in rural settings as people in these communities do not have access to the same number of harm reduction resources, social supports, or healthcare services as in urban centres. For example, people in our working group reported that there can be an hours-long wait for an ambulance to come when someone has experienced an overdose in a rural setting. This means that community members must respond to more serious overdoses and increasingly tragic events for longer periods of time, which can be traumatizing. Furthermore, in rural and remote communities, there are closer social networks given the smaller population size, which can create additional strain for those working in these settings when people pass away—as often clients are part of caregivers' close social networks.

Our group has identified additional challenges that people who use drugs face in receiving adequate support for grief and trauma that were absent from the literature. First, frontline jobs are often precarious and lacking in access to benefit programs, paid vacation, paid sick time, mental health leave, medical coverage, or access to employee assistance programs (Kolla & Strike, 2019; People With Lived Expertise of Drug Use National Working Group et al., 2021). Thus, many people cannot take time off to grieve and/or manage their loss given their precarious employment status and income insecurity. In our experience, workplaces that do offer benefits and employ people who use drugs in frontline overdose response often do not provide access to the same benefit programs that other employees receive, creating a two-tiered hierarchy. Workplaces that provide counselling often cap the services that employees can receive (e.g., cover a maximum of six sessions, provide up to \$350 for counselling) or limit service provision to mobile or telephone delivery methods, despite the high work pressure attributed to overdose response. Second, people who use drugs often fear losing their jobs if they take time off to grieve properly, and can experience being shamed, accused of being too close to the subject matter, or accused of not having appropriate personal and professional boundaries (Giesbrecht et al., 2023). Last, people who use drugs working in frontline roles may use more drugs when experiencing grief and trauma. This can be perceived negatively by employers and serve as grounds for dismissal. Overall, organizations that employ people who use drugs must do a better job at creating a sustainable workforce (for example, see the ROSE intervention by Mamdani et al., 2021), particularly given the emotional strain associated with this work (Greer et al., 2020).

Under the constraints of prohibition, people who use drugs form communities: they use drugs together, take care of one another, and engage in other significant activities such as advocacy and activism (see *Reflections: Relationships and Vicarious Grief*). Thus, they can be quick to self-blame when someone is lost, with members focusing on what they could have done differently instead of the sustained violence of social and structural conditions that increase overdose risk (e.g., failed drug policies, entrenched poverty, discrimination) (Tyndall & Dodd, 2020). To combat this internalized guilt, a variety of toolkits recommend that when someone is experiencing grief, connection and support from colleagues, friends, and family can provide tangible (e.g., helping to arrange the funeral, raising money to support them) and emotional support (Wojtkowiak et al., 2019).

The Meaning Reconstruction Model

Regardless of the type of loss someone experiences during the syndemic, traumatic events can shatter an individual's worldview, leaving them searching for meaning. The *meaning reconstruction model* refers to when people find and better understand their purpose and passion after experiencing a tragic loss and learning how to process that grief (Gillies & Neimeyer, 2006). A Canadian example is Moms Stop the Harm, a national network of families impacted by substance use-related harms

(including deaths), who advocate to change failed drug policies and provide peer support to grieving families and those with loved ones who use or have used substances (Jenkins et al., 2021). This organization creates and builds relationships between people who use drugs and family members who have lost a loved one to overdose, which provides space for people to make meaning of loss together through connection and advocacy.

Advocacy

Related to the meaning reconstruction model is the role of *advocacy* in processing grief. Morris and colleagues (2021) explored how parents who lost a child due to a drug-related death became involved in local drug policy advocacy as a way to reconstruct meaning and engage in community support while processing their grief. Participants explained that while there is an emotional cost to

Reflections: Finding Our Purpose

We have experienced a massive amount of death while continuing to passionately work within the drug policy and harm reduction field. Despite the overwhelming loss we experience, we find purpose in our work. The persistent loss of our loved ones drives our own working group's advocacy work, including the creation of this report and presentation of its themes at the International Conference on Health and Hepatitis in Substance Users in Geneva, Switzerland, in October of 2023. See dope-policy.com for more information about the work we have done since 2018.

advocacy work, it also helped them to heal. Particularly, the mutual support provided by their groups was described as one of the most important benefits of their advocacy work (Morris et al., 2021). However, participants noted that despite the cathartic aspects of this work, “going public” and sharing a family story of substance use can also have considerable personal cost due to the immense stigma associated with drug use (Morris et al., 2021). We extend this further to similarly highlight how grief drives the work and advocacy of people who use drugs. For example, evidence-based harm reduction services developed by people who use drugs, such as overdose prevention sites, take-home naloxone, and a safer supply of drugs (Galea et al., 2006; Ivsins et al., 2020; Wallace et al., 2018), were in part created because of the grief that people were experiencing (see **Reflections: Finding Our Purpose**).

Community Care

Research has illustrated how people who use drugs engage in practices of *community care*, including ways that people care for themselves (e.g., in contexts devoid of social support) and support one another (e.g., despite risk of arrest) within larger social and economic contexts that criminalize drugs and drug use (Austin et al., 2023; Farrugia et al., 2019; Kolla & Strike, 2020). Unfortunately, due to stigma and social inequities, people who use drugs sometimes do not have access

Reflections: (Lack of) Spaces to Grieve for People Who Use Drugs

While mourning for our loved ones, we continue to experience criminalization without compassion. Experiencing grief at the current levels can lead to (increased) drug use and overdose risk (e.g., using alone or not testing one’s drugs) (Boyd et al., 2022; Kenny et al., 2022; Lee et al., 2020; Macmadu et al., 2022; Schlosser & Hoffer, 2022; Thumath et al., 2020). While this type of drug use may be conventionally dismissed as “risky,” it can also be understood as an adaptive strategy to cope when we experience tremendous grief and trauma in the context of profound social inequities (e.g., housing and income security) with insufficient resources to manage them. Some research suggests that using drugs during the grieving process prolongs grief (Wojtkowiak et al., 2019); however, we assert that there is no right or wrong way to grieve, and we need to better understand the role of drugs in the grieving process. Furthermore, while recovery-oriented programming, including Alcoholics Anonymous and Narcotics Anonymous, offers people space to share, reflect, and grieve, these programs are not accessible to people who are actively using substances. We therefore need to prioritize healing spaces that are culturally safe, trauma informed, and incorporate harm reduction approaches (e.g., non-abstinence-based support groups) for people who are using criminalized drugs.

to community and social spaces (e.g., funerals, supportive work environments) to express their grief (see **Reflections: (Lack of) Spaces to Grieve for People Who Use Drugs**). Despite these barriers, people still find ways to engage in community support and create supportive social contexts for grief (see **Reflections: Stigma and Expressions of Grief**). For example, the heART space project is a community-based

participatory art project that young people in British Columbia created to honour their peers who have died from overdose, providing a space for dialogue and creative expression (Selfridge et al., 2021). Significantly, this work created a space for social recognition of the loss of people to overdose, while asserting the right to grieve for young people who use drugs. The authors noted that this space was particularly important for youth, who are uniquely stigmatized for their drug use and often assumed to not experience grief (Selfridge et al., 2021).

Reflections: Stigma and Expressions of Grief

We are often blocked from grieving or cannot openly express our grief because of the stigma associated with drug use. Moreover, traditional grieving rituals, such as funerals, may not be welcoming or accessible spaces for us. Family members might not want us at the funeral, or our drug use might increase following a loss and lead to increased difficulty in attending a funeral. To support grieving among loved ones who are not welcome at the funeral, we discussed holding additional community memorials or celebrations of life to allow us to grieve with our peers, share stories and memories that might not be welcome at the funeral, and offer compassion to each other. We often turn to alternative methods when we feel like we can't express our grief formally; for example, graffiti is one way that we can express our grief publicly while also remaining anonymous.

Social distancing and the ongoing loss of community members during the COVID-19 pandemic further restricted our ability to engage in these activities and connect with and support one another in our grief. As one of our working group members stated:

“All of these emotions are complicated further by grief of losing clients, friends and loved ones to overdoses and COVID, and how difficult it is to grieve those who were lost to the war on drugs during the pandemic, especially when you're isolated.”
(People With Lived/Living Expertise of Drug Use National Working Group, 2021a)

Despite these barriers, people have found some ways to overcome the isolation and connect with others during COVID-19. In particular, we have found that social media is another way to honour and remember a loved one who has lost their life due to an overdose during this time. We have personally employed this method on our website (dope-policy.com) and blog (People With Lived/Living Expertise of Drug Use National Working Group, 2021b).

Where Do We Go From Here?

We must recognize and address the range of grief and trauma experienced by people who use drugs with meaningful support. As described, people who use drugs have many roles and relationships, leading to complex and cumulative expressions of ongoing grief and trauma. Moreover, people who use drugs are differentially impacted by various axes of oppression and marginalization (e.g., colonialism and racism). We therefore need broad policy changes and interventions designed by and for people who use drugs to address our “mourning without end” alongside upstream grief interventions (like reducing overdose deaths). Future interventions must meaningfully involve people with lived and living expertise of drug use when determining project design and implementation to build trust and remain attentive to factors such as discrimination, stigma, and social inequalities (e.g., poverty, housing insecurity). We have highlighted a few promising interventions in the Appendix, and we call for the continued expansion and funding of community-driven initiatives to support people who use criminalized drugs.

Alongside the need for support related to grief and trauma, we call for progressive and evidence-based interventions to prevent harm stemming from drug

prohibition (del Pozo & Beletsky, 2020). There is ample and ongoing research on safer supply, decriminalization, and harm reduction; however, we need government action and community implementation. We require sustainable funding at community, municipal, provincial, and federal government levels for harm reduction programming. We urge governments to cease funding “pilot” projects and start incorporating these lifesaving services in all government budgets. We know what can be done to effectively reduce deaths in the overdose crisis, and this includes barrier-free access to regulated drug supplies (of all drugs) across Canada, national legalization and/or decriminalization of drug possession, and significant improvements to health, social, and housing supports (Csete & Elliott, 2021; Park et al., 2020; Vearrier, 2019).



“Break time from SIS [Supervised Consumption Site] at 2 a.m., January downtown Montreal. Streets are empty and cold.” — Alexandra de Kiewit, 2019; see Reflections: Frontline Work, Grief, and Trauma



Graffiti in an alley that reads “Rest in peace 2 all our fallen brothers and sisters” in the Downtown Eastside neighbourhood of Vancouver (Canada) — Jade Boyd and Ryan McNeil, 2017



Working group members (from left to right) Frank Crichlow, Matthew Bonn, Brandi Abele, Alex Sherstobitoff, and Kathy Pinheiro after presenting this report's themes at the International Conference on Health and Hepatitis in Substance Users (Geneva, Switzerland) — Conor Ashleigh/ INHSU, 2023



Working group members (from left to right) Brandi Abele, Matthew Bonn, Alex Sherstobitoff, and Frank Crichlow presenting this report's themes at the International Conference on Health and Hepatitis in Substance Users (Geneva, Switzerland) — Conor Ashleigh/ INHSU, 2023



Graffiti on a bus stop post on Hastings St. (Vancouver, Canada) reads: "Ben Love You. Demand Safe Supply!! Stop killing my friends" — Samara Mayer, 2022



Graffiti on a public bench in Geneva, Switzerland — Kat Gallant, 2023



Naloxone training sign
— Frank Crichlow,
2019



Community board in harm reduction service
— Frank Crichlow,
2019

Conclusion

In conclusion, people who use drugs are suffering from immense amounts of grief, exacerbated by ongoing trauma produced by structural and social violence (e.g., prohibitionist drug policies) and oppression (e.g., systemic racism, colonialism, misogyny). As people who use drugs, we continue to experience the compounding impact of the devastating loss of friends and family amidst experiences of profound stigma and limited resources. Communities have initiated creative means to support one another and attend to grief, including alternative memorials when people are prevented from attending funerals due to drug use-related stigma. Together with rapid, actionable alternatives to the toxic illegal drug supply and improved social supports (e.g., housing, income, education), the ongoing support of community care and drug-user-led advocacy remains paramount in combatting the devastation of the syndemic.

Appendix:

A Few Community Resources and Interventions

The GLoW Initiative

Provides support to frontline workers, community supporters, etc., dealing with the overwhelming loss of the overdose crisis.

<https://breakawaycs.ca/programs/grief-loss>

Moms Stop the Harm (MSTH)

A Canadian network of families impacted by substance use-related harms and deaths.

<https://www.momsstoptheharm.com>

Holding Hope

Support offered by MSTH, which provides a range of resources for dealing with grief.

<https://www.holdinghopecanada.org/resources>

Canadian Association of People who Use Drugs (CAPUD)

A Canadian network of people with lived and living expertise of drug use focused on advocacy, policy, and creating effective change.

<https://www.capud.ca>

Wish You Were Here, Wish Here Was Better (WYWH, WHWB)

A 2022 mobile public event series for those impacted by “the ongoing overdose crisis—and its cascading systemic issues of precarity, houselessness, and criminalization.”

<https://www.blackwoodgallery.ca/program/wish-you-were-here-wish-here-was-better>

Gone Too Soon: Navigating Grief and Loss as a Result of Substance Use

A handbook published in 2019 by the BC Centre on Substance Use in collaboration with the BC Bereavement Helpline and the Affected Persons Liaison with the BC Coroners Service.

https://www.bccsu.ca/wp-content/uploads/2018/11/Grief_Handbook.pdf

Toward the Heart

The BC Peer Worker Training Curriculum includes an on-line module on dealing with grief and healing.

<https://towardtheheart.com/peer-worker-training> (Module 8)

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