Palliative care interventions for people who use substances during communicable disease outbreaks: a scoping review

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ABSTRACT

Objectives When resources are strained during communicable disease outbreaks, novel palliative care interventions may be required to optimally support people who use substances with life-limiting illnesses. Therefore, we asked the question, ‘what is known about communicable disease outbreaks, palliative care and people who use substances?’, such as palliative care interventions that can improve the quality of life of patients with life-limiting illnesses.

Design We conducted a scoping review that involved comprehensive searches in six bibliographic databases from inception to April 2021 (Medline ALL (Medline and Epub Ahead of Print and In-Process and Other Non-Indexed Citations), Embase Classic+Embase, Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trial, PsycInfo all from the OvidSP platform, Scopus from Elsevier) and grey literature searches. We included English and French records about people ≥18 years old with life-limiting illnesses who use substances during communicable disease outbreaks. We identified, summarised and presented the findings about palliative care interventions in figures, tables and narrative descriptions.

Results We identified 32 records about palliative care interventions for people who use substances during communicable disease outbreaks. The majority focused on palliative care for people who use substances with AIDS during the HIV epidemics (n=27, 84.4%), and approximately half were published in the USA (n=15, 46.9%). Most common substances used were alcohol (n=18, 56.3%), opioids (n=14, 43.8%) and cocaine (n=10, 31.3%). Four groups of palliative care interventions were identified: (1) symptom management (n=20, 62.5%), (2) psychosocial support (n=15, 46.9%), (3) advance care planning (n=8, 25.0%) and (4) healthcare provider training (n=6, 18.8%).

Conclusions Beyond studies on HIV epidemics, there is limited knowledge about palliative care interventions for people who use substances during communicable disease outbreaks. Research and guidance are needed about how best to provide palliative care to this population with complex needs including in resource-limited countries.

INTRODUCTION

The Global Burden of Diseases, Injuries and Risk Factors Study estimated that 451 800 deaths and 16 782 300 years of premature life were lost due to alcohol and substance use in 2016.1 The annual global prevalence of substance use disorders is increasing, with alcohol use disorders being the most prevalent, followed by cannabis and opioid use disorders.1 Non-medical drug use and substance use disorders are associated with risks of unintentional and intentional injuries, non-communicable diseases and infectious diseases.2–4 Additionally, people who use substances often have comorbid medical and psychiatric conditions and face inequities related to the social determinants of health which affect their healthcare access and outcomes.5 Given this high morbidity and mortality, some people who use substances may benefit from palliative care.
Palliative care addresses the suffering experienced by people with life-threatening illnesses using interventions that include symptom management, psychosocial support, spiritual care and advance care planning (ACP). However, people who use substances can have restricted access to palliative care due to limited social supports, poverty and stigma. Institutions and providers may restrict delivery of community-based services such as home care to environments that they deem unsafe or high risk. Furthermore, zero-tolerance policies towards non-medical use of drugs can prevent or deter people who use substances from admission to palliative care units and hospices for end-of-life care. During public health emergencies, such as the COVID-19 pandemic, these inequities are magnified.

Preliminary searches of PubMed and Web of Science databases in May 2020 did not identify any reviews addressing palliative care needs for people who use substances during communicable disease outbreaks (eg, Ebola, COVID-19, H1N1). Therefore, we conducted a scoping review to comprehensively identify and synthesise existing and emerging evidence. Specifically, this review’s research question was, ‘what is known about communicable disease outbreaks, palliative care and people who use substances? We focused on epidemics and pandemics related to communicable diseases (ie, infectious diseases), rather than non-communicable conditions such as opioid-related overdoses and obesity. Our review focused on four palliative care-related outcomes: (1) interventions, (2) access to services, (3) policies/guidelines and (4) clinical programmes. In this article, we will present the findings about palliative care interventions, which was defined a priori as per the WHO definition as approaches that improve the quality of life of patients with life-threatening illnesses and their families through the prevention and relief of suffering by identification, assessment and treatment of physical, psychosocial and spiritual problems. We will report the findings about palliative care access, policies and guidelines and clinical programmes separately.

**METHODS**

**Protocol and registration**

We published our scoping review’s protocol as an open-access journal article in October 2021. We based our methodology on the Joanna Briggs Institute’s Manual for Evidence Synthesis, which builds on the contributions from Arksey and O’Malley and Levac et al, and the Preferred Reporting Items for Scoping Reviews (PRISMA-ScR) reporting guidelines.

**Eligibility criteria**

Table 1 summarises the PECOS (Population, Exposure, Comparison or Control, Outcomes and Study Characteristics) framework that we used to structure the evidence eligibility criteria. This review included people who use prescription drugs for non-medical purposes and/or unregulated substances and people who received treatment for substance use disorder. Communicable disease outbreaks were defined a priori as epidemics or pandemics related to infectious diseases (eg, HIV, Ebola, COVID-19).

**Table 1 Scoping review eligibility criteria according to the PECOS framework**

| **PECOS framework** | **Eligibility criteria** |
|---------------------|-------------------------|
| Population          | Adults (≥18 years of age) |
| Exposure            | Communicable disease outbreaks (eg, HIV epidemic, COVID-19 pandemic) |
| Comparison/control* | N/A                      |
| Outcome             | Quantitative outcomes and qualitative themes about palliative care interventions, access to services, policies/guidelines and clinical programmes |
| Study characteristics | Any country Published in English or French Peer and non-peer reviewed literature Any publication year |

*This review included literature with and without comparison or control groups, including grey literature.

**Information sources and search strategy**

The information specialist in our team (RF) developed a comprehensive search strategy to identify studies in each of the following six databases, from their inception to April 2021: Medline ALL (Medline and Epub Ahead of Print and In-Process and Other Non-Indexed Citations), Embase Classic+Embase, Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trial, PsycInfo all from the OvidSP platform and Scopus from Elsevier. Each search strategy comprised a combination of controlled vocabulary terms and text words, adapting the database-specific search syntax. There were no date or publication type restrictions. Where applicable, we limited the search to human studies, adults ≥18 years of age and languages for which at least two team members had fluency (English/French). Online supplemental appendix A presents our search of the Ovid Medline (R) ALL 1946 to 20 April 2021 as an example of our search strategy. We modelled our search strategies of the other databases based on the Ovid Medline search; these search strategies are available from the authors on request. We used the reference manager, Endnote, to store data from these database searches.

In addition, we conducted supplemental searches, including grey literature searches, over the same timespan to identify published literature that was not indexed in the bibliographic databases and used reverse snowballing to screen the reference list of the included studies.
for additional relevant evidence. The following grey literature resources were searched: TRIP medical database, Google, websites of prominent health organisations including, but not limited to, Centres for Disease Control and Prevention, Canadian Centre on Substance Use and Addiction and Centre of Addiction and Mental Health and associations of palliative care, public health (communicable disease) and substance use. A list of the grey literature websites is shown in online supplemental appendix B. We customised search strategies based on each resource’s available searching feature. We hand searched reference lists of retrieved articles to identify additional relevant evidence.

Selection of sources of evidence
Records identified from the database searches were imported into Covidence, a web-based literature review software, which was used to detect and remove duplicates. Two independent reviewers screened the title and abstracts of the remaining records according to the eligibility criteria, and then applied the same process to the full-text articles. Disagreements were resolved by consulting a third reviewer. We screened records without abstracts based only on their title. If there were conference proceedings or abstracts without full text, we excluded these due to the limited available information.

We imported the results from the grey literature searches into Google Sheets. Similar to the database searches, we assessed each record’s eligibility by applying the PECOS criteria. Any disagreements between the two reviewers assessing the records were resolved by consulting a third reviewer.

Data charting process and data items
We developed a standardised data charting form using Google Sheets to extract the following variables: author/organisation, publication year, journal, country of the corresponding author, article type (commentary/ opinion article, conference/workshop, guideline, news article, programme report, other), publication language, countries and settings in which studies were conducted (acute care, inpatient palliative care, long-term care, community, home care, infectious diseases clinic, palliative care clinic), populations (life-limiting diagnoses, drugs used, sex and gender, age, ethnicities), target audiences (healthcare professionals, researchers, policymakers, governments), communicable diseases and palliative care outcomes (palliative care interventions, access to palliative care services, policies/guidelines related to palliative care and palliative care clinical programmes). Online supplemental appendix C provides details about the a priori definitions used to distinguish each of the outcomes.

Summary of results
We developed a PRISMA-ScR flow diagram to map out the review process. We analysed the data by first combining all outcomes, and then separately according to each of the four palliative care outcomes. We analysed our data in two ways consistent with our scoping review methodology: first, we analysed the quantitative data using descriptive statistics and then summarised them in tabular forms. Second, we organised the qualitative data thematically to present a narrative account of the literature and identified gaps in the existing knowledge by identifying the main areas of interest among the extracted data.

Patient and public involvement
There were no patients involved in this review. The research team includes healthcare professionals who provide palliative care for people who use substances and several team members who work and care for people who use substances in the context of hospital and community-based work. Our research team also includes a knowledge user, Canadian Virtual Hospice, that provides comprehensive online knowledge about palliative and end-of-life care. These members provided guidance on the design and completion of this review and are assisting with our knowledge dissemination plans.

RESULTS
From a total of 9088 records (5817 from electronic databases and 3271 from grey literature), we identified 32 records about palliative care interventions for people who use substances during communicable disease outbreaks. There were three main reasons for excluding records: wrong population (eg, people with curative diagnoses), wrong exposure (eg, non-communicable disease public health emergencies) and wrong outcomes (eg, not related to palliative care). Figure 1 presents the PRISMA-ScR flow diagram that summarises the review findings.

The included records were published between 1988 and 2021, and approximately half were from the USA (n=15, 46.9%). The majority focused on human immunodeficiency virus (HIV) (n=27, 84.4%) and the life-threatening diagnosis of acquired immunodeficiency syndrome (AIDS) (n=27, 84.4%). We identified records about other communicable disease outbreaks, such as COVID-19 (n=6, 18.8%) and Ebola (n=2, 6.3%) and other life-limiting illnesses, such as cancer (n=8, 25.0%). The most common substances used were alcohol (n=18, 56.3%) and opioids, including heroin (n=14, 43.8%) and cocaine (n=10, 31.3%). Fourteen records (43.8%) also reported on intravenous drug use. Table 2 summarises the characteristics of the included records, and online supplemental appendix D presents the individual sources of evidence.

We identified four groups of palliative care interventions from the records: (1) symptom management (n=20, 62.5%), (2) psychosocial support (n=15, 46.9%), (3) ACP/goals of care (n=8, 25.0%) and (4)
staff education (n=6, 18.8%).16 21 25 32 37 39 Figure 2 and the following sections provide summaries of the knowledge extracted and synthesised from the included records about each of these interventions.

Summary of results
Symptom management (n=20; Table 3)
The reported symptom management interventions for people with life-limiting illnesses who use substances during communicable disease outbreaks are summarized in table 3.

Interdisciplinary approach
An interdisciplinary approach to symptom management is recommended in the literature for people with life-limiting illnesses who use substances during communicable disease outbreaks.16 18 24 27 35 40 47 Symptoms can be a result of substance use and withdrawal. For example, cocaine can cause paranoid psychosis and alcohol withdrawal can cause seizures.16 33 44 People who use substances may also have comorbid medical conditions and, commonly, concurrent mental health illnesses.30 The literature suggests that, ideally, primary care physicians should coordinate treatment plans, provide close follow-up and involve other healthcare professionals on a consultative basis.16 18 24 Box 1 summarises the various

Table 2 Summary of characteristics of records about palliative care interventions (n=32)

| Characteristic                     | n (%) |
|-----------------------------------|-------|
| Record type                       |       |
| Research article                  | 14 (43.8) |
| Guidelines                        | 11 (34.4) |
| Book chapter                      | 3 (9.4) |
| Commentary/opinion article        | 2 (6.3) |
| Review                            | 1 (3.1) |
| Other                             | 1 (3.1) |
| Target audience                   |       |
| Healthcare professionals          | 31 (96.9) |
| Researchers                       | 15 (46.9) |
| Policy makers                     | 6 (18.8) |
| Governments                       | 4 (12.5) |
| General                           | 3 (9.4) |
| Other                             | 3 (9.4) |
| Country                           |       |
| USA                               | 15 (46.9) |
| Canada                            | 3 (9.4) |
| UK                                | 3 (9.4) |
| India                             | 1 (3.1) |
| Italy                             | 1 (3.1) |
| Japan                             | 1 (3.1) |
| Portugal                          | 1 (3.1) |
| Vietnam                           | 1 (3.1) |
| General                           | 6 (18.8) |
| Communicable disease              |       |
| HIV                               | 27 (84.4) |
| COVID-19                          | 6 (18.8) |
| Hepatitis                         | 6 (18.8) |
| Tuberculosis                      | 5 (15.6) |
| Influenza                         | 3 (9.4) |
| Ebola                             | 2 (6.3) |
| Measles                           | 2 (6.3) |
| Cholera                           | 1 (3.1) |
| Dengue                            | 1 (3.1) |
| Diphtheria                        | 1 (3.1) |
| Malaria                           | 1 (3.1) |
| Methicillin resistant staphylococcus aureus | 1 (3.1) |
| Mumps                             | 1 (3.1) |
| Rubella                           | 1 (3.1) |
| SARS                              | 1 (3.1) |
| Tetanus                           | 1 (3.1) |
| Yellow fever                      | 1 (3.1) |
| Setting                           |       |
| Community (including home)        | 15 (46.9) |

Continued
Disciplines recommended in the literature to be involved in the care of people who use substances. Importantly, patients should direct their healthcare and be encouraged to use available services and resources, such as addictions counselling, through community-based organisations.17 24 39

**Non-pharmacologic interventions**

When formulating treatment plans, the literature suggests that non-pharmacologic interventions should be considered.24 For example, focusing on the present ('present-time orientation') can help reduce cravings for those motivated to decrease or abstain from substance use.23 When there are visitor restrictions, advocating for essential care partner visits can help patients who are experiencing delirium in hospital.35 Sleep quality can be improved by limiting alcohol and caffeine intake at bedtime.33 44 For dyspnoea and cough, the literature reports that the following interventions can be helpful: smoking cessation,44 saline gargles,27 ginger and honey,27 supplemental oxygen,27 fan,27 yoga to assist with positioning,27 relaxation therapy,27 cognitive behavioural therapy27 and thoracentesis and paracentesis.27 These interventions, in combination with pharmacologic treatments, can help manage symptoms experienced by people who use substances.

**Pharmacologic treatments**

When considering pharmacologic treatments, the literature suggests that healthcare providers should take detailed medical and medication histories. The presence of comorbidities can influence medication choice and dosing. For example, benzodiazepines can relieve dyspnoea and anxiety in addition to treating alcohol withdrawal seizures.35 Patients’ opioid use history can help providers assess their tolerance and efficacy and guide initial dosing for relief of pain, dyspnoea and cough.35 40 43 The literature recommends that healthcare providers distinguish between patients who are actively using unregulated opioids, patients who formerly used unregulated opioids and patients on opioid agonist treatment (OAT) (ie, methadone, buprenorphine) because different opioid prescribing practices may be required.16

Successful pain management for people who use substances should take into consideration their substance use history.21 The literature recommends that patients with hepatic impairment or alcohol use disorder should receive a maximum of 3000 mg/day of acetaminophen.43 If patients experience constant pain and/or dyspnoea, opioids should be dosed around the clock and provided on an as needed basis.29 35 Higher opioid doses are often needed to adequately control symptoms experienced by patients with a history of active or past drug use and long-term opioid use.16 32 34 37 40 43 For people who use substances living with HIV/AIDS, the US Centre for Substance Abuse Treatment recommends that healthcare providers use medication routes and formulations that are less likely to be diverted or used non-medically.

### Table 2 Continued

| Characteristic                              | n (%)  |
|--------------------------------------------|--------|
| Acute care unit                            | 10 (31.3) |
| Palliative care unit                       | 10 (31.3) |
| Infectious disease clinic                   | 6 (18.8) |
| Palliative care clinic                      | 5 (15.6) |
| Clinic (not infectious disease or palliative) | 6 (18.8) |
| Long-term care                             | 5 (15.6) |
| Other (eg, prison, shelter)                 | 6 (18.8) |
| General or not reported                     | 7 (21.9) |

**Life-limiting illness**

**Drug**

- Alcohol 18 (56.3)
- Opioid 14 (43.8)
- Intravenous drug use 14 (43.8)
- Cocaine 10 (31.3)
- Stimulants 8 (25.0)
- Cannabis 6 (18.8)
- Tobacco 5 (15.6)
- Benzodiazepines 4 (12.5)
- Other 17 (53.1)

**Ethnicity**

- Black 14 (44)
- White 11 (34)
- Hispanic 5 (16)
- Asian 4 (13)
- Indigenous 2 (6)
- Other 3 (9)
- Not reported 13 (41)

**Intervention**

- Symptom management 20 (62.5)
- Psychosocial support 15 (46.9)
- Advance care planning/goals of care 8 (25.0)
- Healthcare provider training 6 (18.8)

*Table 2* Overview of palliative care interventions for people who use drugs during communicable disease outbreaks.
### Table 3  Summary of reported symptom management interventions for people with life-limiting illnesses who use substances during communicable disease outbreaks (n=20)

| Author (year) | Symptom management intervention subthemes | Interdisciplinary approach | Non-pharmacologic interventions | Pharmacologic treatments | Treatment plans |
|---------------|------------------------------------------|----------------------------|---------------------------------|--------------------------|-----------------|
| Batki (2000)  | Care should be a collaboration between addictions medicine, primary care, pain medicine, palliative care | | Distinguish between patients who are actively using unregulated opioids, patients who formerly used unregulated opioids, and patients on opioid agonist treatment | Set boundaries and have consistent treatment plans |
|               | Symptoms can be result of life-limiting illnesses, co-morbid conditions and substance use | | | |
|               | | | Patients with histories of active or past substance use and long-term opioid use likely require higher opioid doses for symptom management | Use opioid treatment agreements |
|               | | | Consider use of medication routes and formulations that are less likely to be diverted or used non-medically | Taper opioids under medical supervision |
|               | | | Be aware that people residing with patients may take or use their opioids | |
|               | | | Acute pain control: continue with methadone (opioid agonist treatment) and use short-acting opioids | |
|               | | | Avoid mixed opioid agonist-antagonists | |
| Coughlan (2004) | | | Patients with history of active or past substance use and long-term opioid use likely require higher opioid doses for symptom management | |
| Dong (2021)   | Care should be a collaboration between infection prevention and control, palliative care, psychology, social work, spiritual care | Advocate for essential care partner visits | Consider use of benzodiazepines for management of dyspnoea, anxiety, alcohol withdrawal seizures | Never withhold opioids required for symptom management |
|               | | | Use patients’ opioid use history to guide pain, dyspnoea and cough management | |
|               | | | Dose opioids around the clock and as needed if patients have constant pain or dyspnoea | |
|               | | | Opioid agonist treatment may need to be adjusted or changed to help manage symptoms | |
| Fantoni(1996) | | | Patients with histories of active or past substance use and long-term opioid use likely require higher opioid doses for symptom management | |
| Fraser (1988) | Engage patients in their care | | | Set boundaries and have consistent treatment plans |
|               | | | | Use opioid treatment agreements |
|               | | | | Develop strategies to deal with breaches of established care plans |
| Hall (2018)   | Use present-time orientation to help treat drug cravings | | | |

Continued
### Table 3  Continued

| Author (year) | Interdisciplinary approach | Non-pharmacologic interventions | Pharmacologic treatments | Treatment plans |
|---------------|---------------------------|---------------------------------|--------------------------|-----------------|
| Johnson (2012)²⁴ | Care should be a collaboration between addictions medicine, complementary medicine, nursing, primary care, palliative care, social work | Consider non-pharmacologic interventions for symptom management | Management of symptoms should consider substance use history | Set boundaries and have consistent treatment plans |
| | Engage patients in their care | | | Use opioid treatment agreements |
| | | | | Taper opioids under medical supervision |
| Kelleher (1997)³⁵ | Engage patients in their care | | | Develop strategies to deal with breaches of established care plans |
| Kimball (1996)³⁶ | | Dose opioids around the clock and as needed if patients have constant pain or dyspnoea | Document unregulated substance use | Set boundaries and have consistent treatment plans |
| Krakauer (2007)³⁷ | | | | Use opioid treatment agreements |
| Marie Curie (2019)³⁸ | Care should be a collaboration with infectious disease | | | |
| Merlin (2013)³⁷ | Care should be a collaboration between palliative care and psychiatry | Dyspnoea/cough management: saline gargles, ginger, honey, supplemental oxygen, fan, yoga, relaxation therapy, cognitive behavioural therapy, thoracentesis, paracentesis | | |
| Perry (2013)³⁰ | Symptoms can be result of life-limiting illnesses, co-morbid conditions and substance use | | | |
| Selwyn (2000)¹⁸ | Care should be a collaboration between primary care and palliative care | | | |
| Shernoff (1998)³⁴ | | Patients with histories of active or past substance use and long-term opioid use likely require higher opioid doses for symptom management | | |
| Task Force in Palliative Care (2020)⁴⁵ | Symptoms can be result of life-limiting illnesses, co-morbid conditions and substance use | Limit alcohol and caffeine intake at bedtime | | |
| | | Dyspnoea/cough management: smoking cessation | | |
| Volling (2020)⁴³ | | Patients with histories of active or past substance use and long-term opioid use likely require higher opioid doses for symptom management | | |
| | | Total daily recommended maximum dose of acetaminophen is 3000 mg for patients with hepatic impairment or alcohol use disorder | | |

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Open access

Table 3 Continued

| Author (year)          | Symptom management intervention subthemes | Pharmacologic treatments | Treatment plans |
|------------------------|-------------------------------------------|---------------------------|-----------------|
|                        | Interdisciplinary approach                | Non-pharmacologic interventions |                  |
|                        | Care should be a collaboration with addictions medicine | Use patients’ opioid use history should be used to guide pain, dyspnoea and cough management |                  |
| World Health Organization (2018) | Restrictions on opioid prescribing should be eliminated |                  |
| World Health Organization (2021) | Symptoms can be result of life-limiting illnesses, co-morbid conditions and substance use | Encourage good sleep hygiene |                  |
|                        | Limit alcohol and caffeine intake at bedtime |                  |

Treatment plans

Boundary setting and consistent treatment plans can reduce the risks associated with prescribing controlled substances (eg, opioids) for people who use substances.16 17 24 41 Box 2 summarises the risk mitigation strategies described in the literature that healthcare providers can incorporate into their practices. Opioid treatment agreements can be used to outline these strategies.16 17 24 41 Healthcare providers, including home care managers, should document any instances of unregulated drug use by patients to communicate with other healthcare providers in case safety issues arise from the substance use.36 Healthcare providers should also have coordinated strategies to deal with breaches of established care plans.17 39 If opioid therapy needs to be discontinued, it should be tapered under medication supervision as abrupt discontinuation will cause withdrawal.16 21 However, if indicated for symptom management, especially at the end of life, opioids should never be withheld or substituted with non-opioid analgesics because of past or current substance use.16 35

Box 1 Recommended healthcare disciplines to be involved in the care of people who use drugs

Addictions medicine.16 24 40
Alternative medicine.24
Infection prevention and control.35
Infectious disease.47
Nursing.24 35
Primary care.16 18 24
Palliative care.16 18 24 27 35
Pain medicine.16
Psychiatry.27
Psychology.35
Social work.24 35
Spiritual care.35

Box 2 Recommended risk mitigation strategies when prescribing opioids and other controlled substances to people who use substances

Designate one prescriber for the controlled substances.16 24
Dispense limited amounts of controlled substances (eg, 1-week supply).16
Inform patients that lost or stolen prescriptions will not be replaced.16
Establish limits for acceptable behavior.17
Monitor medication compliance with routine drug testing and prescription monitoring systems.41
Provide guidance on safe handling and storage of opioids.41

(eg, controlled release oral or transdermal patches); parenteral routes (eg, peripheral intravenous) may have higher risk because they can be used to administer unregulated drugs (eg, heroin).16 Furthermore, the US Centre for Substance Abuse Treatment states that healthcare providers should be aware that other people who use substances may reside with the person living with HIV/AIDS and take or use their opioids.16 During communicable disease outbreaks, the WHO recommends that all restrictions on opioid prescribing should be eliminated.46 For patients on OAT, the literature suggests that physicians managing end-of-life symptoms should collaborate with the patient’s OAT prescribers. The OAT may need to be dosed more frequently, changed to a different opioid or supplemented with additional agents.35 In general, the literature recommends that healthcare providers continue their patient’s usual methadone dose and use short-acting opioids for acute pain control.16 Mixed opioid agonist-antagonists (eg, pentazocine) should be avoided as they can precipitate withdrawal.16
Psychosocial support (n=15; Table 4)

The reported psychosocial interventions for people with life-limiting illnesses who use substances during communicable disease outbreaks are summarized in table 4.

Structural vulnerability

Interventions that address structural vulnerability experienced by people who use substances can help minimise barriers to care exacerbated by communicable disease outbreaks. The International Association for Hospice and Palliative Care recommends that health systems and palliative care teams conduct social histories that include evaluation of the economic status of people and their families who are at risk for, recovering from or experiencing homelessness in the context of COVID-19. Studies about people living with HIV demonstrate that housing can help people engage in treatment, including for their substance use disorders. Healthcare providers are recommended to regularly review whether patients and their caregivers require financial assistance (eg, disability coverage, advice about benefits). These interventions can help address underlying inequities that affect the health of people with life-limiting illnesses who use substances.

Mental health

People who use substances often have concurrent mental health illnesses that can worsen during communicable disease outbreaks, particularly with public health measures such as quarantine and physical distancing. The following counselling strategies were described in the literature about people with life-limiting illnesses who use substances with concurrent mental health illnesses during HIV epidemics. Counselling should focus on adaptation to the life-limiting illness, grief and preparing for death and dying. Patients may use the belief system ‘I’m going to die very soon’ to rationalise certain behaviours (eg, resuming drug use). Healthcare providers should consider framing to patients that they are living with the illness (eg, HIV), rather than dying from it. The literature reports that counselling can be delivered in different formats including 12-step programmes, art therapy and psychodynamic psychotherapy. However, some patients, particularly those at the end of their lives, may not be able to engage in counselling. In these situations, fast-acting medications may be helpful (eg, methylphenidate for depression). Additionally, patients with severe mental health illnesses may experience suicidal ideation. The US Centre for Substance Abuse Treatment recommends that healthcare providers should be aware of their jurisdictions’ laws related to disclosure of information about self-harm. At the outset of treatment, healthcare providers should inform patients of their professional responsibilities and actions they will take if patients share this information with them.

Grief and bereavement

People with life-limiting illnesses who use substances can encounter unique challenges during bereavement. Emotional processing can be more challenging when people are focused on their basic needs (eg, shelter, food). Social isolation and limited coping strategies can contribute to severe, complicated grief. The US Centre for Substance Abuse Treatment recommends substance use programmes provide counselling for patients with life-limiting illnesses and those who experience the deaths of their significant others. Grief and bereavement counselling can be delivered using innovative strategies, such as art therapy, expressive movements, psychodrama, commemorative projects and living legacies. However, limiting the duration of group therapy programmes should be considered because perpetual grieving may occur if too many members become sick or die (eg, groups for patients with AIDS). In addition to facing their own mortality, people who use substances with life-limiting illnesses may experience grief and bereavement from the deaths of their friends and family from communicable diseases (eg, HIV, COVID-19) and substance use (eg, opioid-related poisoning). Family and friends of patients may need to be connected with drug use programmes and resources. For terminally ill people who are incarcerated, the WHO recommends compassionate release if they have family or friends in the community. Additionally, patients with limited financial resources may require assistance with funeral arrangements. The goals are to allow people to have an opportunity to address important relationships and to die with dignity.

ACP and goals of care conversations (n=8; Table 5)

During communicable disease outbreaks, patients are recommended to complete ACP early in their illness trajectories to improve their comfort level, preserve their dignity and assist with prioritising the use of medical resources for those most in need. However, patients focused on surviving may be reluctant to discuss these topics. Past experiences (eg, systemic discrimination) may make some patients reluctant to accept a palliative approach as they may have fears of abandonment or receiving substandard care. The reported ACP and goals of care interventions for people with life-limiting illnesses who use substances during communicable disease outbreaks are summarized in table 5.

An example of a population where ACP may be challenging is people living with HIV. With advances in HIV treatment, HIV is no longer considered a ‘terminal’ illness. Some people with HIV may prefer to focus on the present and avoid discussing death. Collaborative healthcare provider–patient treatment decision-making
| Author (year)                          | Psychosocial support intervention sub-themes                                                                 |
|---------------------------------------|-------------------------------------------------------------------------------------------------------------|
| Batki (2000)                           | Structural vulnerability: Communicable disease outbreaks can worsen mental health illnesses and substance use, Emotional processing can be challenging for people focused on their basic needs |
|                                       | Mental health: Counselling should focus on adapting to the life-limiting illness, grief and preparing for death and dying, Social isolation and limiting coping strategies can contribute to complicated grief |
|                                       | Grief and bereavement: Healthcare providers should be aware of and inform their patients of their professional responsibilities if patients express suicidal ideation, Substance use programmes should provide counselling |
| Dong (2021)                            | Social isolation and limiting coping strategies can contribute to complicated grief                           |
| Enggist (2014)                         | Consider compassionate release of incarcerated terminally ill people                                         |
| Fantoni (1996)                         | Social isolation and limiting coping strategies can contribute to complicated grief                          |
| Halman (2014)                          | Housing can help with treatment engagement: Communicable disease outbreaks can worsen mental health illnesses and substance use |
| Health Care for the Homeless Clinicians’ Network (2018) | Housing can help with treatment engagement: Communicable disease outbreaks can worsen mental health illnesses and substance use |
| Kaufman (1993)                         | Communicable disease outbreaks can worsen mental health illnesses and substance use                         |
|                                       | Counselling can be delivered as psychodynamic psychotherapy                                                 |
| Merlin (2013)                          | Consider fast-acting medications (eg, methylphenidate) for some patients                                      |
| Sheroff (1998)                         | Frame to patients that they are living with (not dying from) their life-limiting illness                       |
| Skinner (2020)                         | Conduct social histories that include evaluation of economic status                                           |
| Tagarro (2013)                         | Counselling can be delivered as art therapy                                                                   |

Continued
and prior family discord over medical decisions are factors that are associated with conducting ACP discussions in the HIV population. ACP is an important intervention that can help structurally vulnerable populations place trust wisely and minimise communication challenges when receiving healthcare.

Patients should ideally have goals of care conversations with healthcare providers with whom they already have trusting relationships. The literature suggests that these conversations use trauma-informed approaches and be supportive, non-confrontational, collaborative and iterative, especially in the setting of acute illnesses. Decisions about continuing treatments (eg, HIV antiretroviral therapy) should consider factors such as pill burden, cost, patient and family preference, adverse effects and any remaining benefits associated with the medications. When managing symptoms, healthcare providers should be aware that some patients may not want to receive certain medications (eg, opioids, benzodiazepines) because of their drug use history. Patients faced with life-limiting illnesses may also seek unapproved medications or alternative treatments. Unless these treatments are known to be harmful, healthcare providers do not need to discourage patients from trying them.

**Healthcare provider training (n=6; Table 6)**

Healthcare provider training about palliative care principles and practices can promote an approach to care that overcomes stigma associated with drug use and improves the quality of life of people with life-limiting illnesses who use substances. The reported healthcare provider interventions for people with life-limiting illnesses who use substances during communicable disease outbreaks are summarized in table 6. According to the literature, healthcare providers need to learn to be comfortable with discussing difficult topics with patients including religion and spirituality, sexuality and sexual orientation, substance use, death and dying and grief. As a starting point, healthcare providers should examine their personal beliefs about death and dying, as their own fears may affect the treatments that they provide for patients. Healthcare providers are advised to be non-judgemental, open-minded, aware of cultural differences (including using cultural consultants for training and support) and, when in doubt, to ‘defer to the concepts of health and stability over pathology and dysfunction’. Figure 3 is a cross-cultural communication

### Table 4

| Author (year) | Psychosocial support intervention sub-themes |
|--------------|---------------------------------------------|
|              | Structural vulnerability | Mental health | Grief and bereavement |
| Task Force in Palliative Care (2020)44 | Communicable disease outbreaks can worsen mental health illnesses and substance use |
| Wood (1997)40 | Regular review whether patients and caregivers require financial assistance |
| Wrubel (2009)35 | Counselling can be delivered as 12 step programmes |
| Zilber (2006)21 | Counselling can be delivered as psychodynamic psychotherapy |

**Table 5** Advance care planning and goals of care interventions (n=8)

| Author (year) | Interventions |
|--------------|---------------|
| Batki (2000)16 | Goals of care conversations should use trauma-informed approaches and be supportive, non-confrontational, collaborative and iterative |
| Dong (2021)35 | Past experiences may make patients reluctant to accept palliative approach |
| Hall (2018)23 | Patients with HIV may prefer to focus on present rather than plan for the future |
| Hansen (2017)22 | Collaborative healthcare provider and patient treatment decision-making and prior family discord over medical decisions are associated with advance care planning discussions in HIV population |
| Merlin (2013)27 | Some patients may require assistance with identifying substitute decision-makers |
| Tagarro (2013)38 | Treatment discussions should consider factors like pill burden, cost, patient and family preference, adverse effects and benefits |
| Wenger (2001)19 | Patients may require assistance with identifying substitute decision-makers |
| Yao (2021)45 | Complete advance care planning early in illness trajectories |
40 years. Since HIV was first identified in the 1980s, antiretroviral therapies have transformed it from a life-threatening condition to a chronic, manageable condition. In comparison to the long-standing HIV epidemic, capacity to provide palliative care may be more limited in new and emerging communicable disease outbreaks, particularly when response efforts are focused on identifying and containing the disease. Furthermore, as a blood-borne infection, the precautions required to prevent and minimise transmission of HIV are different from communicable diseases transmitted by respiratory droplets and airborne routes (eg, tuberculosis, COVID-19). This review identified a knowledge gap about how palliative care interventions for people who use substances should be provided in communicable disease outbreaks other than HIV. Though the knowledge identified in our scoping review is generally applicable to other life-limiting illnesses and communicable disease outbreaks, novel models of care (eg, virtual care) are likely required to deliver high-quality, equitable palliative care for people who use substances that prevents and minimises risk of transmission of infectious diseases other than HIV.

The intersecting factors of life-limiting illnesses, substance use, comorbid conditions and structural vulnerability can make providing symptom management complex for people who use substances receiving palliative care. This review identified non-pharmacologic and pharmacologic recommendations for people who use substances, including opioid prescribing strategies for people on OAT. These recommendations are consistent with expert consensus recommendations about safer opioid prescribing for people receiving palliative care and management of advanced cancer-related pain in people with opioid use disorder. Based on individual circumstances and barriers, care plans should be individualised and adapted to provide high-quality, trauma-informed care that does not exacerbate barriers to care. Furthermore, the majority of the knowledge about tools that can be helpful for patients with life-limiting illnesses (eg, AIDS) who use substances and are culturally different from their healthcare providers.

**DISCUSSION**

In this scoping review, we identified 32 records that described palliative care interventions about symptom management, psychosocial support, ACP and goals of care conversations, and healthcare provider training for people who use substances during communicable disease outbreaks. Approximately half of the records were research articles, published in the USA and focused on providing palliative care to people who use alcohol and opioids in community settings. Moreover, the majority of records were about the global HIV epidemic and people with AIDS, published between 1988 and 2018.

The HIV epidemic has been ongoing for more than 40 years. Since HIV was first identified in the 1980s,
symptom management during communicable disease outbreaks was from studies and guidelines about palliative care in community settings (eg, home), acute care units and palliative care units in high-income countries (USA, Canada and UK). Access to palliative care and essential medications (eg, opioids) for this population can be restricted in communicable disease outbreaks. More research is needed to examine symptom management for people who use substances who reside in settings with limited resources, such as streets, unstable housing, prisons and low-income and middle-income countries.

When managing symptoms for people who use substances with life-limiting illnesses, palliative care providers should evaluate risk for non-medical use of opioids, opioid use disorder and opioid-related poisoning. Different opioid prescribing strategies may be required for people who use substances who are at high risk of these opioid-related harms (eg, daily to weekly dispensing of opioids prescribed for symptom management). Healthcare providers should not withhold or discontinue opioids necessary for symptom management or restrict access to services and resources. Health and social harms associated with non-medical opioid use can be reduced by harm reduction strategies, such as needle distribution programmes, supervised consumption sites, naloxone distribution programmes and drug checking services. This review did not identify how these harm reduction strategies can be incorporated into palliative care for people who use substances during communicable disease outbreaks when healthcare resources may be limited.

This review identified strategies that can be incorporated into palliative care to support people who use substances with concurrent mental health disorders. An estimated 37% of people with alcohol use disorder and 53% of people with other substance use disorders have a diagnosed mental health disorder. Mental health disorders and drug use can prevent people from identifying changes in their health, seeking out care and participating in ACP and medical decision-making discussions. Communicable disease outbreaks can amplify these challenges by impairing access to services and treatments for mental health and addictions. Substance use and associated harms can increase as a result. For example, the COVID-19 pandemic has significantly worsened the public health crisis related to opioid poisonings and deaths in Canada and the US. A partnership approach between addictions, mental health and palliative care providers is recommended to provide care for people who use substances with life-limiting illnesses and mental health disorders.

Through ACP and goals of care discussions, people who use substances can convey their health-related values and wishes to their caregivers and healthcare providers. This review identified important considerations that healthcare providers should be aware of when providing these interventions for this population: people who use substances with life-limiting illnesses may be reluctant to accept a palliative approach to their care because of strong survival instincts, past experiences with discrimination and mistrust of the healthcare system. Consequently, healthcare providers who have trusting relationships with this population are best suited to engage them in ACP and goals of care discussions. This recommendation is aligned with previous studies, including a qualitative study that found harm reduction services providers (eg, needle exchange programmes) are well suited to facilitate referrals to end-of-life care services for people who use substances who regularly access their programmes. Effort should be made in communicable disease outbreaks to maintain and leverage these established relationships. ACP and goals of care conversations are important to assist with triaging and clinical decision-making, especially when life-saving resources (eg, ventilators) are limited.

Palliative care delivery in communicable disease outbreaks should consider the intersectional risk environment of people who use substances. Health outcomes of people who use substances are shaped by social location (eg, gender, religion) and social-structural factors (eg, poverty, drug laws). Studies included in this review encourage healthcare providers to engage in self-reflection and to learn and practice cultural humility and safety, which is consistent with healthcare professional training programmes in countries like Canada and New Zealand. A knowledge gap exists about how palliative care education for people who use substances that uses health equity and culturally safe lenses can be incorporated into emergency preparedness, response and recovery plans.

Limitations
This comprehensive scoping review synthesised knowledge about palliative care interventions for people who use substances during communicable disease outbreaks. The methods were guided by rigorous scoping review methodologic frameworks and reporting guidelines but there were limitations. Studies that were not published in English and French were excluded. This review also does not include literature published in databases after April 2021 and grey literature sources after August 2021, which is important given the evolving COVID-19 pandemic. As previously mentioned, most included records were about people who use substances in the context of the HIV epidemic in community and inpatient settings located in high-income countries. Therefore, generalisability of these review findings to other communicable diseases outbreaks, resource-limited settings and countries should be done with caution.

Conclusion
Health, economic and social inequities are magnified when people who use substances with life-limiting illnesses require healthcare during epidemics and pandemics. This review synthesises existing and emerging evidence...
about symptom management, psychosocial support, ACP and healthcare provider education about palliative care for people who use substances. We identified knowledge gaps that need to be addressed to provide equitable, high-quality palliative care for people who use substances during communicable disease outbreaks. These findings provide accessible and relevant evidence for healthcare professionals and decision-makers that can be applied to the current COVID-19 pandemic and future communicable disease outbreaks.

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