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COVID-19 Articles Fast Tracked Articles

The Role and Response of Palliative Care and Hospice Services in Epidemics and Pandemics: A Rapid Review to Inform Practice During the COVID-19 Pandemic



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Abstract

Cases of coronavirus disease 2019 (COVID-19) are escalating rapidly across the globe, with the mortality risk being especially high among those with existing illness and multimorbidity. This study aimed to synthesize evidence for the role and response of palliative care and hospice teams to viral epidemics/pandemics and inform the COVID-19 pandemic response. We conducted a rapid systematic review according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines in five databases. Of 3094 articles identified, 10 were included in this narrative synthesis. Included studies were from West Africa, Taiwan, Hong Kong, Singapore, the U.S., and Italy. All had an observational design. Findings were synthesized using a previously proposed framework according to systems (policies, training and protocols, communication and coordination, and data), staff (deployment, skill mix, and resilience), space (community provision and use of technology), and stuff (medicines and equipment as well as personal protective equipment). We conclude that hospice and palliative services have an essential role in the response to COVID-19 by responding rapidly and flexibly; ensuring protocols for symptom management are available, and training nonspecialists in their use; being involved in triage; considering shifting resources into the community; considering redeploying volunteers to provide psychosocial and bereavement care; facilitating camaraderie among staff and adopting measures to deal with stress; using technology to communicate with patients and carers; and adopting standardized data collection systems to inform operational changes and improve care. *J Pain Symptom Manage* 2020;60:e31–e40. © 2020 Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.

Key Words

COVID-19, coronavirus, pandemic, palliative care, hospice, end of life

Key Message

An evidence synthesis on the role and response of hospice and palliative care in epidemics/pandemics to inform response to coronavirus disease 2019. Hospice and palliative care services should respond rapidly and flexibly, produce protocols, shift resources to the community, redeploy volunteers, facilitate staff camaraderie, communicate with

patients/carers via technology, and standardize data collection.

Introduction

The relief of suffering, supporting complex decision making, and managing clinical uncertainty are key attributes of palliative care and essential components of the response to epidemics and pandemics.¹ The

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coronavirus disease 2019 (COVID-19) pandemic is escalating rapidly across the globe. Those affected experience symptoms including breathlessness, cough, myalgia, and fever. The mortality risk is especially high among those with existing illness and multimorbidity.

Pandemics such as that caused by COVID-19 can lead to a surge in demand for health care services, including palliative and end-of-life care.² These services must respond rapidly, adopting new ways of working as resources are suddenly stretched beyond their normal bounds. Globally, palliative care is now seen as an essential part of universal health coverage. To inform the palliative care response to the COVID-19 pandemic, we aimed to rapidly synthesize evidence on the role and response of palliative care and hospice services to viral epidemics/pandemics.

Methods

Design

Rapid systematic review according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.

Inclusion/Exclusion Criteria

- Population—patients, carers, health care professionals, other experts, wards, units, and services
- Intervention—palliative care, hospice care, end-of-life care, and supportive care
- Context—viral epidemics or pandemics characterized by rapid transmission through the population and requiring a rapid response from the health system, including Ebola, severe acute respiratory syndrome, Middle East respiratory syndrome, avian influenza, and COVID-19. HIV was excluded because of its slower transmission through the population.
- Findings—role and/or response of palliative care and hospice services
- Study design—case studies, cross-sectional studies, cohort studies, and intervention studies (opinion pieces and editorials excluded)
- Language—no limits

Search Strategy

We searched five databases (MEDLINE [1966–2019], Embase [1980–2019], PsycINFO [1967–2019], CINAHL [1982–2019], and Web of Science [1970–2019]). The search strategy comprised terms for palliative care, hospice care, and end-of-life care as well as terms for pandemics and epidemics including specific named pandemics (Appendix). We identified and screened the reference lists of relevant systematic

reviews, government and nongovernmental organization reports, opinion pieces, and included articles.

Study Selection

One researcher (S. N. E.) completed all searches and removed duplicate records. Articles were screened in EndNote (version X9, Clarivate Analytics, Philadelphia, PA) using titles and abstracts by R. L. C., K. E. S., and S. N. E. Full texts were screened by K. E. S. and N. L.

Data Extraction

A bespoke data extraction form was created in Excel (Microsoft Corporation, Redmond, WA). Data were extracted by two researchers (K. E. S. and N. L.) and checked by a third researcher (A. E. B.). We did not appraise the quality of included studies.

Analysis

We conducted narrative synthesis and used the framework proposed by Downar and Seccareccia² to group recommendations. This framework, based on an established model of intensive care surge capacity, suggests that a palliative pandemic plan should include focus on systems, space, staff, and stuff.²

Results

We identified 3088 articles from database searches (search date: March 18, 2020) and identified six additional articles through screening the reference lists of relevant articles and reports. After removing duplicates, 2207 articles remained. Thirty six articles underwent full-text review, and 10 articles were included in the analysis (Fig. 1; Table 1).

The 10 articles were published between 2004 and 2020. Two articles concerned planning for pandemics,^{3,4} seven articles described data collected during epidemics/pandemics,^{5–11} and one article studied an epidemic retrospectively.¹²

The settings included West Africa,^{6–9} Taiwan,¹² Hong Kong,¹⁰ Singapore,¹¹ the U.S.,⁴ and Italy.⁵ One article had no defined setting.³ Eight of the articles concerned specific epidemics/pandemics (including Ebola,^{6–9} severe acute respiratory syndrome,^{11,12} influenza,^{3,10} and one on COVID-19³).

We synthesized findings according to Downar and Seccareccia model of systems, staff, space, and stuff (Table 2).

Discussion

We provide the first evidence synthesis to guide hospice and palliative care teams in their response to the

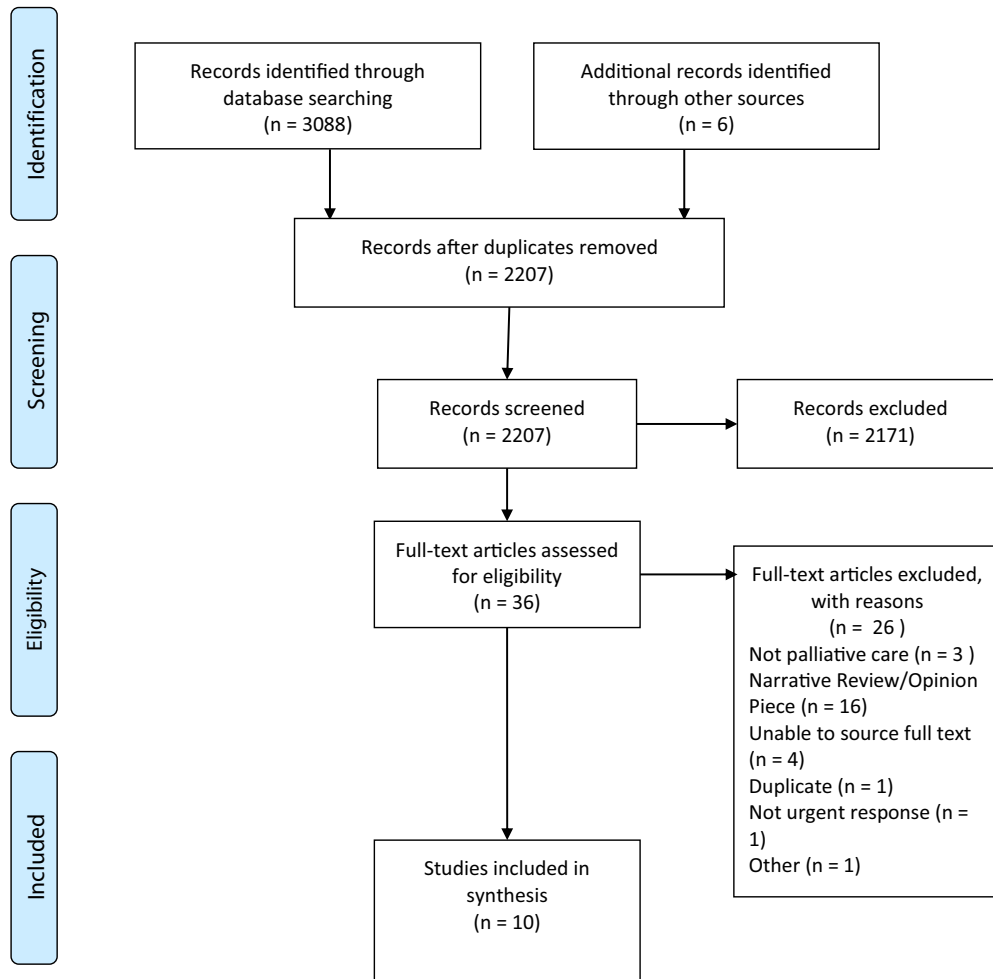


Fig. 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart.

COVID-19 pandemic. Key findings were the need for teams to be flexible and rapidly redeploy resources in the face of changing need. For hospital teams, this involves putting in place protocols for symptom control and training nonspecialists in their use. Hospice services may see a shift in need and should be prepared to focus their resources on community provision.

This was a rapid review, and we did not assess quality of studies or grade our recommendations. We found existing evidence to be limited. All identified studies were observational, quantitative data were rare, and there were no studies with an experimental design. Most studies were from Asia or Africa, with one study from Europe, and one from the U.S. This reflects the fact that Europe and the U.S. are less experienced at responding to pandemics than other regions, and this may in turn result in a lack of preparedness to respond to COVID-19. Although the importance of palliative care in response to pandemics has been well documented,^{1,13} this is not reflected in pandemic

plans or in palliative care training, and the research literature is sparse.

There were gaps in evidence, particularly around the role of palliative care teams in acute hospitals. There was also relatively little data on provision of palliative care in community settings, although in two studies, a reduction in demand for inpatient care was seen and led to the suggestion to shift resources into the community.^{5,12} Community palliative care can facilitate advance care planning and symptom control and helps prevent hospital admissions among people near the end of life.¹⁴ It is likely that community palliative care may help prevent hospital admissions among people dying from COVID-19 who would prefer to remain at home or in their care home, although this has not been tested. However, the rapid escalation of breathlessness in patients with COVID-19 who develop acute respiratory distress syndrome may make this challenging.¹⁵ Severe breathlessness and respiratory disease are both known to be associated with increased hospital admissions at the

Table 1
Description of Included Studies

Authors, yr	Context	Study Aim	Study Design	Setting/Participants	Findings and Author Recommendations
Costantini et al., 2020 ⁵	Italy, coronavirus (COVID-19)	To examine the preparedness for and impact of COVID-19 on hospices in Italy to help inform the responses of other countries	Cross-sectional telephone survey	16 hospices	<p>Hospice response to COVID-19:</p> <ul style="list-style-type: none"> • All hospices had rapidly implemented changes in practice, including transfer of staff to community settings, changes in admission criteria, and daily telephone support for families • Lack of PPE • Lack of hospice-specific guidance • Assessments of risk and potential impact on staff varied greatly <p>Authors recommended that governments urgently recognize the essential contribution of hospice and palliative care to the COVID-19 pandemic and ensure these services are integrated into the health care system response. Availability of PPE and setting-specific guidance is essential</p>
Battista et al., 2019 ⁶	West Africa, EVD	To identify care measures and barriers and facilitators to their implementation for patients with EVD	Cross-sectional online survey	29 clinicians and decision makers (24 physicians, three nurses, and two involved in project management and coordination)	<p>Barriers to the provision of supportive care:</p> <ul style="list-style-type: none"> • Insufficient numbers of health workers (maintenance, surveillance, and laboratory professionals) • Improper tools to document clinical data • Insufficient material resources (drug supplies, intravenous catheters, and lines) • Unadapted PPE • Limited sharing of protocols, advice, and standards of care within organizations <p>Facilitators to the provision of supportive care:</p> <ul style="list-style-type: none"> • Team camaraderie • Ability to speak the local language • Treatment protocols in place <p>Authors recommended that these areas of consensus are incorporated into guidelines to ensure standards of care are met</p>
Loignon et al., 2018 ⁷	West Africa, EVD	To document barriers to supportive care in Ebola treatment units	Qualitative telephone interviews	29 clinicians and decision makers, comprising 25 physicians, three nurses, and one other	<p>Barriers to the provision of supportive care:</p> <ul style="list-style-type: none"> • Lack of material and human resources (access to diagnostic and monitoring equipment) • Organizational structure limited the provision of clinical care (lack of protocols and deficient management structures) • Delayed and poorly coordinated policies limited the effectiveness of global and national response (insufficient political leadership and early epidemiological surveillance) <p>Authors recommended that relevant protocols are available, and organizational structures are</p>

Dhillon et al., 2015 ⁸	West Africa, EVD	To describe the treatment course of a man admitted to an Ebola treatment center and to describe some of the challenges identified	Case report	One 33-yr-old man admitted to an Ebola treatment center who died from Ebola-related complications 18 days later	<p>improved to provide supportive care in future outbreaks</p> <p>Challenges identified in providing care for an Ebola patient:</p> <ul style="list-style-type: none"> • Lack of consistency/continuity of staff • A decision maker was not identified • No recognition that the patient was dying • There was emphasis on saving life, and any protocols specific to palliative care were not implemented <p>Authors recommend that communication is paramount in an environment where there are multiple caregivers, identification of a lead decision maker is helpful, and knowledge of the basics of palliative is essential, particularly in low-resource settings</p>
Michaels-Strasser et al., 2015 ⁹	Sierra Leone, EVD	To assess the outcome or effectiveness of community care centers for rapid isolation and palliative care of people with suspected Ebola disease	Cross-sectional assessment using direct observation, a site assessment survey, and staff interviews	11 community care centers and 58 key informants	<p>Description and assessment of community care centers:</p> <ul style="list-style-type: none"> • Centers ranged from tents to repurposed hospital wards and schools and were set up swiftly (median 10 days) • Common features were proximity to community, small size (8–28 beds), ability to triage and isolate cases, and transport to Ebola treatment units when beds became available • Community care centers engaged and supported communities and fostered trust • Limited data to assess effectiveness, with registers and forms not standardized <p>Authors recommended that the creation of community care centers could be an effective and scalable response, if they have standardized design, include monitoring and evaluation instruments, and training and supervision manuals</p>
Cheng et al., 2014 ¹⁰	Hong Kong, avian influenza	To explain measures taken by palliative care services in Hong Kong during the H7N9 influenza	Case study of a service	The first confirmed case of human avian influenza A (H7N9)	<p>Response to avian influenza within a palliative care unit:</p> <ul style="list-style-type: none"> • Visiting hours for palliative units were limited to less than four hours per day, with not more than two visitors per visit • Visitors to public hospitals were required to put on surgical masks and perform hand hygiene before and after visiting patient areas • Volunteer services and clinical attachment in public hospitals were suspended • The palliative unit handled the restriction on family visits on compassionate grounds <p>Authors highlight the ethical dilemma that arises between dual need for infection control and</p>

(Continued)

Table 1
Continued

Authors, yr	Context	Study Aim	Study Design	Setting/Participants	Findings and Author Recommendations
Matzo et al., 2009 ³	Hypothetical mass casualty event from an influenza pandemic or other event	To understand the role of palliative care in mass casualty events and to make recommendations	Qualitative telephone interviews and group meeting with experts	10 disaster management and public health experts	comprehensive psychosocial care, with volunteers being integral to the interdisciplinary model of palliative care Issues for palliative care in mass casualty event: <ul style="list-style-type: none"> • Role of palliative care with scarce resources • Treatment decisions of those likely to die • Knowing what palliative care services to provide, along with personnel and settings • Ensuring training, supplies, and organisational or jurisdictional arrangements Authors recommended: <ul style="list-style-type: none"> • Training for nonpalliative care professionals in management of symptoms and psychological support • Plan for management of specific populations (elderly at home, those with learning disabilities) • Planning for and ensuring ethical allocation of scarce resources • Ensuring provision of palliative care at all medical care sites Planning to provide palliative care during mass casualty events should be part of the current national and local disaster planning for training guidelines, protocols, and activities
Cinti et al., 2008 ⁴	U.S., simulation exercise	To describe learning after simulation exercises for pandemic events	Simulation exercises with recommendations	A large tertiary care center with 913 beds	An ACC was described as four pods accommodating a total of 250 patients, providing limited supportive care for noncritical pandemic influenza patients and some who would require palliative care Authors concluded that: more attention was needed on palliative care and fatality management; plans should include involvement of clergy; palliative care protocols are essential, and there should be training for site leads in their use; and palliation medications should be included on the formulary
Chen et al., 2006 ¹²	Taiwan, SARS	To describe changes in hospice inpatient utilization during and after the SARS epidemic in 2003 in Taiwan	Retrospective study using administrative data	Hospice wards within 15 hospitals	Changes in hospice inpatient utilization during SARS epidemic: During the peak SARS period, the number of admissions to the 15 hospice wards decreased to 69% of those in the previous year, and inpatient day units reduced to 54%. It was not known whether the decrease in utilization was due to patients' voluntary decisions or hospital

policies, and the study could not determine whether the needs of patients with terminal illnesses were met during the epidemic. The authors concluded that the ability to shift resources from inpatient to community settings would improve care and that seamless continuity of care between facilities and settings should be ensured at all times.

Psychosocial impact of providing holistic care in an epidemic:

- Consequences of isolation
- Impact of uncertainty creating difficulties for patients, families, and staff in preparing for death
- Impact for health care workers (risk of contracting disease and not being able to grieve)
- Disruption of bereavement for families (management of bodies after deaths)

Authors recommend that in an epidemic palliative care should include measures to improve connectedness, training in communication and bereavement counseling, and measures to help health care workers deal with stress

Eight health care professionals (doctors, nurses, social workers, and pharmacists) in a palliative care unit

Qualitative interviews

To describe the psychosocial impact of providing holistic care in an epidemic

Leong et al.,
2004¹¹
Singapore,
SARS

COVID-19 = coronavirus disease 2019; PPE = personal protective equipment; EVD = Ebola virus disease; ACC = alternative care center; SARS = severe acute respiratory syndrome.

end of life.¹⁶ Therefore, rapid community response may be needed to manage advanced disease in COVID-19 if people are to remain at home.

Two studies reported cessation of hospice volunteer services in response to pandemics.^{5,10} An alternative role for volunteers may be in provision of psychological support for patients and carers, which could occur by using digital technology or telephones. In light of the social distancing measures being widely used in response to COVID-19, volunteers may have a wider role in supporting communities, for example, helping the most vulnerable with shopping for food and medicines.

Providing palliative care in pandemics can be compromised by the hostile environment, infection control mechanisms, and extreme pressure on services.¹⁰ In addition, the family unit of care may be disrupted. Even so, provision of palliative care is an ethical imperative for those unlikely to survive and may have the advantage of diverting dying people away from overburdened hospitals as well as providing the care that people want.³ Pandemic situations introduce complex ethical challenges concerning allocation of scarce resources, and palliative care teams are well placed to help patients and carers discuss preferences and make advance care plans.

Data collection systems to understand outcomes and share learning are important in a palliative pandemic response. However, these are frequently lacking.⁹ Such data should ideally include numbers of patients seen, as well as their main symptoms and concerns, treatments, effectiveness of treatment and outcomes. There is also a need to understand the prevalence of palliative care needs that are not met by palliative and hospice services. In a pandemic expected to last for several months such as COVID-19, implementing systems of data collection early would help services to plan for and improve care and could be used to project future needs.

Conclusion

Providing holistic care in a pandemic can be compromised by extreme pressure on services. Hospice and palliative care services can mitigate against this by maintaining the ability to respond rapidly and flexibly; ensuring protocols for symptom management and psychological support are available, and nonspecialists are trained in their use; being involved in triage; considering shifting resources from inpatient to community settings; considering redeploying volunteers to provide psychosocial and bereavement care; facilitating camaraderie among staff and adopting measures to deal with stress; use of technology to communicate with patients

Table 2
Synthesis of Evidence and Recommendations for the Palliative Care Response to COVID-19

Systems	<p>Policies</p> <ul style="list-style-type: none"> • Require flexibility and rapid changes to systems and policies^{5,10} • Limiting visitor hours/numbers^{5,10} • Change in admission criteria⁵ • Systems of daily telephone support for families⁵ • Stopping volunteer services¹⁰ • Palliative care and hospice care should be part of the national and Local epidemic/pandemic planning^{3,4} <p>Training and protocols</p> <ul style="list-style-type: none"> • Palliative care protocols for nonspecialist staff on management of symptoms and psychological support are essential^{3,4,6,7} • Training for site leads in the use of the protocols⁴ • Education and training for nonspecialist staff in basics of palliative care,⁸ including in communication and bereavement counseling¹¹ • Consider separate guidelines for specific populations such as people in care homes and those with intellectual disabilities³ <p>Communication and coordination</p> <ul style="list-style-type: none"> • Sharing of protocols, advice, and standards of care within organizations⁶ • Identification of a decision maker to improve communication, particularly where multiple health professionals may be involved outside their usual practice⁸ • Rapid triage to assess likelihood of response to treatment³ and recognition of dying⁸ <p>Data</p> <ul style="list-style-type: none"> • Standardized information collection⁹ • Continuous monitoring and evaluation to inform operational changes or quality of services⁹
Staff	<p>Deployment of staff</p> <ul style="list-style-type: none"> • Flexibility of deployment, such as moving staff from acute setting to the community^{5,12} • Sufficient staff numbers⁸ • Restricting contact with volunteers for infection control,^{5,10} whereas acknowledging volunteers are integral to the interdisciplinary model in palliative care and can make important contributions to psychosocial and bereavement care¹⁰ <p>Skill mix of staff</p> <ul style="list-style-type: none"> • Involving spiritual care and chaplains in the pandemic response^{3,4} • Involving psychologists with expertise in palliative care³ <p>Ensuring resilience of staff</p> <ul style="list-style-type: none"> • Facilitating camaraderie among staff important to minimize negative psychosocial effects on staff, which include distress about risks of contracting the disease, grieving relatives, or friends while working⁶ • Measures to improve connectedness among staff¹¹ • Training in communication and bereavement counseling¹¹ • Measures to help health care workers deal with stress¹¹
Space	<p>Moving to community provision</p> <ul style="list-style-type: none"> • Consider shifting resources from inpatient to community settings where demand may be higher^{5,12} • Consider the setup of community care centers to expand outside hospital with standardized designs, include monitoring and evaluation instruments, and make use of training and supervision manuals. Community engagement to foster trust is important⁹ <p>Use of technology</p> <ul style="list-style-type: none"> • The role for virtual technology to enable communication, where visiting is restricted, for example, providing a daily update for families^{5,10}
Stuff	<p>Medicines and equipment</p> <ul style="list-style-type: none"> • Relevant symptom medications should be included in formularies,⁴ in the case of COVID-19—breathlessness, cough, fever, delirium, anxiety, as well as pain • Basic supplies of medications, intravenous catheters, and lines⁶ • Access to diagnostic and monitoring equipment⁷ <p>PPE</p> <ul style="list-style-type: none"> • Sufficient supplies of PPE that are adaptable to the person^{5,6}

COVID-19 = coronavirus disease 2019; PPE = personal protective equipment.

and carers; and adopting standardized data collection systems to inform operational changes and improve care. Long-term priorities should include ensuring palliative and hospice care are integrated into pandemic plans.

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Supplementary Data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.jpainsymman.2020.03.029>.

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Appendix

Appendix. Search Strategy

There were no restrictions for language or publication date. Searches were completed on March 18, 2020.

MEDLINE and Embase

(palliative care/OR palliative medicine/OR palliate\$.mp. OR hospices/OR terminally ill/OR terminal care/OR hospice\$.mp. OR end of life.mp. OR EOL.mp.) AND (exp pandemics/OR pandemic\$.mp. OR epidemic\$.mp. OR epidemics/OR exp disease outbreaks/OR disease outbreaks.mp. OR SARS.mp. OR SARS virus/OR Severe Acute Respiratory Syndrome/OR coronavirus/OR coronavirus.mp. OR exp coronavirus infections/OR ebolavirus/OR influenza, human/OR influenza.mp. OR hemorrhagic fever, ebola/OR mers.mp. OR flu.mp. OR Middle East Respiratory Syndrome Coronavirus/OR Tuberculosis/OR Pulmonary tuberculosis/OR Tuberculosis, multi-drug resistant/OR Extensively drug resistant tuberculosis/OR TB.mp.)

PsycINFO

(palliative care/OR palliate\$.mp. OR hospice/OR terminally ill patient/OR terminal care.mp. OR hospice\$.mp. OR end of life.mp. OR EOL.mp.) AND (exp pandemics/OR pandemic\$.mp. OR epidemic\$.mp. OR exp epidemics/OR disease outbreaks.mp. OR

SARS.mp. OR Severe Acute Respiratory Syndrome.mp. OR coronavirus.mp. OR influenza/OR swine influenza OR ebola.mp. OR ebolavirus.mp. OR influenza.mp. OR mers.mp. OR flu.mp. OR Middle East Respiratory Syndrome Coronavirus.mp. OR Tuberculosis/OR Pulmonary tuberculosis/OR multi-drug resistant tuberculosis.mp. OR extensively drug resistant tuberculosis.mp. OR TB.mp.)

CINAHL

Searched for the below as title, abstract, and keywords.

(Palliative care OR palliative medicine OR palliat* OR hospice* OR terminally ill OR terminal care OR end of life OR eol) AND (pandemic* OR epidemic* OR disease outbreak OR SARS OR Severe acute respiratory syndrome OR SARS virus OR coronavirus OR coronavirus infections OR influenza OR flu OR MERS OR middle east respiratory syndrome OR ebola virus OR ebola OR Tuberculosis OR multidrug-resistant tuberculosis)

Web of Science

TS=((palliative care OR palliative medicine OR palliat* OR hospice* OR terminally ill OR terminal care OR eol) AND (pandemic* OR epidemic* OR disease outbreak OR SARS OR Severe acute respiratory syndrome OR SARS virus OR coronavirus OR coronavirus infections OR influenza OR flu OR MERS OR middle east respiratory syndrome OR ebola virus OR ebola OR Tuberculosis OR multidrug-resistant tuberculosis))