

The underrepresentation of palliative care in global guidelines for responding to infectious disease outbreaks: a systematic narrative review

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Background: The importance of palliative care provision has been highlighted in previous humanitarian emergencies. This review aimed to examine the breadth and depth of palliative care inclusion within global guidelines for responding to infectious disease outbreaks.

Methods: The review was conducted using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis guidelines. Electronic searches of MEDLINE, Embase, Cumulative Index to Nursing and Allied Health, PsychInfo and grey literature were performed. Inclusion criteria were guidelines (recommendations for clinical practice or public health policy) for responding to infectious disease outbreaks in the general adult population. Results were limited to the English language, between 1 January 2010 and 17 August 2020. Analysis of the included articles involved assessing the breadth (number of palliative care domains covered) and depth (detail with which the domains were addressed) of palliative care inclusion.

Results: A total of 584 articles were retrieved and 43 met the inclusion criteria. Two additional articles were identified through handsearching. There was limited inclusion of palliative care in the guidelines examined.

Conclusions: There is an opportunity for the development of guidelines that include information on palliative care implementation in the context of infectious disease outbreaks in order to reduce the suffering of key vulnerable populations worldwide.

Keywords: epidemics, guidance, infectious disease outbreaks, pandemics, palliative care, recommendations.

Introduction

Palliative care describes care that is focused on improving the quality of life of people who are suffering from a chronic or life-limiting illness. Physical, psychosocial and spiritual care is provided not only to the patient, but also to their family and community. The effectiveness of palliative care in reducing the burden of serious health-related suffering for patients and their families is well documented and consequently it has been described as an essential element of universal health coverage.^{1–5}

In 2014, the World Health Assembly formally recognised the limited availability of palliative care services and the large degree of avoidable suffering that occurs within the global context. The Lancet Commission on Palliative Care and Pain Relief estimated that in 2015 more than 25 million people worldwide died without receiving palliative care.¹ The World Health Assembly urged all member states to develop, strengthen and integrate palliative care services throughout their continuum of care.⁶ Despite this commitment and the established evidence base, there remain significant gaps in the widespread implementation of this approach to care.^{1,2,4} One particular area of focus more recently has

been the role of palliative care in humanitarian emergencies.^{3,7,8} Previous humanitarian crises such as natural disasters, acts of terrorism and infectious disease outbreaks have highlighted the importance of palliative care in situations where large numbers of people suffer from chronic, life-limiting or life-threatening illness or injury who may not benefit, not want or not be offered lifesaving treatments but who nevertheless require care.^{7,9–12} In 2018, the World Health Organization (WHO) released a guide on integrating palliative care and symptom relief into the response to humanitarian emergencies and crises.¹³ While palliative care is slowly gaining recognition as a key component of healthcare in humanitarian crises, this does not seem to have translated into any significant increase in the delivery of palliative care services on the ground.^{1,3,11,12}

Patients who are suffering from a chronic or life-threatening illness during an infectious disease outbreak face particularly complex and difficult situations. Most frequently discussed in the literature are the possible limits of available resources, meaning that life-sustaining treatments may need to be rationed. Less frequently noted is the need for social isolation to help reduce the contagion yet simultaneous requirements for care, meaning care delivery is changed and sometimes compromised.^{14–16} In these and many other similar situations of complexity, the integration of palliative care should be seen as an essential element of optimum care.^{9,17}

The coronavirus disease 2019 (COVID-19) pandemic, a current crisis of global scale, has seen the proliferation of guidelines and standards aimed at supporting health systems and services to implement quality healthcare in the midst of the pandemic. COVID-19 makes stark the importance of palliative care delivery alongside lifesaving interventions, but the degree to which these guidelines and others responding to infectious disease outbreaks have heeded the WHO guidelines and integrated palliative care is not yet known.^{16,18} This review aims to answer the question: to what extent is palliative care included in global guidelines that have been developed to support healthcare systems and providers to respond to infectious disease outbreaks?

Methods

Patient and public involvement

In this review we followed recommended approaches and guidelines as appropriate to our research question. Patient and public involvement was not required during the research process.

Databases and search terms

The narrative review with a systematic approach included both peer-reviewed and grey literature guidelines. MEDLINE, Embase, PsychInfo and Cumulative Index to Nursing and Allied Health were searched for relevant English-language articles published between 1 January 2010 and 17 August 2020. This time period was chosen to ensure inclusion of only those guidelines that are up-to-date, considering the rapidly evolving nature of guidelines responding to infectious disease outbreaks. This timeframe included significant recent notable infectious disease outbreaks, including the current COVID-19 pandemic, the Middle East Respi-

ratory Syndrome coronavirus (MERS-CoV) outbreak (Middle East 2012 and Republic of Korea 2015), the West African Ebola outbreak (2014–2016) and the 2017, 2018 and current Democratic Republic of Congo Ebola outbreak.^{19–21} The search strategy used a combination of free-text and medical subject heading (MeSH) terms to capture the following concepts: guideline (e.g. 'guideline' [MeSH]) and context (e.g. 'disease outbreak' or 'pandemic' [MeSH]) (see supplementary file). The search aimed to capture those guidelines that a general health practitioner or policymaker would likely access when responding to an infectious disease outbreak. For this reason, palliative care or words related to palliative care were not used in the search string, as it is unlikely that general health practitioners or policymakers would use these terms in their search for guidelines about responding to infectious disease outbreaks.

Grey literature was identified through searching websites of major international non-governmental organisations (INGOs), national entities and multilateral institutions such as the WHO (Table 1). Specific health-focused INGO, national and multilateral organisation documents were chosen in consultation with experts in the field and drawing on the grey literature search cited in Nouvet et al.¹² Search terms for the identification of grey literature included 'guidelines' or 'guidance' combined with 'epidemic', 'pandemic' or 'disease outbreak'.

Both peer-reviewed literature and guidelines from prominent global entities published as grey literature were selected to ensure coverage of a wide scope of articles. National, multilateral and INGO guidelines often follow processes drawing on the best available evidence and expert review and are widely used by policymakers and health professionals. Peer-reviewed articles provide rigor and complimentary information to such documents. Hence it was important to use guidelines from both resources to ensure an accurate representation of guidelines that are developed for responding to infectious disease outbreaks.

Inclusion and exclusion criteria

After removal of duplicates, articles were reviewed by title and abstract and those that met the inclusion criteria underwent a full-text review. Articles were eligible for inclusion if they met all of the following criteria: guideline (recommendations for clinical practice or public health policy),²² target population (adult, age ≥ 18 y) without a focus on a particular medical condition and context (infectious disease outbreak).

Exclusion criteria were target population (those that focused on certain clinical conditions, e.g. diabetes) and context (humanitarian crises other than an infectious disease outbreak).

Data analysis

Documents were initially classified according to their likely intended audience. Those that provided guidance to governing bodies and organisations regarding how to respond to an infectious disease outbreak as a population were classified as policymaker documents. Those that were primarily focused on providing guidance to front-line clinicians were categorised as documents aimed at clinicians and those that had a target audience of policymakers and clinicians fell under the category 'both' (Table 2).

Table 1. Organisation websites used to strengthen and triangulate grey literature search

Organisation	Website
Active Learning Network for Accountability and Performance (ALNAP)	https://www.alnap.org
Catholic Relief Services (CRS)	https://www.crs.org/
Inter-agency standing committee (IASC)	https://interagencystandingcommittee.org/
International Committee of the Red Cross (ICRC)	https://www.icrc.org/en
International Federation of Red Cross and Red Crescent Societies (IFRC)	https://www.ifrc.org/en/-/
International Rescue Committee (IRC)	https://www.rescue.org/
Médecins Sans Frontières International (MSF)	https://www.msf.org/
National Institute for Health and Care Excellence (NICE)	https://www.nice.org.uk/
United Nations High Commissioner for Refugees (UNHCR)	https://www.unhcr.org/
United Nations Office for the Coordination of Humanitarian Affairs (UNOCHA)	https://www.unocha.org/
World Health Organisation (WHO)	https://www.who.int/

Each article was then graded as to the breadth and depth of coverage of palliative care. The breadth of an article was graded according to the number of palliative care domains covered. This was done using a typology that consisted of nine domains, including pain and symptom control, psychosocial care, spiritual care, information/communication, advance care planning, end-of-life care, family support, bereavement support and a final domain of not otherwise specified. These were adapted from the National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care.²³ The grades were broken into nil (no domains mentioned), low (1–3 domains), moderate (4–6 domains) and high (≥ 7 domains). An article was said to include a domain if there was at least one sentence describing that domain. Analysis of the presence of the domains involved a full-text analysis of each article and identification of the presence of the words palliative care or related words or themes (e.g. end-of-life-care). Second, if the topic of palliative care was present in the article, the specific domain(s) covered was then recorded. Specific mention of words of a domain were sought (e.g. bereavement support) as well as searching for words associated with the domain (e.g. grieving). This process ensured the accurate identification of the palliative care domains in each article. If a sentence included the words or themes of more than one domain, then it was recorded under each of the domains that were present in the sentence. The presence of each domain was recorded only if the domain was being discussed in the context of palliative care. For example, psychosocial well-being of patients was only reported if it was mentioned in reference to palliative care rather than the general psychosocial well-being of a patient.

The depth of palliative care inclusion of an article was graded according to the number of sentences that described each domain. The grades were classified as greater depth, when the majority of the domains of palliative care that were mentioned were described by more than one sentence, and minimal depth, as anything less than this. This enabled the identification of those articles that may have covered multiple domains but did so in little detail.

In addition, themes emerging from the document review were collated, synthesized and integrated to guide the discussion as presented.

Ethics approval

Ethics approval was not required for this review.

Results

From an initial 584 articles, 30 duplicates were removed and a total of 45 articles were identified for full-text analysis (Figure 1). Articles aimed at policymakers accounted for 55% ($n=25$) of the articles, while 38% ($n=17$) were aimed at clinicians and 7% ($n=3$) were aimed at both (Table 2). Of the 28 documents aimed at policymakers, only one stated that palliative care was an essential health service and named palliative care as a performance indicator for monitoring essential health services during the COVID-19 pandemic.²⁴ This was an updated version of a previous guideline that did not include palliative care.²⁵

The included articles had a limited focus on palliative care. Most (58% [$n=26$]) did not mention palliative care, 20% ($n=9$) had a low breadth of coverage, 13% ($n=6$) had a moderate breadth of coverage and 9% ($n=4$) had a high breadth of coverage (Table 2). Information/communication, advance care planning and end-of-life care were the most frequently covered domains (20% [$n=9$]). These were followed closely by access and psychosocial care (18% [$n=8$]). The prespecified domain that was covered the least was bereavement support (9% [$n=4$]) (Table 3). Furthermore, of the 19 articles that included palliative care, 95% ($n=18$) did so in minimal depth, leaving only 5% ($n=1$) that explored palliative care in greater depth (Table 2). The documents that mentioned palliative care commonly highlighted ensuring access to palliative care, however, just one of these guidelines provided further details on which systems and measures needed to be put in place to ensure this access.²⁶

Guidelines specific to the COVID-19 pandemic accounted for 82% ($n=37$) of the articles, leaving 18% ($n=8$) aimed at another infectious disease outbreak, e.g. Ebola. Of the guidelines specific to the COVID-19 pandemic, 46% ($n=17$) mentioned palliative care, 6% of which ($n=1$) explored palliative care in greater depth (Table 2). Of those that were not developed in response to the COVID-19 pandemic, 50% ($n=4$) mentioned palliative care, none of which explored palliative care in greater detail (Table 2).

Table 2. Articles included in this review

Title, author, year	Target audience	COVID-19 or non-COVID-19	Level of coverage and depth	Further comments
Maintaining essential health services: operational guidance for the COVID-19 context interim guidance, WHO, 2020 ²⁴	Policy-makers	COVID-19	High coverage (8 domains) Minimal depth	Previous version ²⁵ had no mention of palliative care Article was only updated after an editorial highlighted omission of palliative care ¹⁸
Clinical management of COVID-19, WHO, 2020 ²⁶	Clinicians	COVID-19	High coverage (eight domains) Greater depth	Guideline adapted from two previous versions, both of which had no coverage of palliative care ^{33,34}
Clinical care for severe acute respiratory infection: toolkit, WHO, 2020 ²⁷	Clinicians	COVID-19	Low coverage (one domain) Minimal depth	Only mentioned palliative care as an endpoint to a triage decision framework
Triage: care of the critically ill and injured during pandemics and disasters: CHEST Consensus Statement, Christian et al., 2014 ²⁸	Clinicians	Non-COVID-19 (pandemics in general)	Low coverage (one domain) Minimal depth	Palliative care was included as an endpoint in a triage decision framework
Home care for patients with suspected or confirmed COVID-19 and management of their contacts, WHO, 2020 ³¹	Clinicians	COVID-19	Moderate coverage (four domains) Minimal depth	Highlighted the need for access to community palliative care Limited guidance around key activities Provided link to WHO's Integrating palliative care and symptom relief into responses to humanitarian crises document ¹³
COVID-19 rapid guideline: managing symptoms (including at the end of life) in the community, NICE, 2020 ³²	Clinicians	COVID-19	Moderate coverage (four domains) Minimal depth	Management of COVID-19 patients in the community with limited palliative care coverage Limited guidance around key activities
COVID-19 strategy update, WHO, 2020 ³⁵	Policy-makers	COVID-19	No coverage	Predominant focus on saving lives: 'WHO's singular focus is on working to serve all people to save lives and stop the pandemic' Global strategic objective: 'reduce mortality by providing appropriate clinical care for those affected by COVID-19'
Preparedness for cyclones, tropical storms, tornadoes, floods and earthquakes during the COVID-19 pandemic, WHO, 2020 ³⁶	Policy-makers	COVID-19	No coverage	Guideline targeted towards mass casualty events in the setting of COVID-19
Operational and planning guidelines to support country preparedness and response, WHO, 2020 ³⁷	Policy-makers	COVID-19	Low coverage (one domain) Minimal depth	No explicit reference to palliative care as an essential health service Limited guidance around key activities

Table 2. Continued

Title, author, year	Target audience	COVID-19 or non-COVID-19	Level of coverage and depth	Further comments
Strengthening preparedness for COVID-19 in cities and urban settings, WHO, 2020 ³⁸	Policy-makers	COVID-19	No coverage	Aim of article: help policy-makers identify effective approaches and implement recommendations that enhance the prevention, preparedness and readiness for COVID-19 and similar events in urban settings Listed essential services excluding palliative care
Practical actions in cities to strengthen preparedness for the COVID-19 pandemic and beyond, WHO, 2020 ³⁹	Policy-makers	COVID-19	No coverage	Included a chapter on actions to be taken for access to healthcare services during COVID-19 and the continuation of essential health services
Monitoring and evaluation framework: COVID-19 strategic preparedness and response, WHO, 2020 ⁴⁰	Policy-makers	COVID-19	No coverage	Aim of article: outline indicators for monitoring and evaluation of responses to COVID-19 Predominant focus on saving lives
Preventing and managing COVID-19 across long-term care services: policy brief, WHO, 2020 ⁴¹	Policy-makers	COVID-19	High coverage (eight domains) Minimal depth	Limited guidance around key activities
Critical preparedness, readiness and response actions for COVID-19, WHO, 2020 ⁴²	Policy-makers	COVID-19	No coverage	Provided 'preparedness, readiness and response actions for each transmission scenario for COVID-19' Provided links to other WHO technical guidance documents which did contain palliative care information, albeit limited
Preparedness, prevention and control of coronavirus disease for refugees and migrants in non-camp settings, WHO, 2020 ⁴³	Policy-makers	COVID-19	No coverage	Predominant focus on saving lives
Operational considerations for case management of COVID-19 in health facility and community, WHO, 2020 ⁴⁴	Policy-makers	COVID-19	No coverage	Predominant focus on saving lives
Interim ethical recommendations in medical management in the COVID-19 crisis, Philippine College of Physicians, 2020 ⁴⁵	Clinicians	COVID-19	High coverage (seven domains) Minimal depth	Recognised the need for palliative care Lack of guidance around key activities Predominant focus on saving lives: '...the ultimate goal is to save the most lives...'

Table 2. Continued

Title, author, year	Target audience	COVID-19 or non-COVID-19	Level of coverage and depth	Further comments
Ethical guidelines for leaders in health care institutions during the COVID-19 pandemic, Tan et al., 2020 ⁴⁶	Clinicians	COVID-19	Moderate (five domains) Minimal depth	Identified the allocation of scarce resources as a key ethical dilemma during COVID-19 Recognised the need for palliative care Limited guidance around key activities
Consensus for prevention and management of coronavirus disease 2019 (COVID-19) for neurologists, Jin et al., 2020 ⁴⁷	Clinicians	COVID-19	No coverage	Predominant focus on saving lives
COVID-19 rapid guideline: critical care in adults, NICE, 2020 ⁴⁸	Clinicians	COVID-19	Low coverage (three domains) Minimal depth	Focused on advance care planning and palliation in relation to triage Limited guidance around key activities
Community-based healthcare including outreach and campaigns in the context of the COVID-19 pandemic, WHO and UNICEF, 2020 ⁴⁹	Polymakers	COVID-19	Low coverage (two domains) Minimal depth	One sentence on advanced care planning and end-of-life care Limited guidance around key activities
Public health and social measures for COVID-19 preparedness and response in low-capacity and humanitarian settings, ICRC et al., 2020 ⁵⁰	Polymakers	COVID-19	No coverage	Predominant focus on saving lives
Scaling-up COVID-19 outbreak readiness and response operations in camps and camp-like settings, IFRC et al., 2020 ⁵¹	Polymakers	COVID-19	No coverage	Aim of article: provide optimised care for infected patients Chapter on case management and continuity of essential health services that included links to other WHO technical guidance documents which did contain palliative care information, albeit limited
Responding to COVID-19: guidance for humanitarian agencies, Ramalingam et al., 2020 ⁵²	Polymakers	COVID-19	No coverage	Did not specify palliative care as an appropriate and relevant part of management Lack of guidance on how to operationalise recommendations and what this specifically included
Long-term care facilities and the coronavirus epidemic: practical guidelines for a population at highest risk, Dosa et al., 2020 ⁵³	Polymakers	COVID-19	No coverage	Predominant focus on saving lives Recommendations for appropriate preparedness include 'reduce morbidity and mortality among those infected'

Table 2. Continued

Title, author, year	Target audience	COVID-19 or non-COVID-19	Level of coverage and depth	Further comments
Israel Ad Hoc COVID-19 Committee: guidelines for care of older persons during a pandemic, Clarfield et al., 2020 ⁵⁴	Clinicians	COVID-19	Moderate coverage (five domains) Minimal depth	A short document, yet contained a reasonable amount of palliative care information One of the authors was a palliative care specialist
COVID-19: how to prepare for the pandemic?, Lodha and Kabra, 2020 ⁵⁵	Policy-makers	COVID-19	No coverage	Provided strategies to prevent and cope with the healthcare surge capacity
Management of SARS-CoV-2 infection: recommendations of the Polish Association of Epidemiologists and Infectiologists as of March 31, 2020, Flisiak et al., 2020 ⁵⁶	Clinicians	COVID-19	Low coverage (one domain) Minimal depth	Guideline for managing the various severities of COVID-19 infection, e.g. stable patients, unstable patients and patients in critical condition. 'Palliative treatment' falls under management for stable patients only Predominant focus on saving lives Limited guidance around key activities
COVID-19 response strategy, Catholic Relief Services, 2020 ⁵⁷	Policy-makers	COVID-19	No coverage	No mention of palliative care when describing quality healthcare for both COVID-19 and non-COVID-19 patients
Guidance note on COVID-19 acute respiratory disease for UNHCR operations, UNHCR, 2020 ⁵⁸	Policy-makers	COVID-19	No coverage	Rudimentary guideline that had limited guidance around key activities
Global Humanitarian Response Plan: COVID-19, UNOCHA, 2020 ⁵⁹	Policy-makers	COVID-19	No coverage	Predominant focus on saving lives
Contingency plan for the intensive care services for the COVID-19 pandemic, Sedes et al., 2020 ⁶⁰	Policy-makers	COVID-19	No coverage	Guideline regarding a plan to deal with an increase in intensive care unit (ICU) demand during COVID-19. Palliative care not explicitly mentioned, yet emphasised importance of strict ICU admission criteria. Detailed exclusion criteria for admission to ICU with no further detail on next steps for these patients
One size does not fit all: mitigating COVID-19 in humanitarian settings, International Rescue Committee, 2020 ⁶¹	Policy-makers	COVID-19	No coverage	Predominant focus on saving lives
COVID-19 in humanitarian crises: a double emergency, International Rescue Committee, 2020 ⁶²	Policy-makers	COVID-19	No coverage	Predominant focus on saving lives

Table 2. Continued

Title, author, year	Target audience	COVID-19 or non-COVID-19	Level of coverage and depth	Further comments
Recommendations of the working groups from the Spanish Society of Intensive and Critical Care Medicine and Coronary Units (SEMICYUC) for the management of adult critically ill patients in the coronavirus disease (COVID-19), Ballesteros et al., 2020 ⁶³	Clinicians	COVID-19	Low coverage (one domain) Minimal depth	Recommendations from different working groups, e.g. the bioethics working group Palliative care mentioned once as a recommendation given by the bioethics working group, but no comprehensive guidance was provided. All working groups had predominant focus on saving lives
Clinical practice guidelines by the Infectious Diseases Society of America: 2018 update on diagnosis, treatment, chemoprophylaxis, and institutional outbreak management of seasonal influenza, Uyeki et al., 2019 ⁶⁴	Clinicians	Non-COVID-19 (influenza)	No coverage	Paragraph on treatment for influenza that focused on curative treatment without mention of palliative care, yet had sentences describing influenza's significant morbidity and mortality, e.g.: 'Seasonal influenza A and B virus epidemics are associated with significant morbidity and mortality each year in the United States and worldwide' 'Most people recover from uncomplicated influenza, but influenza can cause complications that result in severe illness and death...'
Management of a cholera epidemic, Olson et al., 2018 ⁶⁵	Clinicians and policymakers	Non-COVID-19 (cholera)	No coverage	Predominant focus on saving lives
Tuberculosis, Varaine and Rich, 2017 ⁶⁶	Clinicians and policymakers	Non-COVID-19 (TB)	Moderate coverage (four domains) Minimal depth	One paragraph on palliative care for those whose treatment has failed
Guidance for managing ethical issues in disease outbreaks, WHO, 2016 ⁶⁷	Policymakers	Non-COVID-19 (disease outbreaks in general)	Low coverage (one domain) Minimal depth	No mention of palliative care in chapter entitled 'Situations of particular vulnerability' Recognised importance of access to palliative care but had limited guidance around key activities Predominant focus on saving lives

Table 2. Continued

Title, author, year	Target audience	COVID-19 or non-COVID-19	Level of coverage and depth	Further comments
Clinical management of patients with viral haemorrhagic fever, WHO, 2016 ⁶⁸	Clinicians	Non-COVID-19 (viral haemorrhagic disease)	Moderate coverage (four domains) Minimal depth	Acknowledged that palliative care and end-of-life care should be undertaken when 'required/indicated', but no further detail given Covered two of the domains of palliative care (support for family and symptom management), but not in the context of palliative care Palliative care was discussed in most depth in the context of children suffering from viral haemorrhagic disease
Management of a measles epidemic, Danet and Fermon, 2013 ⁶⁹	Clinicians and policymakers	Non-COVID-19 (measles)	No coverage	Describes case fatality rate up to 20% in some settings, no mention of palliative care for either the clinician or the policymaker Predominant focus on saving lives
UNICEF cholera toolkit, UNICEF, 2013 ⁷⁰	Clinicians	Non-COVID-19 (cholera)	No coverage	Predominant focus on saving lives
Critical care triage: recommendations and standard operating procedures for intensive care unit and hospital preparations for an influenza epidemic or mass disaster, Christian et al., 2010 ⁷¹	Policymakers	Non-COVID-19 (influenza)	Low coverage (one domain) Minimal depth	Predominant focus on saving lives First goal: 'minimise loss of life due to critical injuries or illness during a mass casualty event' Recognised the need for palliative care but limited guidance around key activities to achieve this Stated that palliative care could be given alongside active medical therapy
Management of influenza, Erlikh et al., 2010 ⁷²	Clinicians	Non-COVID-19 (influenza)	No coverage	Predominant focus on saving lives
Pandemic (H1N1) 2009 influenza, Patel et al., 2010 ⁷³	Clinicians	Non-COVID-19 (influenza)	No coverage	Section on intensive care and triage describing process of reverse triage (withdrawing care from a critical care patient)

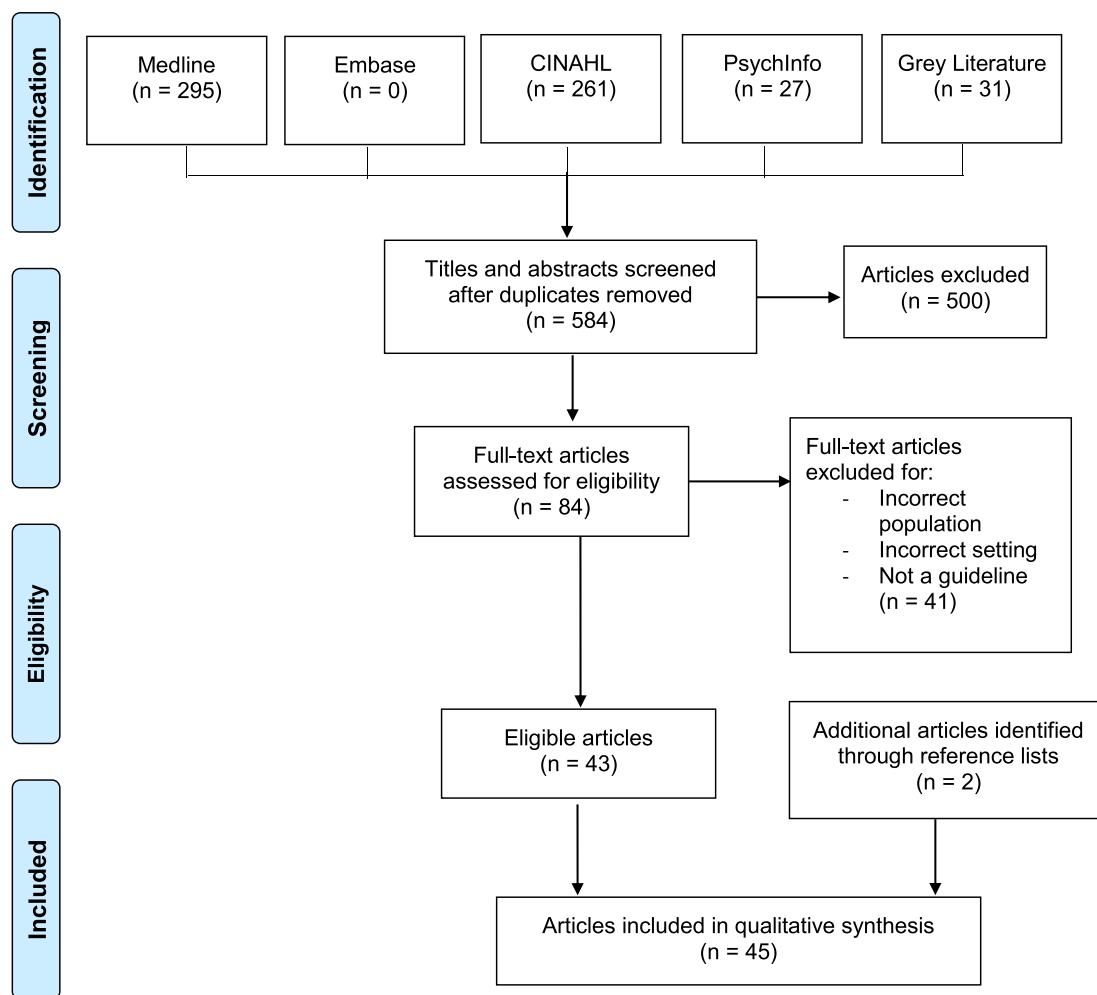


Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analysis flow chart of returned results.

Discussion

The literature and guidelines detailing management of infectious disease outbreaks revealed a series of important findings for palliative care that may be broadly understood through three themes: limited inclusion of palliative care, a lack of guidance around key activities limits palliative care and COVID-19 pandemic guidelines had limited palliative care. These are discussed in turn.

Limited inclusion of palliative care

This analysis revealed that guidelines had very limited coverage of palliative care. More than half of the articles failed to give any substantial guidance for alleviating pain, reducing suffering and/or enhancing dignity in the face of significant illness or likely or even inevitable death. This finding corroborates the systematic literature review by Nouvet et al.¹² that found guidance documents pertaining to the provision of palliative care in humanitarian crises (including infectious disease outbreaks) were limited. Previous literature suggests that one of the reasons that pallia-

tive care may have been neglected in guidelines, and thus humanitarian crises, is because palliative care tends to challenge the convention of modern medicine where there is a bias of curative medicine over medicine aimed at improving quality of life.^{3,8} This approach is in line with global health metrics that measure success by mortality rates and the number of lives saved rather than number of lives whose suffering was minimised or quality of life improved.³

Furthermore, the ‘false dichotomy’ between palliative and curative approaches creates an imperative to save lives and results in a neglect of all else, including palliative care.^{3,8} This dichotomy is evident in the articles that referenced the American College of Chest Physicians consensus statement.^{27,28} This statement included a triage decision flow diagram showing palliative care only as an endpoint in the triage decision process rather than integrated as an additional support system to be offered alongside life-prolonging treatments or an approach that demanded detailed description.²⁹ Such a representation of palliative care in guidelines contributes to a narrative that curative and palliative treatments are mutually exclusive and runs counter to definitions of palliative care as part of a continuum of care to improve quality

Table 3. The percentage and number of domains covered in the guidelines

Domain ^a	Percentage	Number	References
Information/communication	20	9	23, 31, 40, 44, 45, 47, 48, 53, 62
Advance care planning	20	9	23, 25, 31, 40, 44, 45, 47, 48, 53
End-of-life care	20	9	23, 25, 30, 40, 44, 48, 53, 65, 67
NOS—access	18	8	25, 30, 36, 40, 44, 45, 66, 70
Psychosocial care	18	8	23, 25, 30, 40, 44, 45, 65, 67
NOS—triage	13	6	26, 27, 45, 47, 53, 70
Family support	13	6	23, 25, 40, 44, 53, 65
Spiritual care	11	5	25, 40, 44, 45, 67
Pain and symptom control	11	5	23, 25, 30, 31, 65
Bereavement support	9	4	23, 25, 40, 67
NOS—performance indicator ^b	2	1	23
NOS—palliative care in general	2	1	55

NOS: not otherwise specified.

^aDomains adapted from the National Consensus Project's Clinical Practice Guidelines for Quality and Palliative Care.²³

^bPalliative care listed as a performance indicator for monitoring success of a response to an outbreak.

of life rather than a last resource for when curative options have become futile.²⁹

A lack of guidance around key activities limits palliative care

Where palliative care was included in guidelines, there was a lack of detailed guidance for successful implementation within an infectious disease outbreak setting. Omitting the details and specifics of how to operationalise recommendations and implement services makes it extremely challenging to successfully integrate palliative care within these contexts.

Infectious disease outbreaks create a unique situation wherein minimising disease transmission becomes one of the major goals of a public health approach. Community palliative care services are essential in these contexts, as the care needs of those patients with chronic and life-limiting illness persist or may even increase. Usual systems of care may be disrupted due to restriction of movement, reduced access to support services and caregiver illness or exposure risk. If palliative care needs can be responded to in the community in a way that minimises disease transmission, this cohort of patients will be less likely to require hospital admission, thus preserving the resources of hospitals to respond to the acute needs of the broader community.^{15–17} This creates a great incentive to provide the necessary education and have the systems in place to enable palliative care to be successfully and safely delivered at home;³⁰ however, only two documents provided guidance on palliative care provision in the community in the event of an infectious disease epidemic and both provided only minimal details as to how this can be achieved.^{31,32} Furthermore, guidelines lacked details on what to do to manage the suffering of acutely ill patients triaged as expected to die due to the infectious disease itself. Nouvet et al.¹² also describe this lack of detail, stating ‘a number of guidelines and statements, written for a range of crisis situations, recommend either pallia-

tive care or some form of symptom relief/accompaniment for patients who will not survive, but end there’. The absence of detailed guidance has repercussions not only for the patient and their loved ones who are not receiving optimal care, but also for the healthcare professionals involved, who may experience a lack of agreement within teams, the need to make decisions without clear rationales and moral distress.¹²

COVID-19 pandemic guidelines have limited palliative care

There was a minimal difference in the percentage of articles that mentioned palliative care in the COVID-19-specific guidelines compared with the non-COVID-19-specific articles. Of note, the only COVID-19-specific article that provided detailed guidance on caring for those facing life-limiting or chronic conditions and their families was in its third edition.²⁶ The two previous versions failed to mention palliative care.^{33,34} This suggests that the authors of the other COVID-19-specific papers, which were all published in 2020, are not drawing on the large amount of recent literature that has detailed the importance of palliative care in contexts such as infectious disease outbreaks when there are undoubtedly large numbers of people suffering from severe illness.^{1,9,10,17}

Implications

The absence of palliative care in these guidelines, which are developed to support healthcare systems, services and providers to implement quality healthcare during infectious disease outbreaks, creates a cycle of palliative care exclusion that will likely continue into the future. Over the course of the COVID-19 pandemic, distressing stories have arisen from populations across the world, where patients are dying alone, without their loved ones by their side and often without basic symptom control

measures.^{14,15} The lack of palliative care services in the setting of infectious disease outbreaks currently may in turn reflect the lack of palliative care inclusion in guidelines in the past.¹² In this review, palliative care has, for the majority, been neglected in guidelines responding to infectious disease outbreaks. Without major changes in these documents that are developed to support health systems within these contexts, it is likely this exclusion will continue. This creates an opportunity for change. The suffering of people need not occur if strategies are put in place to ensure palliative care provision, both in guidelines and in policies and practices. The development of policies and guidelines that include clear recommendations for palliative care management and implementation will likely reduce suffering and improve outcomes for particularly vulnerable populations worldwide.

Limitations

Limitations of this study include the fact that peer-reviewed literature and guidelines published by INGOs, national entities and multilateral institutions differ in regards to their production and publication but were treated equally in this review. Because of this, conclusions should be interpreted with caution. In addition, INGOs and multilateral organisations such as the WHO were the focus of the grey literature search, with less representation of national guidelines for high-income settings. These organisations predominantly focus on low-income settings and therefore do not encompass the full scope of the representation of palliative care in guidelines responding to disease outbreaks. Further research could involve analysis of the inclusion of palliative care in pandemic planning and management in high-income settings and comparison with those of low-income settings. Lastly, the search was limited to English-language articles and to 2010 to current. This means some useful guidelines may not have been captured, as they were either published prior to 2010, e.g. those published in response to the systemic inflammatory respiratory syndrome (SIRS) outbreak in 2002–2003, and those that are not in English, e.g. those published in response to the Italian COVID-19 crisis.

Conclusions

Recent literature has described a ‘growing consciousness of need’ for palliative care in humanitarian emergencies, including infectious disease outbreaks, an essential step towards the successful implementation of palliative care within healthcare responses to crises.^{1,3} This review reveals that although there is a growing appreciation for palliative care, there continues to be very limited inclusion of palliative care in guidelines and hence limited implementation in the setting of infectious disease outbreaks. Further development of guidelines and policies that detail the management and implementation of palliative care is crucial to deliver best-practice care to patients in the context of infectious disease outbreaks and to reduce the burden of unnecessary suffering in such times.

Supplementary data

Supplementary data are available at *International Health* online (<http://inthealth.oxfordjournals.org>).

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