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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 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 synthesise evidence for the role and response of palliative care and hospice teams to viral epi/pandemics, to inform the COVID-19 pandemic response. We conducted a rapid systematic review according to PRISMA guidelines in five databases. Of 3094 papers identified, ten were included in this narrative synthesis. Included studies were from West Africa, Taiwan, Hong Kong, Singapore, the United States and Italy. All had an observational design. Findings were synthesised using a previously proposed framework according to 'systems' (policies, training and protocols, communication and coordination, data), 'staff' (deployment, skill mix, resilience), 'space' (community provision, use of technology) and 'stuff' (medicines and equipment, personal protective equipment). We conclude that hospice and palliative services have an essential role in the response to COVID-19 by: 1) responding rapidly and flexibly; 2) ensuring protocols for symptom management are available, and training non-specialists in their use; 3) being involved in triage; 4) considering shifting resources into the community; 5) considering redeploying volunteers to provide psychosocial and bereavement care; 6) facilitating camaraderie among staff and adopt measures to deal with stress; 7) using technology to communicate with patients and carers; 8) adopting standardised data collection systems to inform operational changes and improve care.

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 epi/pandemics, to inform response to COVID-19. 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; standardise data collection.

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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 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 synthesise evidence on the role and response of palliative care and hospice services to viral epi/pandemics.

Methods

Design

Rapid systematic review according to PRISMA guidelines.

Inclusion/exclusion criteria

- Population – Patients, carers, health care professionals, other experts, wards, units, services
- Intervention – palliative care, hospice care, end of life care, supportive care

- Context - Viral epidemics or pandemics characterised by rapid transmission through the population and requiring a rapid response from the health system, including Ebola, SARS, MERS, Avian influenza, and COVID-19. HIV was excluded due to 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 1) terms for palliative care, hospice care and end of life care, and 2) terms for pandemics and epidemics including specific named pandemics. (Appendix A). We identified and screened the reference lists of relevant systematic reviews, government and NGO reports, opinion pieces, and included papers.

Study Selection

One researcher (SNE) completed all searches and removed duplicate records. Papers were screened in EndNote using titles and abstracts by RLC, KES and SNE. Full texts were screened by KES and NL.

Data Extraction

A bespoke data extraction form was created in Excel. Data were extracted by two researchers (KES and NL) and checked by a third (AEB). We did not appraise the quality of included studies.

Analysis

We conducted narrative synthesis, and used the framework proposed by Downar and Seccareccia to group recommendations.² 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 papers from database searches (search date 18th March 2020) and identified six additional papers through screening the reference lists of relevant papers and reports. After removing duplicates 2207 papers remained. 36 papers underwent full text review, and 10 were included in the analysis (Figure 1, Table 1).

The 10 articles were published between 2004 and 2020. Two papers concerned planning for pandemics,^{9,10} seven papers described data collected during epi/pandemics,^{3-8,12} and one paper studied an epidemic retrospectively.¹¹

The settings included West Africa,⁴⁻⁷ Taiwan,¹¹ Hong Kong,⁸ Singapore,¹² the United States,¹⁰ and Italy.³ One paper had no defined setting.⁹ Eight of the papers concerned specific epi/pandemics (including Ebola,⁴⁻⁷ SARS,^{11,12} Influenza,^{8,9} and one on COVID-19³).

We synthesised 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 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 non-specialists 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 United States. This reflects the fact that Europe and the United States 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. While 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, though in two studies a reduction in demand for inpatient care was seen and led to the suggestion to shift resources into the community.^{3,11}

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, though this has not been tested. However, the rapid escalation of breathlessness in patients with COVID-19 who develop acute respiratory distress syndrome (ARDS) may make this challenging.¹⁵ Severe breathlessness and respiratory disease are both known to be associated with increased hospital admissions at the 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.^{3,8} 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 employed 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.⁸ 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.⁹ 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.⁷ 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 1) maintaining the ability to respond rapidly and flexibly; 2) ensuring protocols for symptom management and psychological support are available, and non-specialists are trained in their use; 3) being involved in triage; 4) considering shifting resources from inpatient to community settings; 5) considering redeploying volunteers to

provide psychosocial and bereavement care; 6) facilitating camaraderie among staff and adopting measures to deal with stress; 7) use of technology to communicate with patients and carers; 8) adopting standardised data collection systems to inform operational changes and improve care. Longer term priorities should include ensuring palliative and hospice care are integrated into pandemic plans.

Tables and Figures

Table 1: Description of included studies

Table 2: Synthesis of evidence, and recommendations for the palliative care response to COVID-19

Figure 1: PRISMA flow chart

Contributions

KES conceived the idea for the study and wrote the protocol with input from IJH. SNE planned and carried out the searches. RC, SNE, NL and KES screened articles. KES and NL extracted data. KES wrote the manuscript with significant input from AEB, SNE and IJH. All authors critically reviewed and agreed the final manuscript.

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The authors have no conflicts of interest to declare.

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Table 2: Synthesis of evidence and recommendations for the palliative care response to

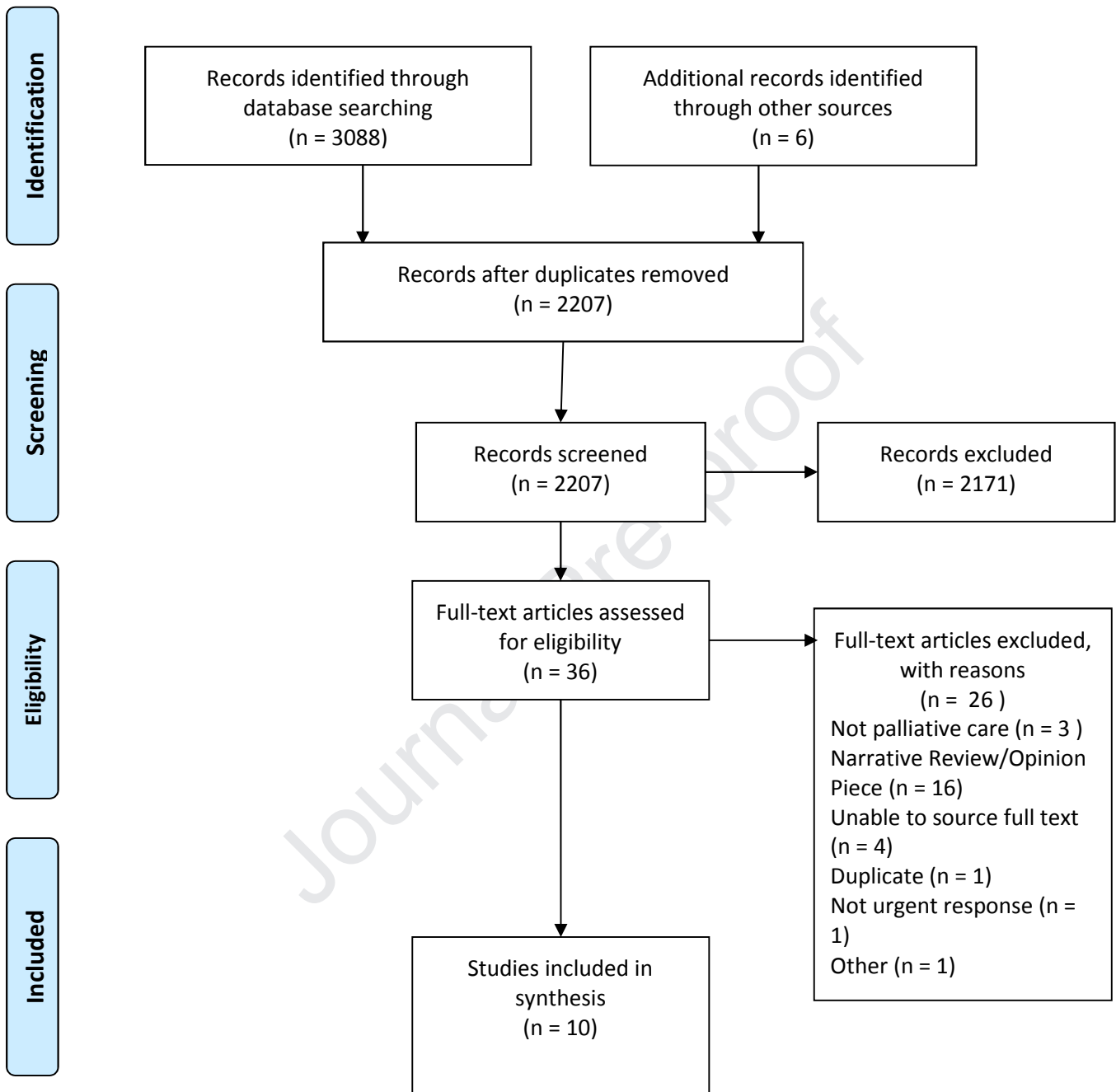
Systems	<p>Policies</p> <ul style="list-style-type: none"> • Require flexibility and rapid changes to systems and policies^{3,8} • Limiting visitor hours/ numbers^{3, 8} • Change in admission criteria³ • Systems of daily telephone support for families³ • Stopping volunteer services⁸ • Palliative care and hospice care should be part of the national and local epi/pandemic planning^{9,10} <p>Training and Protocols</p> <ul style="list-style-type: none"> • Palliative care protocols for non-specialist staff on management of symptoms and psychological support are essential^{4,5,9,10} • Training for site leads in the use of the protocols¹⁰ • Education and training for non-specialist staff in basics of palliative care⁶, including in communication and bereavement counselling¹² • Consider separate guidelines for specific populations such as people in care homes and those with intellectual disabilities⁹ <p>Communication and coordination</p> <ul style="list-style-type: none"> • Sharing of protocols, advice and standards of care within organisations⁴ • Identification of a decision maker to improve communication, particularly where multiple health professionals may be involved outside of their usual practice⁶ • Rapid triage to assess likelihood of response to treatment⁹ and recognition of dying⁶ <p>Data</p> <ul style="list-style-type: none"> • Standardised information collection⁷ • Continuous monitoring and evaluation to inform operational changes or quality of services⁷
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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^{3, 11} • Sufficient staff numbers⁶ • Restricting contact with volunteers for infection control^{3, 8}, while acknowledging volunteers are integral to the interdisciplinary model in palliative care and can make important contributions to psychosocial and bereavement care⁸ <p>Skill mix of staff</p> <ul style="list-style-type: none"> • Involving spiritual care and chaplains in the pandemic response^{9, 10} • Involving psychologists with expertise in palliative care⁹ <p>Ensuring resilience of staff</p> <ul style="list-style-type: none"> • Facilitating camaraderie among staff important to minimise negative psychosocial effects on staff, which include distress about risks of contracting the disease, grieving relatives or friends while working⁴ • Measures to improve connectedness among staff¹² • Training in communication and bereavement counselling¹² • Measures to help healthcare workers deal with stress¹²
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^{3, 11} • Consider the setup of community care centres to expand outside hospital with standardised designs, include monitoring and evaluation instruments, and make use of training and supervision manuals. Community engagement to foster trust is important⁷ <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^{3, 8}
Stuff	<p>Medicines and equipment</p> <ul style="list-style-type: none"> • Relevant symptom medications should be included in formularies¹⁰, in the case of COVID-19 – breathlessness, cough, fever, delirium, anxiety, as well as pain • Basic supplies of medications, intravenous catheters and lines⁴ • Access to diagnostic and monitoring equipment⁵ <p>Personal protective equipment</p>

- Sufficient supplies of PPE that are adaptable to the person^{3,4}

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Figure 1. PRISMA flow chart



Appendix A: Search Strategy

There were no restrictions for language or publication date. Searches were completed 18th March 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))