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## Supporting adults bereaved through COVID-19: a rapid review of the impact of previous pandemics on grief and bereavement

--Manuscript Draft--

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<b>Abstract:</b>	<p>The global COVID-19 pandemic is likely to have a major impact on the experience of death, dying and bereavement. This study aimed to review and synthesise learning from previous literature focused on the impact on grief and bereavement during other infectious disease outbreaks. We conducted a rapid scoping review according to the principles of the Joanna Briggs Institute and analysed qualitative data using thematic synthesis. From the 218 identified papers, 6 were included in the analysis. They were four qualitative studies, one observational study and a systematic review. Studies were conducted in West Africa, Haiti and Singapore. No research studies have focused on outcomes and support for bereaved people during a pandemic. Studies have tended to focus on survivors i.e. those who had the illness and recovered, recognising that some of these individuals will also be bereaved people. Previous pandemics appear to cause multiple losses both directly related to death itself but also in terms of disruption to social norms, rituals and mourning practices. This affects the ability for an individual to connect with the deceased both before and after the death, potentially increasing the risk of complicated grief. In view of the limited research, specific learning from the current COVID-19 crisis and the impact on the bereaved would be pertinent. Current focus should include innovative ways to promote connection and adapt rituals while maintaining respect. Strong leadership and coordination between different bereavement organisations is essential to providing successful post-bereavement support.</p>

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4<sup>th</sup> May 2020

Dear Professor Casarett

**Re: Supporting adults bereaved through COVID-19: a rapid review of the impact of previous pandemics on grief and bereavement**

We wish to submit the above manuscript to be considered as a COVID-19 fast track publication in the 'Journal of Pain and Symptom Management.'

This scoping review synthesises previous literature from other infectious disease outbreaks, which focused on the impact on grief and bereavement, to inform current debate and practice in COVID-19. Our review found that previous pandemics appear to cause multiple losses both directly related to death itself but also in terms of disruption to social norms, rituals and mourning practices.

Potentially, there is an increased risk of complicated grief. It is noteworthy that previous studies have focused on survivors, recognising that some of these individuals will also be bereaved people. Current focus should include innovative ways to promote connection and adapt rituals while maintaining respect. Additionally, strong leadership and coordination between different bereavement organisations is essential to providing a successful post-bereavement support service.

We suggest that our review complements and extends a previous publication within your journal that has provided a focus on grief, namely:

Wallace CL, Wladkowski SP, Gibson A et al. Grief during the COVID-19 Pandemic: Considerations for Palliative Care Providers. Journal of Pain and Symptom Management 2020, doi:

<https://doi.org/10.1016/j.jpainsymman.2020.04.012>

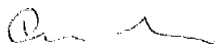
We think, moreover, that our manuscript provides unique learning in terms of relevant knowledge from previous pandemics as well as highlighting the need to innovate practice and plan for a coordinated response for post-bereavement support. Hence, the two manuscripts are complementary in their focus.

Our manuscript is currently slightly over the recommended word count limit. If the editors wish for this to be further reduced, we would be more than willing to do this.

We can confirm this manuscript represents original research, has not been previously published and has not been submitted elsewhere for publication.

Should you require any further information, we would be more than delighted to provide this.

Yours sincerely



Dr Catriona Mayland, (and on behalf of the co-authors, Dr Andrew Harding, Professor Nancy Preston, Professor Sheila Payne)

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**Supporting adults bereaved through COVID-19: a rapid review of the impact of previous  
pandemics on grief and bereavement**

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## **ABSTRACT**

The global COVID-19 pandemic is likely to have a major impact on the experience of death, dying and bereavement. This study aimed to review and synthesise learning from previous literature focused on the impact on grief and bereavement during other infectious disease outbreaks. We conducted a rapid scoping review according to the principles of the Joanna Briggs Institute and analysed qualitative data using thematic synthesis. From the 218 identified papers, 6 were included in the analysis. They were four qualitative studies, one observational study and a systematic review. Studies were conducted in West Africa, Haiti and Singapore. No research studies have focused on outcomes and support for bereaved people during a pandemic. Studies have tended to focus on survivors i.e. those who had the illness and recovered, recognising that some of these individuals will also be bereaved people. Previous pandemics appear to cause multiple losses both directly related to death itself but also in terms of disruption to social norms, rituals and mourning practices. This affects the ability for an individual to connect with the deceased both before and after the death, potentially increasing the risk of complicated grief. In view of the limited research, specific learning from the current COVID-19 crisis and the impact on the bereaved would be pertinent. Current focus should include innovative ways to promote connection and adapt rituals while maintaining respect. Strong leadership and coordination between different bereavement organisations is essential to providing successful post-bereavement support.

## **KEY WORDS**

COVID-19, coronavirus, pandemic, bereavement, grief, mourning, review

## **KEY MESSAGE**

The multiplicity of loss associated with pandemics impacts upon cultural norms, rituals and usual social practices related to death and mourning, potentially increasing the risk of complicated grief. Innovative ways to promote connection with people before and after the death, recognition of the need to adapt rituals and mourning practice to honour the dead and provide comfort to survivors, is recommended.

## INTRODUCTION

The global COVID-19 pandemic is likely to have a major impact on the individual and societal experience of death, dying and bereavement. Due to social isolating measures and lack of usual support structures, this also is likely to influence experiences of grief and mourning. How palliative care and hospice teams respond to these challenges has been recognised.<sup>1</sup>

Many factors can influence bereavement including the nature of the death, existing family and social support networks and cultural context. 'Complicated grief' is characterised by intense grief, which can last longer than socially expected or cause impairment in daily functioning.<sup>2</sup> Risk factors that can contribute to 'complicated grief', include, but are not exclusive, to the following:

- Nature of death e.g. sudden, traumatic or violent resulting in a lack of preparedness or limiting the opportunity to 'say goodbye'<sup>2</sup>
- Nature of the environment e.g. limited end-of-life care discussions, 'aggressive' medical care, concurrent caring demands or other stressors such as financial costs<sup>3,4</sup>
- Pre-existing factors in the bereaved person e.g. low levels of social support, mental health concerns.<sup>2</sup>

Traditionally, a 'blanket' approach to bereavement support is offered by palliative care - but this means the same level of support is offered to everyone, regardless of need and without identification of those at most risk of complicated grief.<sup>5</sup>

Specific factors associated with COVID-19 related deaths could potentially increase the risk of an adverse outcome in bereavement, such as a more intense or prolonged grief reaction.

These factors include the rapidity or unexpected nature of the death. Additionally, the isolation and the physical barriers may prevent sensitive and timely communication and



limit opportunities to 'say goodbye'. Learning from recent infectious disease outbreaks and the subsequent impact on grief and bereavement may guide current care to support families before the death, as well as inform service developments for the provision of ongoing post-bereavement support following deaths from COVID-19.

## **RESEARCH QUESTIONS**

- What can we learn from previous pandemics / infectious disease outbreaks about the subsequent impact these types of death had on bereavement?
- Which factors may hinder or enhance experiences?

## **METHODS**

A rapid scoping review of the literature, in keeping with the principles of the Joanna Briggs Institute, was undertaken.<sup>6</sup> Analysis of qualitative data was conducted using thematic synthesis.<sup>7</sup>

Using specified inclusion and exclusion criteria (Textbox 1), we searched five databases (MEDLINE (1966-2020), CINAHL (1982-2020), EMBASE (1974-2020), Psycinfo (1806-2020), and TRIP (2000-2020)). The search strategy (Textbox 2) comprised of key terms for:

- Bereavement, grief and mourning
- Pandemics and epidemics including specific named pandemics.

Additionally, we searched and screened the reference lists for any included papers. Three researchers (CRM, AH, MC) completed all the searches. Papers were screened initially by title and abstract (CRM, AH) and full texts were independently screened (CRM, AH).

Data was extracted using a specially designed proforma on the aim, setting, country, participants' characteristics, study design and findings. Verbatim findings from the qualitative studies were extracted with a specific focus on data relevant to bereavement, grief or mourning. Two researchers (CM, AH) independently coded text line-by-line, including relevant participant quotes, according to its meaning and content. The two reviewers then discussed similarities and differences between the codes to start grouping them into descriptive themes.<sup>7</sup> Our research questions, additional synthesis, reflection and discussion (CM, AH, SP, NP) generated analytical themes from the studies' data.

## **RESULTS**

We identified 218 papers from searches conducted on 7<sup>th</sup> April 2020. An additional two papers were identified from reference lists. After removal of duplicates (n=14), 195 were excluded following review of title and abstract. From the remaining 11 papers, five were excluded after full text review and six were included in the analysis (Figure 1).

There were four qualitative studies,<sup>8-11</sup> one observational study<sup>12</sup> and one systematic review.<sup>13</sup> Within the qualitative studies, one study focused on palliative healthcare professionals (HCP) involved in the Severe Acute Respiratory Syndrome (SARS) epidemic in Singapore,<sup>8</sup> two studies focused on West African Ebola 'survivors',<sup>10, 11</sup> and one study focused on Haitian community members during the cholera outbreak.<sup>9</sup> The observational study was based on patients attending mental health support services in Sierra Leone after the Ebola outbreak<sup>12</sup> and the systematic review was focused on Ebola survivors.<sup>13</sup>

There was no study which specifically focused on bereaved people and the impact that a death linked to a pandemic had on their subsequent grief. Studies tended to focus on ‘survivors’ of the illness i.e. those who had had the illness and recovered and their subsequent psychological well-being. It was recognised, however, that these survivors could also be bereaved people and indeed some of them may have experienced multiple bereavements.<sup>13</sup> For example, one study reported 13/143 (9%) of people attending a nurse-led mental health out-patient clinic were relatives of the deceased or survivors.<sup>12</sup> The paper described that both groups presented with normal grief or mild depressive or anxiety symptoms. They also reported on the stigma and discrimination these individuals had faced within their communities.<sup>12</sup>

## **Themes**

The overarching theme was the ‘multiplicity of loss’ with three identified subthemes, namely ‘uncertainty’, ‘disruption of connectiveness and autonomy’, and ‘factors to enhance experiences’. Themes are discussed with supporting quotations in Table 1.

## **Multiplicity of loss**

The overarching theme referred to the experience of loss at many different levels. This included the death of family members and witnessing other individuals dying, but also represented the symbolic loss of an individuals’ way of life, culture and usual social practices. The mode of transmission of these types of illnesses challenged cultural norms e.g. desire to provide compassionate care for their family and showing respect and reverence for the deceased.<sup>9, 11</sup>

### ***Uncertainty***

Uncertainty surrounded two main areas – the prognosis of the disease, and beliefs and perceptions about the illness. In the context of SARs, uncertainty reported about the nature of the illness could affect whether or not families prepared for death and had the opportunity to ‘say goodbye’.<sup>8</sup> Additionally, uncertainty surrounded perceptions and beliefs about the illness, including information provided by relevant authorities e.g. governments, charitable organisations.<sup>9</sup> Areas of uncertainty could lead to fear, among patients, family carers and HCP,<sup>8</sup> which occurred on both an ‘individual and collective’ level.<sup>9</sup> Unaddressed fear could manifest as insecurity, psychological distress, drive stigmatisation, and sometimes violent reactions towards individuals and institutions.<sup>8,9</sup>

### ***Disruption of connectiveness and autonomy***

Multifaceted disruptions affected the ability to connect, between patients, family carers and HCPs, as well as restricting choice. Physical barriers and isolation were created by the need for HCP and family to wear Personal Protective Equipment (PPE), and the limitation in visiting and physical contact.<sup>8,11</sup> Usual social support mechanisms were lost because of the inability of family members to visit the patient.<sup>10</sup> Additionally, family members were unable to directly support each other through their grief.<sup>8</sup>

Due to choices being limited e.g. decisions about preferred place of death, autonomy could be compromised.<sup>8</sup> Additionally, interruption to the usual rituals and practices observed after death were described.<sup>9,10</sup> These disruptions could impact on the subsequent bereavement due to the absence of a memorial or tangible place to subsequently visit.<sup>13</sup>

### ***Factors to enhance experiences***

There was recognised uncertainty about the long-term impact of these experiences on the bereaved.<sup>9</sup> The identified studies reported on a number of factors which could potentially have a positive impact on the subsequent grief, including:

- Opportunities to promote social connections and facilitate communication with family members e.g. designated meeting rooms with transparent dividers.<sup>10</sup>
- Wherever possible, respecting rituals in keeping with faith or culture e.g. allowing support from a religious leader.<sup>9</sup> In the Haiti cholera outbreak, a mourning tent was placed outside the treatment centre to allow family to say a final goodbye.<sup>10</sup>
- Psychosocial support interventions provided both via formal mental health services<sup>12</sup> as well as community initiatives.<sup>9, 10</sup>

## **DISCUSSION**

### **Main findings**

Although no previous study has focused solely on bereaved people, previous pandemics appear to cause multiple losses both directly related to death itself but also in terms of disruption to social norms, rituals and mourning practices. The disruption affecting an individuals' ability to connect with the deceased both before and after the death may potentially impact on grief. In particular, the usual societal and cultural rituals can seem rushed, altered or absent.

In view of the limited research in this area, specific learning from the current COVID-19 crisis and the impact on the bereaved would be pertinent.

## **What this study adds**

The multiplicity of loss compounds what is already a challenging situation and links with bereavement theories regarding the impact of previous multiple losses.<sup>2</sup> In the context of the COVID-19 pandemic, the uncertainty surrounding the illness and the loss of the usual rituals could lead to distress from unanswered questions or a struggle to accept the death.

Our review confirms the increased prevalence of risk factors associated with complicated grief e.g. sudden/unexpected death, low social support.<sup>2</sup> Responses to loss can vary – important influences include the ability to find meaning and make sense of the loss within an individuals' existing worldview.<sup>14</sup> Other humanitarian emergencies relating to war and atrocity also show variable psychological responses influenced by the personal, subjective meaning of events.<sup>15</sup>

Potential ways to guide current care, promoting 'connectiveness' and encouraging reverence and dignity, even in challenging circumstances, seem key. Novel ways of using technology to aid communication and bonds has been advised.<sup>1</sup> The principles of individualised care remain crucial and exploring innovative ways to support beliefs and rituals are needed.

Although we can't be certain of the subsequent impact on bereavement, preparation is needed to help develop and provide the most appropriate form of post-bereavement support. In the UK organ retention crisis, access to timely and instructive information in the post-bereavement period was key – staff, however, were not always trained and prepared for this.<sup>16</sup> Strong leadership and partnerships between different organisations are essential to establishing successful post-bereavement support.<sup>12</sup>

## **Limitations**

As well as there being few studies, most came from countries with strong cultural and spiritual belief systems that may differ from Western societies. The impact of misperceptions, however, and the doubts about the authenticity of information from relevant authorities have widespread application and are relevant for our current crisis.

A formal quality appraisal of the studies was not conducted, although this is not necessarily needed for scoping reviews.<sup>6</sup> It is important to highlight, however, that two of the studies weren't specifically designed as research projects.

## **Conclusion**

The multiplicity of loss associated with pandemics impact upon cultural norms, rituals and usual social practices related to death and mourning, potentially increases the risk of complicated grief. A focus on promoting connection with people before and after the death, adapting rituals and mourning practice in a respectful manner, and planning for a coordinated response to post-bereavement support is recommended.

### **Text box 1. Inclusion and exclusion criteria**

#### **Inclusion criteria**

- Journal article (including case reports, case series or field reports)
- Studies of bereaved people ( $\geq 18$  years old) OR issues relating to anticipatory grief or bereavement
- Focused within the context of previous pandemics / infectious disease outbreaks

#### **Exclusion criteria**

- Any deaths relating to HIV or other non-infectious disease outbreaks e.g. suicide, mass tragedies such as natural disasters or war
- In language other than English
- Letters, book chapters, conference abstracts, opinion pieces or commentaries
- Focus on children ( $< 18$  years old) (either as the deceased or the bereaved)



## Textbox 2: Search terms used for rapid scoping review in Medline

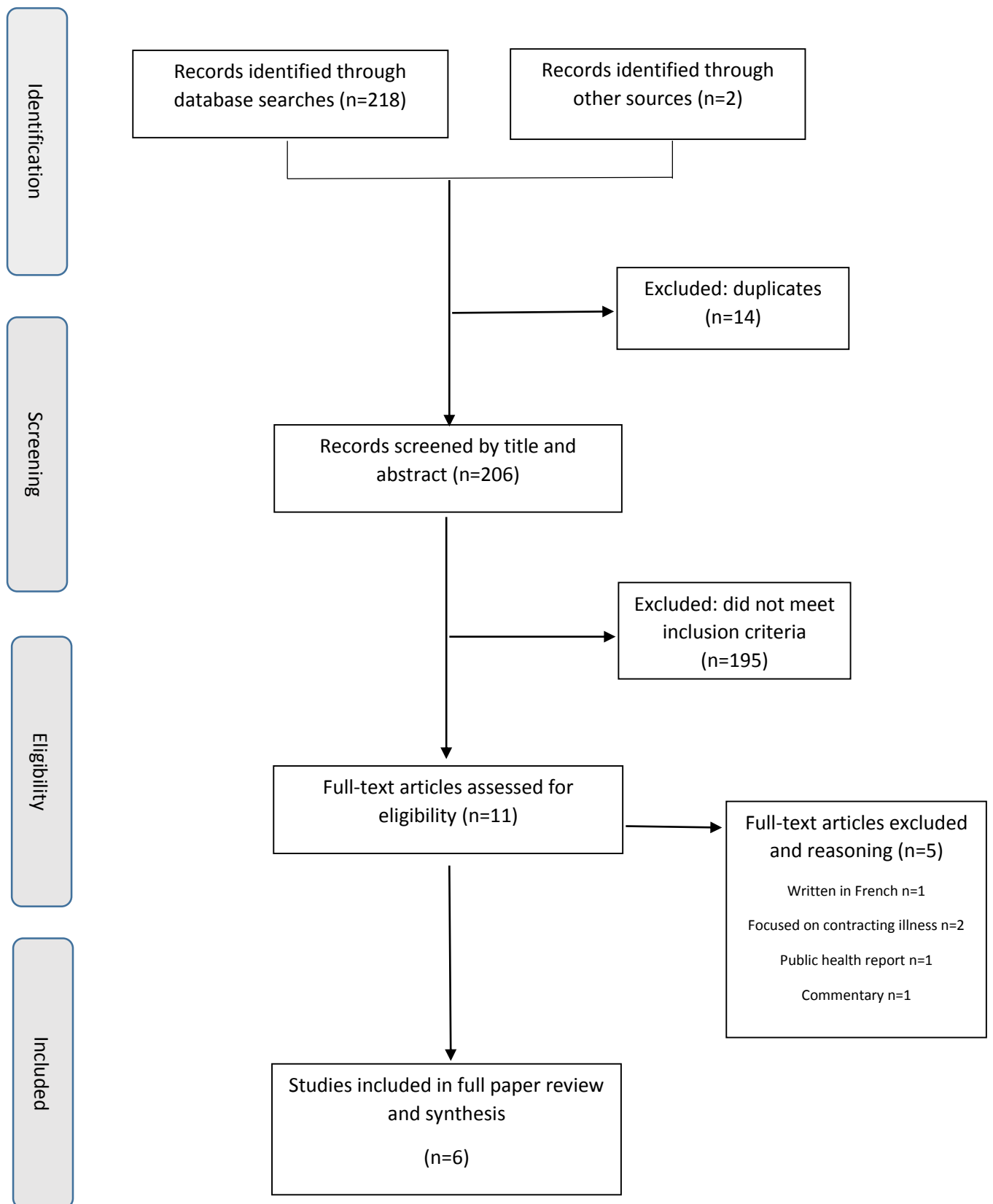
### Bereavement

1. Bereavement/ or bereave\*.mp.
2. Grief/ or grief.mp.
3. grieving.mp.
4. mourn\*.mp.

### Pandemics and epidemics

5. Hemorrhagic Fever, Ebola/ or Ebola.mp.
6. Ebolavirus.mp. or Ebolavirus/
7. SARS virus.mp. or SARS Virus/
8. MERS.mp. or Middle East Respiratory Syndrome Coronavirus/
9. human influenza.mp. or Influenza, Human/
10. pandemics.mp. or Pandemics/
11. pandemic\$.mp.
12. epidemics.mp. or Epidemics/
13. epidemic\$.mp.
14. outbreaks.mp. or Disease Outbreaks/
15. Severe Acute Respiratory Syndrome/
16. Coronavirus/ or coronavirus.mp.
17. 1 or 2 or 3 or 4
18. 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
19. 17 and 18

Figure 1. Results of rapid literature review



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## **DECLARATIONS**

### **Authorship**

CRM, NP and SP conceived and designed the study. CRM and AH completed all the searches, conducted the screening, extracted data and conducted the initial analysis. All authors contributed to the analysis and interpretation of the data. CRM drafted the manuscript. All authors provided input into the manuscript and approved the submitted version.

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### **Conflicts of interest**

The authors declare that there is no conflict of interest.

### **Acknowledgements**

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Table 1. Multiplicity of loss, subthemes and exemplar excerpts from selected papers

Subtheme	Description	Exemplar excerpts from selected papers
<b>Uncertainty</b>	Prognosis: not knowing whether individuals and families needed to prepare for death	<i>'For SARS, death can hit suddenly. Families usually do not have the chance to hear the last words of patients or say their last words to patients.'</i> <sup>8</sup>
	Information: uncertainty surrounding beliefs about the illness, including information provided by relevant authorities	<i>'It is a poison brought by foreigners to divide us'</i> <sup>9</sup> <i>'It is a disease brought by nongovernmental organisations (NGOs) in order to get more money'</i> <sup>9</sup>
<b>Disruption of connectiveness and autonomy</b>	Multiple disruptions having an impact on the ability to 'connect' and limiting choices	<b>Physical barriers</b> <i>'...because you just see people, through this mesh, or they have some kind of eye glass on their face, you only see a small part of a body'</i> <sup>11</sup>  <i>'They could not be near their loved ones, (or) touch them, (or) whisper to them. Everything had to be done through the cold glass panel.'</i> <sup>8</sup>
		<b>Psychosocial barriers</b> <i>'Family members....had to take care of children or elderly in their homes, or they were too afraid to come into the ETU,* or they did not have money for transportation.'</i> <sup>10</sup> * EYU=Ebola Treatment Unit  <i>'I saw him walk out and sit in the common area and cry quietly to himself. Nobody was there to be with him.'</i> <sup>8</sup>  <i>'The subsequent isolation undermined their healing process and affected their ability to cope, as they received little support during their mourning and could not share their traumatic experiences.'</i> <sup>10</sup>
		<b>Loss of autonomy</b> <i>'The patient has no choice over where he dies or over who will be present when he dies.'</i> <sup>8</sup>  <i>'Going home to die was not possible for the majority of patients due to the difficulties in the discharge process.'</i> <sup>8</sup>

		<p><b>Interruption to usual rituals and practices</b>  <i>'...the rituals and funerals are either absent or shortened (when the body is abandoned or taken away rapidly to be buried in mass graves).'</i><sup>9</sup></p> <p><i>'In the Haitian culture and belief system, respect for the dead and ancestors are of tremendous importance, with consequences to individual and collective wellbeing.'</i><sup>9</sup></p> <p><b>Loss of memorialisation</b>  <i>'When corpses were cremated, without funerals or formal burial, they did not even have a grave to visit.'</i><sup>10</sup></p> <p><i>'the usual processes for grieving become difficult...as there were no graves to visit or corpses were buried in unmarked graves or cremated without formal burial ceremony.'</i><sup>13</sup></p>
<b>Factors to enhance experiences</b>	Opportunities to promote social connections	<i>'Designated meeting rooms with transparent dividers may allow visits of relatives inside the ETU.'</i> <sup>10</sup> (ETU = Ebola Treatment Unit)
	Respect for rituals in keeping with faith or culture	<i>'The mourning tent placed inside the CTC allows family members to gather and say a last goodbye to their beloved ones.'</i> <sup>9</sup> (CTC = Cholera Treatment Centre)
	Psychosocial support interventions	<i>'..psychosocial support interventions can play an important role in the response to such an epidemic.'</i> <sup>9</sup>
		<i>'Support of family, friends, faith, and participation in a survivor's association were frequently mentioned coping strategies..'</i> <sup>10</sup>



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**ICMJE Author Disclosure Form**

**coi\_disclosure CM completed 4.5.2020.pdf**

