

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository: <https://orca.cardiff.ac.uk/id/eprint/148470/>

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Torrens-Burton, Anna , Goss, Silvia, Sutton, Eileen, Barawi, Kali, Longo, Mirella , Seddon, Kathy, Carduff, Emma, Farnell, Damian JJ , Nelson, Annmarie , Byrne, Anthony, Phillips, Rhiannon, Selman, Lucy E and Harrop, Emily 2022. "It was brutal. It still is": A qualitative analysis of the challenges of bereavement during the COVID-19 pandemic reported in two national surveys. *Palliative Care and Social Practice* 16 , pp. 1-17. 10.1177/26323524221092456

Publishers page: <https://doi.org/10.1177/26323524221092456>

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See <http://orca.cf.ac.uk/policies.html> for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



Figure 1: Main themes and sub-themes

1. Troubled deaths: guilt, anger and unanswered questions

- Difficulties getting through to staff or talking directly to patient
- Difficulty getting answers or information about the patient
- Misinformation/conflicting information given about patient and policies
- Unhelpful or insensitive attitudes of staff
- Lack of involvement in care decisions
- Perceived poor patient care and suffering
- Limited visits/time with loved one, including PPE concerns or frustrations
- Myself or other family unable to visit/say goodbye
- Difficulty processing/accepting death
- Feelings of guilt, emptiness, anger relating to death
- Mental health problems and trauma

2. Mourning, memorialisation and death administration

- Unable to prepare the body and say final goodbye
- Restricted funeral size
- Unable to attend the funeral
- Absent or constrained service features (e.g. singing, flowers, locked cemetery)
- No wake or collective celebration of life
- Being physically alone before, during and after funerals
- Restrictions on visiting cemetery/spreading ashes/other memorialisation activities
- Feelings of sadness, regret and guilt relating to restrictions/unable to give the send-off deserved
- Restricted practices making it hard to find closure and begin to grieve
- Role of funeral homes and directors
- Experiences of online and recorded services
- Positive funeral experience (e.g. intimate, less pressure)
- Difficulties, stress and distress sorting out practical affairs

3. Mass bereavement, the media and the ongoing threat of the pandemic

- Contending with multiple recent bereavements
- Anger and upset caused by public attitudes, behaviour, conspiracy theories and second wave
- Anger, frustration and blame relating to management & wider consequences of pandemic
- Media reports-dehumanisation and constant reminders of the death
- Fear for myself and others catching or dying of covid

4. Grieving and coping (alone and with others)

- Isolated from support networks at end of life and during early bereavement
- Unable to support others grieving
- Missing physical contact and comfort from close others-difficulties communicating and expressing feelings
- Feelings of loneliness and isolation, inc. lack of empathy and understanding relating to pandemic context
- Lack of social contact/opportunities for collective grieving making it harder to come to terms with loss
- Restrictions making it hard to cope and find new meaning and purpose
- Lack of time and space to grieve
- Benefits to grieving in isolation and reduced contact

5. Work and employment

- Insensitivity and lack of compassion
- Insufficient bereavement leave and pressure to return to work
- Anxieties over job/livelihood loss
- Workload pressures, esp. frontline staff
- Isolation due to homeworking and furlough

6. Support from the health and social care system

- Bereavement service support (reported elsewhere for BeCovid)
- No or unsatisfactory follow up contact after the death
- Support following pregnancy loss
- Difficulties accessing help for other health conditions

Table 3 Comparison of stressors in this analysis with the DPM Pandemic Framework (Stroebe and Schut 2021)

LO Stressors from Strobe & Shut framework	Related LO Stressors from BeCovid & COPE data	RO Stressors from Strobe & Shut framework	Related RO Stressors from BeCovid & COPE data
Lack of emotional & practical preparation time	Sudden and unexpected nature of Covid-19 deaths	– Loss of work, unemployment, livelihood/financial insecurity, furloughs, salary reductions, homelessness	Job loss/ financial worries
Circumstances of terminal illness, dying process (e.g., isolation, desolate dying situation; patient's physical discomfort, difficulty breathing; illness-related uncertainty)	Perceived patient suffering	Lockdown-related difficulties with one's work, harder to get new employment if needed post-loss	<ul style="list-style-type: none"> Isolation caused by working from home, enforced absence/separation from colleagues due to furlough. Pressure to return before ready, exacerbated by fear of job loss or acute workloads of frontline staff*
The traumatic burden for (bereaved) relatives of treatment of their dying relative in isolated ICU conditions	Died alone Perceived lack of dignity	Medical support concerns (e.g., lack of insurance; health care access; failed medical intervention due to lack of resources, facilities, means to pay)	Limited availability of/access to bereavement services
Difficulty/impossibility to say goodbye due to enforced isolation; realization of death more difficult without viewing the body or saying goodbye, associated with denial and avoidance of the loss)	-Myself or other family unable to visit/say goodbye - No change of clothes/preparing the body/seeing body - Difficulty processing/accepting death	Care, management and treatment for existing mental and physical illnesses (associated with accentuation of health care disparities)	Difficulties managing other health conditions/accessing services
Morally distressing circumstances: perceptions of violation to one's own moral or ethical code (relating to suboptimal care of the dying person, due to resource scarcity (including difficulties relating to ethical decisions in limited resources)	Perceived poor treatment/care decisions at End of Life	High-risk frontline, repeated exposure stress; own COVID-19 illness, intensive care admission	Pressures on frontline staff- feeling that can't take time off, constant reminders of own trauma (clinical staff)
Circumstances of death unexpected and/or traumatic (associated with continued confrontation, rumination and complicated grieving, but note avoidance too).	-Sudden/unexpected deaths -Unable to say goodbye or visit	Quarantine/confinement/social isolation (restrictions in social, recreational, and occupational activities, including travel e.g., for attending memorial ceremonies	Forced isolation (covid) Unable to attend memorial ceremonies (myself or close family)

Experience of “staggering”, multiple losses/deaths of close persons and their ongoing nature; threat to oneself (particularly. among vulnerable older, sick)	-Other recent/multiple bereavements	Family (particularly children) and community level difficulties/disruptions in living arrangements (e.g., schooling irregularities: home schooling; access to shops)	<ul style="list-style-type: none"> Family responsibilities and pressures during lockdown e.g. home-schooling Lack of time and space to take a break and find respite from grief*
Frequent reminders of death (rates), media coverage, exposure to distressing images; hearsay, potentially impacting negatively on adaptation	Constant reminders in media coverage	Painful physical separation from family and close friend	Grieving difficult without physical contact and comfort
Pandemic circumstances may be dealt with by suppression of emotions (in certain cultures particularly), linked to avoidance and denial rather than confrontation		Family tensions and quarrels (violence) associated with staying at home, no family/friends visits	Strained relationships
Profound changes in funeral practices, severe restrictions (inc. social & relational ones): enforced direct cremations; banned ceremonial attendances	Restriction to numbers Service features (singing, flower, no service, locked cemetery)	Disruption of connectedness, autonomy and freedom through suspension of gatherings, travel, closing of religious centres, lockdowns, social distancing	Feelings of loneliness and isolation
Lack of opportunity for physically given/received support	Grieving in isolation	Erosion of coping resources (social support), relating to social isolation, (lack of positive appraisal: sense of community, uplift).	<ul style="list-style-type: none"> Lack of social support, due to distancing and perceived lack of empathy or understanding relating to exceptional nature of pandemic bereavement and widespread societal burden* Disrupted coping mechanisms- opportunities for respite and distraction
Lack of social/cultural recognition of the loss, related to impaired support resources; absence of the soothing rituals with opportunity to express grief/comfort	Isolated from support networks at end of life, death and soon after Disrupted mourning practices	Needed support for vulnerable bereaved people may be lacking due to distancing and withdrawal	<ul style="list-style-type: none"> Grieving and coping difficult without physical contact and comfort from close others Feelings of loneliness and isolation
	Lack of time and space to grieve (e.g due to homeschooling) *	(Perceived) rejection (e.g., stigmatization from others due having a COVID-19 death in the family)	
		Impact of negative campaigns, victimization, rise in racism	<ul style="list-style-type: none"> Conspiracy theories Concern over disproportionate impact on BAME communities/health inequalities

		Disruptions to social norms, face-to-face rituals, mourning practices impacting on ongoing life beyond grief, grieving	<ul style="list-style-type: none"> Isolated from support networks at end of life and early bereavement Grieving difficult without physical contact and comfort
		Worries, fears about getting the viral infection, fear of contamination/contaminating others	Fear for myself and others catching or dying of covid
		Difficulties dealing with new technology needed due to distancing (online medical forms, phone appointments, etc.)	Difficulties with death related administration during lockdown
		Uncertainty about the future (under pandemic circumstances)	
		Lack of/disruption of routines, dislocation, loss of pre-crisis ways of life, threatened loss of hopes and dreams for the future, shattered assumptions about normal life and connections with the world	Disrupted coping mechanisms e.g difficulty engaging in previous or new activities, getting out the house

***new additions to the DPM pandemic framework identified from BeCovid and COPE data analysis**

Table 4 Comparison of reactions in this analysis with the DPM Pandemic Framework (Stroebe and Schut 2021)

LO Reactions from Strobe & Shut framework	Related LO Reactions from BeCovid & COPE data	RO Reactions from Strobe & Shut framework	Related RO reactions from BeCovid & COPE data
	Feelings of guilt/that let loved one down	A rise in level of general anxiety, worries	<ul style="list-style-type: none"> • Societal strains of pandemic; e.g. Not wanting to burden others at time of universal suffering, perceived lack of empathy* • Feeling generally overwhelmed
Anger toward system/officials about the death: “undignified” body disposal; regarding the patient’s own mistakes;	Anger at government handling of pandemic Anger relating to hospital policies and practices at EoL (e.g. patient care, family visiting)	Feelings of lack of safety, insecurity	<ul style="list-style-type: none"> • Fear for myself and others catching or dying of Covid.
Moral responsibility: guilt, anger, anguish, distress exacerbated by feelings of moral responsibility	Feelings of guilt/ that let loved one down	Experiencing prejudice against oneself	
Loneliness; excessive bitterness and a sense of perceived purposelessness in life.	Feelings of loneliness and isolation/ diminished meaning and purpose relating to loss of relationship with deceased	Feeling upset related to an intolerance of uncertainty	
Anticipatory grief phenomena, which are also threatening, given uncertainty of illness outcome		Loss of feelings of control or purpose	Diminished meaning and sense of purpose related to lack of social/recreational etc activities to occupy oneself with Disrupted coping mechanisms Finding it hard to make decisions
– Disenfranchised grief: 1. Too many COVID-19 deaths for individual recognition, the deceased considered a statistic, causing complications in grieving 2. Linked to failure by deceased to follow mandated rules, impacting on social interactions in bereavement	Dehumanising effect of mass bereavement death as a statistic	Feeling trapped through isolation	Feelings of loneliness and isolation/unable to move forwards
		Feeling vulnerability to the spread of rumours, misinformation	Alienation and distress related to social discord/conspiracy theories/ others disregard of Covid regulations*
		Fears for one’s own mortality	Fear for myself and others catching or dying of covid

		Experiencing the allocation of blame toward oneself, a victim of discrimination or of hate crimes	
			Acute stress/distress experienced relating to difficulties dealing with death administration*

***new additions to the DPM pandemic framework identified from BeCovid and COPE data analysis**