


PERSONAL VIEWPOINT

Silent suffering of the dying and their families: impact of COVID-19

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Abstract

Death, grief and bereavement all look different in the current COVID-19 pandemic. Patients and families are suffering as a result of COVID-19 itself, and the measures required to contain it. As a result, health professionals need to be aware of potential for additional psychological distress, as well as the risk of prolonged grief disorder.

‘This is a bad time to die’: spoken by the son of a dying man to a palliative care doctor during the COVID-19 pandemic.¹

Death and bereavement are a natural part of life, but for most of our generation, global pandemics are not. The world as we know it and medicine as we practise it are changing constantly as a result of COVID-19. There has been, and continues to be, rapid growth in scientific knowledge about COVID-19 and its effects on human physiology. However, there is also pain and suffering that cannot be ignored. Although healthcare providers and policy makers are under significant stress, patients and families facing serious illness or death are experiencing unimaginable distress and fear.

Bereavement is a natural part of life, but it can negatively impact physical and psychological health.² Prolonged grief disorder (PGD), experienced by approximately 10% of bereaved adults, may include symptoms such as intrusive thoughts, separation distress and feelings of emptiness beyond 6 months after a death.³ Wallace *et al.* described how COVID-19 itself, along with policies and practices to restrict its spread, can impact anticipatory, disenfranchised and complicated grief for patients, families and healthcare providers.⁴ We

cannot underestimate the power of sitting alongside a loved one as they die, having a shared space to reflect on a life and a relationship, and a real chance to ‘say goodbye’. Predictors of PGD such as perceived lack of social support, lack of preparation for the death, diminished quality of the caregiving or dying experience and high distress at the time of death⁵ are all being seen at higher frequency as a result of the COVID-19 pandemic.

Psychological suffering and COVID-19: how are families affected?

Family-centred care promotes presence by the bedside, regular communication with families and multi-disciplinary collaboration in order to support decision-making and caregiving, and reduce stress and anxiety.⁶ Unfortunately, many of these approaches are profoundly limited during the COVID-19 pandemic as clinicians and policy makers face the impossible task of balancing individual and societal needs.

Our experience supports emerging literature about the psychological effects of COVID-19 on death, dying, grief and bereavement. Importantly, we are seeing heightened emotions regardless of whether the cause of deterioration and death is COVID-19 infection. While the vast majority of patients we are caring for do not have COVID-19, COVID-19 factors are significantly

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contributing to distress for our patients and families. This makes sense, given that restrictions to family-centred care do not just affect those diagnosed with COVID-19. Likewise, the impacts of visitor and travel restrictions, social isolation, burial and funeral restrictions, fear of virus transmission and ever-evolving policies are universal. In other words, we are seeing how the very restrictions designed to protect against COVID-19 are contributing to distress and suffering.

The distress of knowing one's loved one is dying alone, the anguish of being unable to say a proper goodbye and the guilt of not providing adequate care are all described in the literature.⁷ We are seeing all of this first-hand.

We are also seeing the pandemic affects decisions about the location of end-of-life care, with families feeling that they have no choice but to be at home as the alternative of restricted visitor access in hospital is intolerable. End-of-life care at home is a significant enough task in itself, let alone when complicated by difficult emotions and decisions, and worse still, ambivalence. Unfortunately, just like hospital, community and home-based care looks different in a pandemic. Community services are facing their own difficult decisions about service provision. While community palliative care services are doing their utmost to prioritise and support end-of-life care with face-to-face visits at home, the COVID-19 pandemic is challenging this, and phone and telehealth is being used where possible.⁸

We have seen family concern about the adequacy of their loved one's symptom assessment and management at end of life, potentially related to infection control measures such as personal protective equipment and reduced frequency of reviews in order to minimise exposure risk. Although these concerns may or may not be valid, we must acknowledge that they are real concerns for families. Furthermore, these concerns are at the very heart of some of the questions we have asked ourselves as palliative care clinicians over the course of the pandemic. For example, what is preferable, a continuous subcutaneous infusion as it ensures delivery of medications regardless of frequency of assessment or intermittent dosing as it relies on regular assessment?

Self-blame is a powerful predictor of grief-related difficulties.⁹ We wonder if this is particularly relevant for families of patients who are less able to express their own needs, for example, individuals with severe dementia. It is difficult to comprehend the added burden for carers who would be by the bedside if not for the pandemic, present to provide familiarity and care, and interpret their loved one's needs and expressions. Although it

is COVID-19 that is to blame for their inability to be present, family and carers may need help to acknowledge this and not blame themselves.

Each family has a unique experience that must be honoured. We bear witness to families experiencing the 'cruelty' of their loved one dying alone in hospital, the 'trauma' of feeling alone and unprepared for their loved one to die at home, and the 'helplessness' of communicating and advocating through a screen. And then there is the 'what next', the grieving alone and the postponement of life celebrations. And all of this is in the context of increased mental health difficulties such as depressive and generalised anxiety symptoms, compared with the pre-pandemic era.¹⁰

What we are hearing from families is not all doom and gloom. We have been struck by families going out of their way to provide feedback and express gratitude for the compassionate care and communication that they have received. Perhaps one of the only certainties at present is uncertainty. In time, the impact of the pandemic on grief and bereavement will become clearer. Equally, in time, we will ideally better understand what we as health professionals can do to mitigate distress, and promote resilience, for patients and families where so much in this pandemic is out of their control.

Conclusion

Unfortunately, the very factors implemented to protect from COVID-19 are likely to contribute to patient and family distress. We must take notice of early anecdotal experience and emerging literature about the likely impact of the COVID-19 pandemic on death, dying, grief and bereavement,^{2,4} including a suggestion to prepare for a 'steep rise in traumatic, disenfranchised, and chronic griefs in the aftermath of the epidemic outbreak'.⁷ And we must look beyond COVID-19 deaths when considering those at risk for PGD; the suffering for families is universal and not solely restricted to those dying from COVID-19. The toll is yet to be appreciated. But perhaps it is the passage of time that will help us know how best to mitigate distress and PGD in the face of the COVID-19 pandemic.

Niebuhr's Serenity Prayer seems relevant:

"God, grant me the serenity to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference".¹¹

Although there is much about the COVID-19 pandemic that we cannot control, as clinicians we have a responsibility to arm ourselves with knowledge and courage to focus on the things we can. We can seek to understand the sources of distress for patients and

families. We can seek to be creative in how we deliver family-centred care during a pandemic. We can learn from colleagues, local and international. It is no easy feat to balance individual and societal needs. But we must not lose sight of the individual.

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