

Dying in the Face of the COVID-19 Pandemic:

Contextual Considerations and Clinical Recommendations

COVID-19 related mortality in the U.S.

Projection models forecasting the progression of coronavirus disease 2019 (COVID-19) have become a part of our daily lives since the novel virus began spreading in the United States (U.S.). The U.S. has the highest number of infected people and COVID-19 related deaths compared to any other country. Since early Spring 2020, the disease spread rapidly across all 50 U.S. states, with Northeastern states facing the highest surge of infection, hospitalizations and deaths. This rapid escalation, coupled with limited existing knowledge about the novel virus, inadequate or ineffective treatment in management of severe cases, limited access to testing, the ease of transmission, limited supply of personal protective equipment (PPE) to prevent the spread of the disease, and confusing information, has led to tremendous fear of contracting and dying from COVID-19. Due to limited testing capabilities, existing data may underestimate the true impact of the virus, as only symptomatic patients are being tested in most parts of the country. Mortality rates are influenced by multiple factors, including testing availability, population demographics, and capacity of the local medical system, among others that may still be unknown (Onder et al., 2020) .

The unique considerations of COVID-19 deaths

Dying is a natural part of life; however, death is often a fearful, frightening event. Dying in the midst of the COVID-19 pandemic presents additional challenges that magnify normative fears and may interfere with a healthy grieving process. For

instance, death from COVID-19 is often brought about unexpectedly as a result of complications from the infection or limited access to needed healthcare (Onder et al., 2020). Further, COVID-19 related death is in many ways a gruesome, lonely, and dehumanized process for patients and families. People are often faced with abrupt separations from their loved ones in order to comply with regulatory precautions to prevent the spread of the disease. This can be a traumatic experience for patients and their family members, as they must endure this separation with a high level of uncertainty, loneliness, and despair. Unable to visit or be near the patient at the hospital, family members often find themselves incapable to obtain information about their health status, while feeling powerless and lacking control about their ability to help or be with their loved ones. Thus, even before a loved one dies, the family will likely experience a form of separation distress, marked by changes in multiple biological and physiological systems that dysregulate normal functioning and compromise health (LeRoy et al., 2019). Family members have to make difficult decisions (e.g., suspending life-support) about their loved one from a distance, further exacerbating preexisting distress. Moreover, when a patient dies, family members are unable to perform usual religious and cultural rituals due to necessary precautionary measures, which can complicate the grieving process and lead to distressing emotions such as shame or guilt (Romanoff, 2010). As patients and families find themselves facing death and grief in unexpected ways that deviate from preconceived expectations, this may lead to unresolved family issues, complicated grief, and trauma.

Clinical implications and recommendations

Strategies to help patients and families at-risk of dying from COVID-19 are of utmost importance to reduce potential traumatization and associated negative health consequences. Clinical recommendations for working with these patients and families include facilitating end of life (EOL) discussions that take into account relevant cultural and contextual considerations (Balaban, 2000; Blank, 2011). For instance, a substantial percentage of COVID-19 patients requiring mechanical ventilation are not able to be extubated and survive, which forces loved ones to make unanticipated and challenging EOL decisions. Assisting families in working through the decision process, validating their emotions (e.g., guilt, shame, blame), and providing them with relevant coping skills that correspond to their cultural values, beliefs, and practices can be essential to ameliorate distress (Garcini et al., 2019). Similarly, assisting families in accessing social support networks while accounting for the contextual challenges faced during the COVID-19 pandemic is vital. The social distancing policies enacted to prevent the spread of the disease can drastically inhibit people's ability to access needed support during this difficult time. We recommend helping families brainstorm creative strategies for maintaining closeness and communication through the use of technology or other preferred ways that could help honor traditional grieving practices in non-traditional ways (e.g., writing letters, art).

For families who have lost a loved-one to COVID-19, acknowledging and working through their negative emotions and grief is imperative. In this regard, using acceptance strategies, focusing on values-based interventions, and giving space to grieve the lack of connection with the living are vital. Additional helpful strategies may include

facilitating problem-solving and decision-making to prevent risky or impulsive decisions (e.g., reduce precautionary health measures, burial-related decisions) and providing them with psychoeducation about the grieving process, particularly learning to identify warning symptoms of complicated grief and trauma. Directly addressing how the COVID-19 pandemic makes death, dying, and grief different is also important in order to help families navigate uncertain situations, validate conflicting emotions, and set expectations for modified coping plans if traditional coping strategies are not available (e.g., family gatherings). Moreover, it is not uncommon while grieving to question religious or spiritual beliefs, as well as life purpose and meaning. While for some, these spiritual connections may strengthen during a crisis, for others tragic losses can result in feeling lost, questioning previously held beliefs, or anger towards a higher being or the deceased. If this is prevalent for a patient whose loved one died of COVID-19, processing these existential questions and emotions may be exacerbated in the context of a global pandemic and will be important to address in supporting the patient's grief processing. Finally, it is important to emphasize providers' self-care as essential. The emotional toll on providers is heavy as they support patients who are losing loved ones to COVID-19. Prioritizing self-care and support for providers is necessary during this crisis, in order to best care for patients and families.

Conclusion

The loss of a loved one is one of life's most distressing events; it can lead to complicated grief and trauma, particularly when death is unexpected and when it deviates from usual expectations and context. Although grief is a universal experience, mourning is influenced by cultural beliefs, practices, and values, as well as by the

context in which death takes place. To maintain a resilient spirit among those who are at-risk of losing a loved one or who have lost a family member to COVID-19, it is important that they be provided with the necessary contextually and culturally appropriate skills and resources to facilitate healing in the face of hardship and uncertainty.

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