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Social isolation at the end of life: A case report of one person's journey navigating the medical landscape during the COVID-19 pandemic

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Case Report

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Abstract

Background. In addition to physical symptom burden, psychological suffering at end of life (EOL) is quite pervasive. As such, the interdisciplinary team in our Palliative and Supportive Care Unit strives to provide quality care sensitive to the physical and psychosocial needs of patients. Involving and allowing for the presence of family members is one way in which we afford our patients some additional comfort. Unfortunately, the current pandemic has placed limitations on this rather fundamental need for both patients and their family members. Here, we present a case illustrating the effects of visitor restrictions/isolation due to COVID-19 on the suffering of a patient at the EOL.

Case description. A male in his 20s with a refractory hematologic malignancy decided to pursue a comfort-based approach to care after a rapid clinical deterioration. Due to visitor restrictions, he had to face this decision with limited support at the bedside, which caused significant distress. He was forced to choose among several immediate family members who would be at his side through his hospitalization, to be his advocate, at times his voice, his confidant, and the person to relay all information to those on the outside. He expressed a wish to be married before he died, which occurred in our palliative care unit. This life goal was one we would normally encourage those he loved to gather around him, but this was not possible. He passed peacefully two days after he was married.

Conclusion. Although social limitations are necessary to help provide safety to the patients and staff in a hospital, they can have a direct impact on the suffering of patients and families at the EOL. Helping to maintain dignity, reflect on their life, and resolve any conflicts in the presence of family members is a benchmark for providing quality palliative care. Being barred from visitation due to isolation, threatens this care and lays the foundation for complicated grief among family members. Further research is needed to help balance the needs of those at the EOL with public safety. One such measure to help ease distress is to allow for more virtual visitation through electronic measures.

Introduction

Psychological suffering at the end of life (EOL) is a universal experience (Block, 2006). This stems from many sources including: grief about current and anticipated losses, fear and uncertainty about the future, unresolved issues from the past, and concerns about loved ones. These are all further impacted by the developmental stage of the patient, culture and society, financial issues, spirituality, family dynamics, a patient's vulnerabilities and existential concerns, as well as coping style (Block, 2006; Krikorian et al., 2020). When planning how to best support the well-being of patients and their families at EOL, it is important to consider preferences and values, and how to achieve this through shared decision-making and clear communication (Steinhauser et al., 2000). Also, when considered collectively, these views and relationships provide a sense of security that might help to mitigate fears associated with one's inevitable death (Maxfield et al., 2010). According to Maxfield et al., an individual's self-esteem secured by the strength of attachments to one's parents, in addition to other worldviews, can provide a buffer against the anxiety related to one's mortality. As one might expect, being in close contact with those that helped to shape one's self-esteem when facing EOL would help to significantly reduce emotional suffering at this time.

In addition to physical comfort, patients describe a "good death" to include being at peace with God, being surrounded by loved ones, receiving treatments that are aligned with their wishes, being treated with respect and dignity, and being afforded the opportunity to resolve conflicts and have a sense of completion within relationships (Steinhauser et al., 2000; Carr et al., 2020). Krikorian et al. (2020) found that despite these core elements, notions of a good death also vary from individual to individual and are fluid in nature, changing during

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the process of dying. This underscores the importance for healthcare workers to not only inquire about the dying individual's wishes, conflicts, and particular societal conditions, but to reassess for these along the disease trajectory. These factors have been threatened during the COVID-19 pandemic, as the emphasis on infection control has demanded public health restrictions to protect patients, family members, and staff. This included stringent changes to hospital visitation policies, which unfortunately has led to amplified feelings of pain and loss at EOL (Carr et al., 2020).

Isolation has long been known to contribute to higher levels of emotional distress and poorer mental health among those hospitalized (Brooks et al., 2020; Usher et al., 2020). Patients in isolation reported higher levels of anxiety depression, and anger and a decrease in self-esteem and sense of control (Gammon, 1998). For family members of isolated patients, being barred from visiting at the EOL, puts them at risk for complicated grief (Chochinov et al., 2020). The survivor is more likely to experience depression, anxiety, and anger when they did not have the opportunity to answer questions such as "was my loved one in pain or alone when they died?" or have the opportunity to say "goodbye" (Carr et al., 2020; Chochinov et al., 2020).

Herein, we present a case of a young patient with a distressing illness and treatment course whose hospitalization during the COVID-19 pandemic compounded the family's distress due to visitor restrictions, resulting in considerable distress for the healthcare team.

Case description

Mr. A was a man in his 20s with a refractory hematologic malignancy and no prior history of illness, initially diagnosed at an outside facility after three to four weeks of increasing fatigue, persistent vomiting, and moderate diarrhea, in addition to night sweats. He was initially started on curative treatment, but he presented with persistent disease after 28 days. He later began a clinical trial, with plans to undergo allogeneic stem cell transplantation. After starting on the trial, he showed persistent disease followed by two hospitalizations requiring mechanical ventilation due to acute hypoxic respiratory failure from a fungal pneumonia. He was discharged to a rehabilitation facility while on long-term antimicrobial therapy but had to be transferred back to our cancer center after two days.

Upon admission, Mr. A was referred to our palliative care team for assistance with symptom management. He had pain in the thoracic spine that worsened with deep inhalation and was managed with as needed doses of oral and intravenous hydromorphone. As his condition continued to deteriorate and his pain worsened, he was placed on hydromorphone continuous infusion.

Mr. A was also referred to supportive care psychology to assist with emotional distress. His primary concern was his fiancé and her coping. Through follow-up psychology sessions, our team learned that the patient recently became engaged after dating for 3 years. Mr. A expressed increasing levels of distress that he could not be with his fiancé and family. He was very close to his father, his stepmother who raised him, and his biological mother. The hospital had visitor restrictions that prevented them from all being together as he was only allowed one visitor. Early on he opted for his fiancé to be his medical power of attorney (MPOA) and the person who would stay with him during hospitalizations. The patient's fiancé frequently expressed how difficult her position was as the liaison between the patient, medical staff, and family. This was also distressing for the healthcare team who empathized with his need to receive in-person support from all three of his parents, but also understood the necessity of the visitor restrictions.

Mr. A's condition continued to decline, and he began to require high flow oxygen. Our palliative care and ICU teams discussed goals of care given his poor prognosis. The patient, his family, and his care teams favored a comfort-based approach. Thus, he was transitioned to our Palliative and Supportive Care Unit (PSCU) for EOL care. In addition to management of pain and dyspnea, our integrative approach involved continued counseling with our psychologist and our chaplain team. Mr. A expressed that although he understood his prognosis and imminence of death, he was experiencing anticipatory grief for the dreams he had yet to experience, including taking a vacation, getting married, and having children. He expressed his desire to marry his fiancé and talked about his wish for her to have their children as he was previously able to bank his sperm.

The interdisciplinary team on the PSCU worked to assist this couple in fulfilling their dream. The patient was awake, alert, and oriented for the planning and ceremony, and was able to participate fully. His father and biological mother were granted exceptions to the visitor policy to be present, but his stepmother, who raised him and who he viewed as a mother, could only attend the ceremony via video conference, along with about 30 other family members and friends.

The patient passed peacefully in the PSCU two days after he was married.

Discussion

This case illustrates how visitor restrictions during the COVID pandemic can adversely impact the well-being of patients, family, and healthcare providers.

The COVID-19 pandemic has forced medical and care facilities across the world to make some very difficult decisions regarding how to maintain a safe working environment by minimizing disease transmission, while also continuing to provide quality care sensitive to the psychosocial needs of patients. The physical and psychological impact of isolation and quarantining has long been studied, with most research indicating the presence of a family member/caretaker having significant benefits for the psychological well-being of the hospitalized patient (Goldfarb et al., 2017). Higher levels of anxiety and depression, with lower levels of self-esteem and sense of control have been found in those isolated due to infection as compared to those who were not isolated (Gammon, 1998). The physical presence of visitors is also shown to reduce symptoms of delirium in patients, thus helping to improve recovery and shorten hospital stays (Granberg et al., 1999; Global Council on Brain Health, 2020). Unfortunately, these caregivers are known to systems as "visitors," most of whom have been restricted from being with their loved ones during the pandemic.

> In the words of Dr. Jason Karlawish, the co-director of the Penn Memory Center, "When this pandemic is over, we ought to compare the outcomes of care in hospitals that recognized the role of caregiver … and those that did not. I'd bet we would find that when caregivers were present, resources and lives were saved. Even more valuable will be the dignity we preserved when faced with a pandemic that threatened humanity … "(Karlawish, 2020)

When we consider mortality, it has been found to increase by 26–32% for those socially isolated, while a person's risk of dying

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increased by 26% for those feeling lonely (Holt-Lunstad et al., 2015). As many people fear dying alone, the pandemic has emphasized the magnitude of concern about a loved one facing these same fears. Although for some, the presence of strangers in the form of healthcare workers might help to lessen these fears, for others, this is unacceptable if a person is going to experience a good death. Exploring a patient's wishes regarding how they choose to experience death, though, is critical. Just as living alone is not an indication that someone has limited social connections or is lonely, dying alone may very well be a choice they wish to make (Nelson-Becker and Victor, 2020).

Maintaining dignity is an important component of what we offer on our PSCU and has long been a benchmark of providing quality palliative care. Dignity therapy, by which the process of generativity can be encouraged and explored to allow patients an opportunity to reflect on and invest in those they will leave behind, is one avenue to enhancing this care (Buonaccorso et al., 2021). Through the process of generativity, Buonaccorso et al. found discussions about significant moments and thoughts that helped to shape how a person will be remembered, in addition to resolving conflicts, seeing family, and sharing their hopes and dreams for those they will leave behind, to be important to not only helping the patient, but the family left to grieve their loss. This sense of completion in relationships has been found to reduce suffering and improve quality of life (Steinhauser et al., 2008). Families and patients barred from visitation during COVID are often denied the opportunity to achieve this sense of completion. Additionally, not having access to their dying loved one, may put families at risk for complicated grief, leaving them with many unanswered questions and no opportunity to confront the reality of death (Chochinov et al., 2020). Indeed, several researchers have proposed that there will be a significant increase in complicated grief as a result of the pandemic (Goveas and Shear, 2020; Jordan et al., 2022). Families are facing these and additional stressors including the possibility of the patient dying alone or in isolation, questioning the care of the dying person, and limited opportunity to receive support, all of which are impacting pre-loss grief (Stroebe and Schut, 2021). Furthermore, limited/no visitation may mean less family/caregiver access to interdisciplinary and medical teams thereby impacting a sense of preparedness for death. High pre-loss grief and low preparedness for death are both associated with complicated grief (Nielsen et al., 2016; Treml et al., 2021).

As we have witnessed time and time again since early 2020, limitations on visitation of family members have greatly influenced a patient's hospital experience and medical outcomes. This is especially true when facing EOL. It is important that we look at how this current experience has impacted ourselves as clinicians, as well as the patients and the caregivers we serve. Allowing virtual visitation through electronic measures may help to ease this distress. Providing phone chargers, iPads for virtual visits, and a system that supports virtual follow-up sessions are helpful resources moving forward. It won't take the place of holding a hand or giving a hug, but it just might improve the feeling of connectedness and completion with loved ones, especially near the EOL (Wakam et al., 2020). Adopting technological measures into practice is not the only means in which challenges to providing human-centered care in a pandemic can be addressed. Palliative care physicians can help educate and support the primary team physicians on expressing empathy, handling strong emotional responses from patients and families, along with training them on how to have difficult conversations (Powell and Silveira, 2020). This is especially important given the limited number of palliative care providers available (Drutchas et al., 2021).

Palliative care providers have also been experiencing moral distress as a result of visitor restrictions. A recent survey conducted of pediatric palliative care providers showed that many had negative memories of not being able to provide what they felt would be the best possible care, along with witnessing family distress (Wiener et al., 2021). This moral distress experienced has prompted studies looking that the increased emotional impact of the pandemic and interventions to aid. An example is provided by Drutchas et al., where a group of researchers used virtual meditation sessions and group reflections by a psychologist as interventions to help palliative providers cope with the increased emotional distress (Drutchas et al., 2021). Further research is needed to know how to help maintain benchmarks of palliative care despite limitations/restrictions imposed by hospital policy.

References

Block SD (2006) Psychological issues in end-of-life care. *Journal of Palliative Medicine* **9**(3), 751–772.

Brooks SK, Webster RK, Smith LE, *et al.* (2020) The psychological impact of quarantine and how to reduce it: Rapid review of the evidence. *The Lancet* **395**(10227), 912–920.

Buonaccorso L, Tanzi S, De Panfilis L, *et al.* (2021) Meanings emerging from dignity therapy among cancer patients. *Journal of Pain and Symptom Management* **62**(4), 730–737.

Carr D, Boerner K and Moorman S (2020) Bereavement in the time of coronavirus: Unprecedented challenges demand novel interventions. *Journal of Aging & Social Policy* **32**(4–5), 425–431.

Chochinov HM, Bolton J and Sareen J (2020) Death, dying, and dignity in the time of the COVID-19 pandemic. *Journal of Palliative Medicine* **23**(10), 1294–1295.

Drutchas A, Kavanaugh A, Cina K, *et al.* (2021) Innovation in a crisis: Lessons learned from the rapid development of an end-of-life palliative care unit during the COVID-19 pandemic. *Journal of Palliative Medicine* **24**(9), 1280–1283.

Gammon J (1998) Analysis of the stressful effects of hospitalisation and source isolation on coping and psychological constructs. *International Journal of Nursing Practice* **4**(2), 84–96.

Global Council on Brain Health (2020). Preserving your brain health during illness or surgery: GCBH recommendations to prevent and treat delirium. Available at www.GlobalCouncilOnBrainHealth.org (Accessed on 20 December 2021)

Goldfarb MJ, Bibas L, Bartlett V, *et al.* (2017) Outcomes of patient- and family-centered care interventions in the ICU: A systematic review and meta-analysis. *Critical Care Medicine* **45**(10), 1751–1761.

Goveas JS and Shear MK (2020) Grief and the COVID-19 pandemic in older adults. *The American Journal of Geriatric Psychiatry* **28**(10), 1119–1125.

Granberg A, Engberg IB and Lundberg D (1999) Acute confusion and unreal experiences in intensive care patients in relation to the ICU syndrome. Part II. *Intensive and Critical Care Nursing* **15**(1), 19–33.

Holt-Lunstad J, Smith TB, Baker M, *et al.* (2015) Loneliness and social isolation as risk factors for mortality: A meta-analytic review. *Perspectives on Psychological Science* **10**(2), 227–237.

Jordan TR, Wotring AJ, McAfee CA, *et al.* (2022) The COVID-19 pandemic has changed dying and grief: Will there be a surge of complicated grief? *Death Studies* **46**(1), 84–90.

Karlawish J (2020) Hospitalized adults need their caregivers – They aren't visitors. In *STAT+*.

Krikorian A, Maldonado C and Pastrana T (2020) Patient's perspectives on the notion of a good death: A systematic review of the literature. *Journal of Pain and Symptom Management* **59**(1), 152–164.

Maxfield M, Solomon S, Pyszczynski T, *et al.* (2010) Mortality salience effects on the life expectancy estimates of older adults as a function of neuroticism. *Journal of Aging Research* **2010**, 260123.

https://doi.org/10.1017/S1478951522000505 Published online by Cambridge University Press

Nelson-Becker H and Victor C (2020) Dying alone and lonely dying: Media discourse and pandemic conditions. *Journal of Aging Studies* **55**, 100878.

Nielsen MK, Neergaard MA, Jensen AB, *et al.* (2016) Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. *Clinical Psychology Review* **44**, 75–93.

Powell VD and Silveira MJ (2020) What should palliative care's response be to the COVID-19 pandemic? *Journal of Pain and Symptom Management* **60**(1), e1–e3.

Steinhauser KE, Christakis NA, Clipp EC, *et al.* (2000) Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* **284**(19), 2476–2482.

Steinhauser KE, Alexander SC, Byock IR, *et al.* (2008) Do preparation and life completion discussions improve functioning and quality of life in seriously ill patients? Pilot randomized control trial. *Journal of Palliative Medicine* **11**(9), 1234–1240.

Stroebe M and Schut H (2021) Bereavement in times of COVID-19: A review and theoretical framework. *Omega (Westport)* **82**(3), 500–522.

Treml J, Schmidt V, Nagl M, *et al.* (2021) Pre-loss grief and preparedness for death among caregivers of terminally ill cancer patients: A systematic review. *Social Science & Medicine* **284**, 114240.

Usher K, Bhullar N and Jackson D (2020) Life in the pandemic: Social isolation and mental health. *Journal of Clinical Nursing* **29**(15–16), 2756–2757.

Wakam GK, Montgomery JR, Biesterveld BE, *et al.* (2020) Not dying alone - Modern compassionate care in the COVID-19 pandemic. *The New England Journal of Medicine* **382**(24), e88.

Wiener L, Rosenberg AR, Pennarola B, *et al.* (2021) Navigating the terrain of moral distress: Experiences of pediatric end-of-life care and bereavement during COVID-19. *Palliative & Supportive Care* **19**(2), 129–134.

https://doi.org/10.1017/S1478951522000505 Published online by Cambridge University Press