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End-of-Life Visitation Guidelines during Pandemic Times

Madeline Chung

Endings matter, not just for the person but, perhaps even more, for the ones left behind.

—Dr. Atul Gawande, *Being Mortal: Medicine and What Matters in the End*

Introduction

Since the start of the pandemic, more than one million Americans have died of COVID-19, and many of these victims experienced death and dying alone, isolated from those who love them because hospitals and other institutions that specialize in hospice or palliative care would not allow family visits. As more dangerous and more contagious variants of the virus emerged over the last three years, hospitals have considered adopting even more restrictive “no-visitor” policies. Those in favor of stricter regulations seek to not only mitigate the introduction and transmission of COVID-19 within hospitals and their local communities, but also to preserve personal protective equipment (PPE) for health workers (Munshi et al., 2020). However, well-intended safety restrictions on visitation can inadvertently increase the levels of suffering, distress, grief, and tragedy that overwhelmingly devastate isolated patients, bereaving families, and distressed care providers (Downar & Kekewich, 2021). In this paper, I argue that medical institutions must be urged to adopt more accommodating end-of-life visitation policies while strictly implementing PPE safeguards and continuously monitoring COVID-19 prevalence in the community. Ultimately, I aim to demonstrate the importance of implementing more compassionate leadership surrounding visitor policies and more ethical initiatives that support person-centered emergency preparedness and crisis response plans.

Not-So-Helpful Public Health Protections

Healthcare teams have always dedicated their time and effort to tirelessly providing optimal care for patients, especially in hospice and palliative care settings where effective pain and symptom management requires high levels of attention. With the alarming severity of COVID-19 symptoms and shortage of medical resources, end-of-life care responsibilities have become more important than ever before. Now clinicians must also face the additional stress of finding an appropriate solution to the moral dilemma of limiting viral exposure while also finding a way to safely integrate familial support in clinical settings. The National Academy of Medicine asserts the importance that “family and/or [designated support persons] are not kept an arm’s length away as spectators but participate as integral members of their loved one’s care team” (Frampton et al., 2020). Growing scientific evidence has consistently demonstrated significant emotional and psychological benefits for patients, family members, and care providers when designated support persons are able to remain at the bedside throughout the course of treatment and/or during the transition to comfort care measures (Frampton et al., 2020). Erring on the side of caution, however, hospitals across the nation have implemented strictly enforced limitations or complete restrictions on family presence in many clinical care settings (Frampton et al., 2020).

This seemingly unprecedented precautionary measure is not new for the intersection of medicine and public health. In the past, hospitals enforced “no visitation” regulations to prevent outbreaks of respiratory viruses like the seasonal influenza (Nassar et al., 2018; Salgado et al., 2002). These rules progressively relaxed not only because policymakers discovered compelling amounts of evidence that showed the beneficial effects of having family present with patients during their hospital stays, but also because researchers found no significant difference in the number of healthcare-acquired infections (HAIs) or septic complications between hospitals with restrictive visitation policies and hospitals with more liberal ones (Goldfarb et al., 2017; Nassar et al., 2018). Additionally, before visitation restrictions and high standards of PPE guidelines were implemented in Wuhan, China, to help prevent an uncontrolled transmission of COVID-19, investigators found that healthcare-acquired infections accounted for a third of all cases, but 98% of these occurrences were caused by hospital staff, not visiting family members or friends (Downar & Kekewich, 2021; Zhou et al., 2020). Strictly enforced “no-visitor” policies are well-intentioned, but studies are not showing a significant difference between restrictive and

liberal visitation policies in protecting patients, staff, and the public from viral exposure. Despite there being limited evidence to support the idea that visitors would contribute significantly to a hospital-related transmission of COVID-19, most healthcare institutions have still not made policy adjustments to increase daily, in-person visitation.

Rather than making efforts to systematize a safe reintroduction of family presence, a focus has been placed on offering families daily access to their loved ones through video meetings or phone calls, which can help reduce, but not eliminate, the risks associated with patient isolation if facilitated properly. Many physicians, nurses, and other bedside clinicians have been too overwhelmed with pandemic-influenced duties to reliably accomplish this task, resulting in a substantial number of unintended and disturbing emotional and psychological consequences for patients and families (Nassar et al., 2018). To resolve this, hospitals will not only have to hire and train new patient caregivers or repurpose staff such as certified nurse assistants to manage and ensure that regular and equitable patient-family communication is taking place for all patients, but they must also make sure to have a strong supply of e-communication devices (Leiter & Gelfand, 2021). Big tech companies like Apple, Amazon, and Google could provide technology as an incentive for hospitals to hire new staff to meet patients' communication needs, but this collaborative partnership would only be successfully facilitated by well-resourced hospitals (Kuntz et al., 2020). In order to improve equity, state and federal governments would have to provide the financial support that is needed for less privileged and poorly resourced care centers to both expand patient access to e-communication devices and increase numbers of appropriately compensated healthcare staff.

Even if these critical healthcare staffing shortages and device limitations were nonissues, replacing in-person visits with e-communication is not an appropriate substitute when dealing with extremely complex and often distressing end-of-life situations and discussions. Studies have shown that some patients and families do not feel comfortable articulating questions or expressing their thoughts and wishes in virtual conferences where privacy and confidentiality might not be guaranteed (Munshi et al., 2020; Kuntz et al., 2020). These communication-related challenges can result in physicians struggling to fully or properly assess a patient's needs and values, or families not getting the opportunity to share meaningful conversations with their loved ones. Moreover, the variability in scheduling meetings can make it difficult to hold impromptu conversations should patients take sudden and

unexpected turns for the worse, stripping away the chance for people to spend those final, valuable moments of time and life together as a family (Kuntz et al., 2020).

Even when arrangements can be made for families to be present before and at the time of their loved one's death, these e-meetings are not always helpful or therapeutic. On the contrary, watching a loved one dying alone on a screen is often such an incredibly guilt-inducing and disturbingly inhumane experience that families are left to face increased risks of prolonged depression and intense, complicated grief (Mayland et al., 2020; Otani et al., 2017). To make matters worse, pandemic-related challenges with staffing shortages and increased demand for e-communication resources from other patients and families have resulted in bereaved family members having to say their virtual goodbyes with a time constraint (Najeeb, 2020). Family inclusion, sensitivity, and respect for grief or other mourning practices and rituals are vitally important to end-of-life practices and to each family member's emotional and mental health outcomes. For these reasons, it is indisputably unacceptable for healthcare facilities to continue operating with virtual meetings as replacements for in-person visitation, not to mention how poorly facilitated, unorganized, and inconsistent the scheduling process can be at times. Care teams must not allow loved ones to become afterthoughts, especially now that people are struggling with social isolation measures, a lack of usual support structures, and a shortage of mental health services.

Devastating Decisions: Dying Alone or Dying at Home?

The standard of care has to center around family visits and communication, not only because there is a duty to promote emotional and psychological well-being, but also because the harms of isolation are intensified for acute and critically ill patients with COVID-19, especially as they approach those final few days before death. When flexible visitor policies and encouraging family-centered care interventions are used in the ICU, patients experience reduced delirium, greater patient satisfaction, better mental health outcomes, and shorter in-patient stays (Munshi et al., 2020; Nassar et al., 2018; Goldfarb et al., 2017). Visitor restrictions only serve to increase the frequency and intensity of delirium and anxiety, which is common for patients with COVID-19 and contributes to extended hospital stays and higher risks of death (Munshi et al., 2020; Helms et al., 2020). Patients in facilities with strong visitor restrictions also experienced delays in

receiving medications, lower chances of psychological recovery, difficulties leaving the bed on their own, treatment or discharge plans that have less alignment with and regard for their personal values and preferences, and severe traumatization upon separation for those with cognitive impairment (Munshi et al., 2020; Zeh et al., 2020). With the benefits and risks associated with family presence restrictions in mind, many individuals with serious symptoms of illness have made the decision to reject acute hospital care and stay at home where they can be with their loved ones as they go through the death and dying process.

Although the benefits of being surrounded by family members are emotionally and clinically significant, there is a predictable and consistent presentation of end-of-life symptoms that can eventually become unsustainably burdensome for the patient, family member, and community care services to manage, making the decision to stay at home rather than go to a palliative care facility particularly distressing (Downar & Kekewich, 2021). The condition of dying is characterized by the human mind and body's progressive deceleration, where people become weaker and bed-bound, struggle to swallow food or fluids, sleep more, feel more confused or agitated, and finally decline in responsiveness until they enter a coma, which is a state of complete unresponsiveness (Ting et al., 2020). People who are dying of COVID-19 often have a rapid development of respiratory failure and hypoxia, resulting in a more rapid deterioration and death (Ting et al., 2020). Managing distressing symptoms can be challenging and even overwhelming without help from healthcare professionals who can administer comfort care treatments when needed, but it is too unthinkable for some patients and loved ones who do not want to be separated (Ting et al., 2020). If our healthcare systems work to preserve family engagement, then people would not be forced to choose between sharing meaningful connections with loved ones before the moment of death and having a well-monitored palliative care plan that reduces end-of-life suffering.

While the significance of family visits and communication is recognized, not all hospitals or medical centers have made the same efforts to develop new policies that demonstrate a commitment to preserving family presence and mitigating the risks of patient isolation. Lacking a universally agreed-upon pandemic preparedness plan has resulted in high levels of variability for visitor restrictions, even "from hospital to hospital [within] the same neighborhood," but "the opportunity to hold a dying family member's hand" cannot be determined by which ER an ambulance happened to take

a patient to (Leiter & Gelfand, 2021). Knowing the profound effects that visitation policies have on levels of “patient advocacy, feeding, mobility, orientation, emotional support in settings of delirium, cognitive impairment, language barriers, end-of-life care, labor and delivery, and transitions to critical care,” we must consider allowing family members to be with their loved ones (Munshi et al., 2020). Inconsistencies in these policies have caused acute care facilities with fewer restrictions and a stronger emphasis in delivering patient-centered care to face an increased burden of patient management due to more incoming transfers and patient/family reluctance about transitioning to facilities that provide palliative care but have greater restrictions (Leiter & Gelfand, 2021). Moving forward, we must find new ways of implementing more consistent visitation guidelines that not only reduce value conflicts between healthcare professionals and patients/families, but also demonstrate greater levels of compassion and respect for dying patients and grieving families, even and especially during pandemic times.

Reducing Moral Distress for Clinicians

Visitation restrictions are associated with significant risks not only to patients and families, but also to healthcare professionals. Studies have revealed that hospital staff either internalize or express “deep regret and symptoms of anxiety or depression about the COVID-19 visitor restrictions” (Munshi et al., 2020; Azoulay et al., 2020). Knowing that many “patients in their final days and hours are often minimally responsive and unable to interact with family members,” hospitals must recognize that visitations must be permitted throughout a patient’s hospital stay, not just potentially offered as an exception only at the moment of imminent death (Downar & Kekewich, 2021). Moreover, with the unpredictability of prognostication due to sudden patient deterioration and death that sometimes takes place without the expected warning signs, scheduling an end-of-life visit can be extremely challenging, and this often results in “family members were forced to leave the bedside of patients who appeared to have months to live, [but] were then unable to return quickly enough” to spend quality time with their dying loved one (Munshi et al., 2020; Najeeb, 2020). Hospital administrators need to recognize that family members are not offered any level of reassurance when “a hospital team member [sits] with their loved one during the dying process [if staffing even allows]” in order to prevent patients from spending their last moments of life fully alone (Leiter & Gelfand, 2021). This multi-stakeholder situation becomes especially upset-

ting, frustrating, and stressful when staff do not speak the same language as patients, which creates barriers in effective communication, proper advocacy of patient needs, respect for the grieving process, and expressing love or forgiveness to loved ones (Kuntz et al., 2020). As a result, healthcare workers have “reported substantial distress associated with being a ‘placeholder’ for families at the end of life” (Munshi et al., 2020; Najeeb, 2020). Visitation restrictions that have forced many patients to die in isolation and separated from loved ones is psychologically and emotionally distressing and confusing for patients, family members, and healthcare teams, resulting in an urgent need for public health authorities to renegotiate family presence policies.

For compounding reasons, including a need to prevent emotionally overburdening clinicians, experts in quality, safety, and infectious disease must work with patient-family advocates in order to develop stronger person-centered guidelines that will help hospitals preserve family presence. Assessing and comparing risk between each of the different approaches to visitor policies is difficult to do because direct comparisons cannot be made, but it is clear that we have a duty to prevent the psycho-morbidity that arises when family presence is prohibited at the bedside (Downar & Kekewich, 2021; Leiter & Gelfand, 2021). When exceptions were made for brief visits from one or two family members at the very end of a patient’s life, this usually only applied to “patients who decided to transition to comfort-focused care and, in many cases, stop life support” (Leiter & Gelfand, 2021). If hospitals allow families to visit “only if their loved one transitioned away from life-sustaining measures, [then] rather than helping families say goodbye, [a visitation exception becomes] a form of coercion” (Leiter & Gelfand, 2021). Moreover, by only allowing two visitors to stay at the bedside, families are faced with making incredibly difficult choices about who can share final goodbyes and last moments with a loved one, and hospital staff who have to comply with these rules are forced to play a role in causing pain and distress that can last a lifetime.

Not only did healthcare workers experience intense moral distress over having to enforce these policies, but they also have to consider the ways in which these regulations deeply conflict with a clinician’s ability to uphold the principles of person-centered care and provide patients and families with just and humane care. After witnessing the preventable pain and suffering caused by family separation in acute care and palliative care settings, many healthcare workers support reinstating “safe, compassionate family presence policies within communities... during [these] challenging circumstances

[with COVID-19, especially because they wish to honor” the essential role that family care partners play as members of the care team” (Frampton et al., 2020). Families have to be recognized as part of the standard of care in hospital settings, not viewed as indulgences that can and should be forsaken during public health crises, when their role as care partners actually needs to be regarded with an even greater level of importance. Rightful acknowledgement of the important role families play in clinical settings is a must, even and especially during a pandemic, when clinicians are already overworked and should not be made to feel responsible for enforcing policies that cause patients and families to experience direct harm and intense suffering (Selman et al., 2020). Implementing these humane visitation guidelines will allow clinicians to not only build greater levels of trust with the patients and families they serve, but will also help healthcare workers relieve the tension they feel, promote shared decision-making, and respect the rights of patients and family care partners. By using a well-designed plan and carefully instructing families on how to safely and properly use PPE, hospitals would be able to safely allow family presence at the bedside for sick and dying patients during this pandemic.

Balancing Person-Centered Care and Contagion Control

As local and national public health authorities and hospital administrators work to reintegrate compassionate end-of-life visits for sick and dying loved ones, they must work to limit the spread of COVID-19, especially for hospitals in communities with an already rising prevalence of disease. Respecting family members as care partners in clinical settings is necessary, but increasing visitation will create some difficulties in maintaining adequate physical distancing protocol, particularly near elevators and entrances (Johns Hopkins Medicine, 2020). Although visitation restrictions might appear to be an effective way to “[limit] the number of visitors allowed at one time [and] reduce how many people get exposed to the risk of infection,” research has demonstrated that problems with transmission are not resolved with these policies (Downar & Kekewich, 2021). Family members living in one household often visit sick and dying loved ones in the hospital by “cycling between being at the bedside and being outside the hospital multiple times in a single day” (Downar & Kekewich, 2021). As family members switch out and take turns visiting, they engage in “the removal of personal protective equipment and transit within the hospital [which] is likely to increase the risk of transmission substantially more than simply allowing

all visitors to remain at the bedside for the duration of their visit . . . space permitting” (Downar & Kekewich, 2021). Ultimately, policies that place morally distressing visitor limits at the bedside of sick and dying patients do not truly serve to effectively reduce the chances of COVID-19 transmission between family members, hospital staff, or other patients.

Hospitals must move away from implementing a straightforward “no visitation, no exceptions” policy that must be adhered to at all times and instead focus on using a combination of transparent, evidence-based standards for visitor policies that are tied to rates of viral spread and rigorous use of infection prevention and control (IPAC) measures. Appropriately responding to COVID-19 and reducing the risk of transmission while promoting whole-person welfare can be achieved by: (1) continually reassessing “whether there is a need for restrictions based on current factual evidence” and CDC guidance; (2) minimizing risk of physical presence by following appropriate infection control and prevention guidelines; (3) communicating proactively so that there is transparency about facility policies on PPE use and compliance; (4) using a “shared decision-making approach to communicate risks and benefits in cases where family can be physically” at the bedside; and (5) enlisting “family as members of the care team” who have a duty to follow safety protocols (Frampton et al., 2020). With this plan, there essentially should be no limit on care partners if space allows and the administrators in specific clinical settings believe that it would be safe and feasible, and even in circumstances with the greatest visitation risk level, family members could be cautiously offered compassionate exceptions to restrictions (Johns Hopkins Medicine, 2020).

When our society is inevitably faced with the problem of future global health emergencies, it is imperative that pandemic preparedness plans become centered around flexible guidelines that are not only based on rates of viral spread and visitation risk levels that assess the number of outbreak cases in the community, but also informed by state and county public health information as well as hospital conditions in order to protect patients, relatives/care partners, healthcare teams, and the broader public. While most nosocomial outbreaks originate from “asymptomatic healthcare workers . . . using shared [community] spaces for breaks and meals,” a small percentage of transmission has been caused by asymptomatic visitors who lacked “sufficient education in PPE use or who did not articulate symptoms on entry screening” (Munshi et al., 2020). Therefore, in order to safely preserve family presence, visitors must not only accurately and honestly

report their symptoms, but they must also be educated in the effective and appropriate use of and compliance with PPE, which is a process that may require additional staffing (Munshi et al., 2020; Seibert et al., 2018). Ultimately, visitation should be monitored to ensure that (1) facilities are screening visitors for the ability to comply with precautions; (2) facilities have enough staff to provide instruction to visitors on hand hygiene, limiting surfaces touched, and appropriate use of PPE while on the premises; (3) visitors understand the need to leave patient rooms during procedures that might generate or spread viral aerosols; and (4) visitors are instructed to only visit the patient room and avoid going to other locations in the facility (Seibert et al., 2017; Johns Hopkins Medicine, 2020). The safety and well-being of healthcare workers, patients, and family visitors/care partners must be protected, and with collaborative efforts and compassionate leadership, visitation policies can be made safer, less restricted, and more equitable.

Conclusion

The rigid and uncompromising visitor restrictions put in place by many hospitals and healthcare facilities at the start of the pandemic were reasonable precautions used to limit the spread of a dangerous and poorly understood pathogen. However, now that we have been operating with more than three years of experience dealing with the novel coronavirus and have greater understanding of benefits from proper PPE use and monitoring, healthcare facilities must be urged to adopt new end-of-life visitor policies that respect the psychosocial needs of family members and patients without causing a substantially increased risk of viral transmission. Based on findings discussed throughout this paper, I believe it would be unreasonable to continue operating with complete visitation restrictions in hospitals, especially in end-of-life contexts, where such policies do more harm than good. As public health experts reexamine the safety guidelines used in hospital settings, the threat of global health emergencies must be considered within the context of other threats to health and well-being, such as the unsupported loss of loved ones and compounding grief, which have complex and long-term consequences. The perspectives and voices of patients and families must be strongly regarded in order to promote trust in medical and public health authorities as well as develop policies that are based in scientific justification and compassion. Although we have implemented tools that have helped us become better prepared for managing pandemics, we have failed to address the collective trauma that arises when families are

separated from dying loved ones. Moving forward, visitation policies have to proactively respond to emerging public health crises and emergencies while still operating from a person-centered approach. Unless healthcare authorities take action to reconstruct the system and hospital policies designed to safeguard communities against infectious disease outbreaks, patients will continue to spend their last moments of life isolated from their loved ones, and the failure of medical institutions to address this dire problem will be a defining memory of this pandemic.

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