

FROM THE INSIDE



Alone, the hardest part

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Of all the harrowing images of the COVID-19 pandemic, perhaps none is more heart-wrenching than that of a patient dying alone, without loved ones at their side, amidst chaos and fear. The pandemic has led to drastic changes in how we provide intensive and end-of-life care to patients and their families [1–3]. Age-old cultural and religious traditions surrounding death that comfort the dying and sustain the living, have also fallen victim to the pandemic.

How can we exercise our duty to care while humanizing the dying experience under such extraordinary circumstances?

Worried families, exercising social distancing, desperately seek information, reassurance, and opportunities to be with their loved ones. Front-line clinicians often feel unprepared and overwhelmed with these emotionally intense responsibilities yet try their best to provide impromptu virtual calls with family. These brief interludes offer the chance to utter what needs to be said, to affirm love, and to act as witness to unexpected grief. Clinicians experience extraordinary pressure multi-tasking care while holding mobile devices, listening to one-sided conversations. Although clinicians struggle with fatigue, trauma, and fear for their own safety; it is the dying alone befalling their patients that often breaks them.

Drawing on our pediatric experiences, steeped in traditions of family-centered care [4], we suggest an alternative pathway. Parent presence, even during invasive procedures and resuscitation, is the norm [5]. Throughout hospitalization and sometimes during a child's death, parents are helped to be present for their child in new and different ways. Nurses help parents transition from parent-of-a-well-child to parent-of-a-critically-ill-child

by providing knowledge, skills and support [6]. Witnessing the transformation of parents capable of providing comfort and care to their critically-ill and sometimes dying child is among the most rewarding aspects of pediatric practice. Facilitating human capacity is a core driver of professional satisfaction.

There are reasons to justify limiting family access to patients with COVID-19. The disease is poorly understood [7], diagnostic testing has been unreliable [8], and personal protective equipment (PPE) has been in short supply [9]. The balance outlined in Table 1 will certainly change with the acquisition of new knowledge about SARS-CoV-2, its transmission, tenacity and resultant immunity.

We believe that infection control, public health concerns and family-centered care can coexist and urge reconsideration of adult family member presence at the bedside of patients during COVID-19. We believe this can be accomplished safely with beneficial effects to patients, family, and staff. With careful screening, preparation, and support, we believe many family members would be motivated, grateful, and capable of involvement in their loved one's care. Moreover, family members who feel strongly about exercising their duty to be present for loved ones will likely experience more positive grief resolution and less post-traumatic stress, if afforded such opportunities [10]. If permitted, patients could be calmed by a familiar person at their bedside. The family member could assist with meaningful comforting and care activities that might otherwise require repetitive nurse donning/doffing.

Planning includes thoughtful consideration. Questions to consider include whether the family member has been infected or recovered from COVID-19, is capable of upholding safe practices to prevent the spread of infectious pathogens, and can be helpful to the patient [11, 12]. Not all families will be able to meet these criteria, but when they do, we should strive to make this option possible. At minimum, hospitals need rapid COVID-19

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Table 1 Comparison of in-person contact during COVID-19 pandemic

	No in-person contact	In-person contact
Advantages	<ul style="list-style-type: none"> Eliminates exposure and cross-contamination between patient, family and staff Conserves personal protective equipment Requires less staff coordination and time Unburdens family and staff of decision-making responsibilities regarding contact Relieves family of ambivalence, guilt and fear associated with potential exposure during contact with patient 	<ul style="list-style-type: none"> Provides comfort, security and combats realities of dying unaccompanied by loved one Reduces the number of times staff member may need to enter the room requiring donning/doffing, thus conserving personal protective equipment Permits private shared moments of mourning and parting words/gestures of good-bye Enables cultural/religious rituals associated with dying and death Promotes healthy grief response and bereavement trajectory for family Mitigates family/staff immediate and post-traumatic stress
Disadvantages	<ul style="list-style-type: none"> Denies opportunity for potential comfort, security and accompaniment by loved one during the dying process Complicates family involvement in end-of-life decision-making Denies family private time with dying patient Interferes with fulfillment of perceived responsibilities and duties to the dying family member Disrupts cultural/religious rituals associated with dying and death Derails grief response and bereavement trajectory [10] Degrades the sanctity of dying (with virtual contact) Amplifies possibilities for family-staff disagreement, tension and conflict Limits family/staff end-of-life shared experience 	<ul style="list-style-type: none"> Engenders patient distress/ambivalence regarding putting family members at risk for infection Increases exposure and cross-contamination between patient, family and staff Requires health screening and testing Requires usage of personal protective equipment Requires increased logistical support, staff education, coordination with family and resources Engenders stress, guilt, disagreement amongst family since decisions need to be made regarding patient contact Amplifies possibilities for family-staff disagreement, tension and conflict Engenders staff discomfort or stress in interacting with family who may be viewed as additional focus of intervention and responsibility

testing, adequate PPE, and a cadre of family facilitators. Rapid COVID-19 testing could confirm which family member could possibly be the patient's designated family person [12]. Family facilitators, drawn from experienced psychosocial support staff, relocated pediatric or non-ICU adult nurses, and/or palliative care staff can constitute a team working hand-in-hand with clinical staff to liaise with each family [13].

We have learned that family members can provide what is needed for their loved ones under the most unfortunate circumstances [14]. Further, these opportunities can mitigate angst and regret, and promote positive coping and grief. Providing options while clearly outlining expectations and boundaries is essential. Family facilitators can screen and educate families while serving as the primary contact for those who cannot be present. Orientation would require information about donning/doffing and entering/leaving the room. Designated hours and the amount of time spent in the patient's room could be individualized and pre-determined, during periods when

facilitators are available, to encourage family members to return home for rest and refreshment.

We believe front-line clinicians may experience some peace-of-mind knowing that the needs of family members are being sensitively addressed by family facilitators, experienced in communication skills and anticipatory grief support and counseling. Knowing that patients are not alone but have family present to provide comfort and care can serve as a source of relief for extended family. Given that typical bereavement support, spiritual/religious customs, and funeral services are not available during COVID-19, the psychological benefit of family presence becomes that much more compelling.

In the interim, providing consistent virtual visits with families on hospital-provided mobile devices is important. Of note, virtual visits may perpetuate disparities in care; as low income and elderly family members may have decreased access to these technologies [15]. Virtual and in-person visits are a false equivalent; virtual contact inherently limits the human connection that provides

meaningful elements of end-of-life decision-making and care.

In conclusion, the added value of family caregivers in the context of critical illness should not be overlooked amidst the COVID-19 pandemic. We urge clinicians to think differently during these extraordinary times and consider a decision-making framework that minimizes infection risk, honors patient/family relationships, upholds culturally important rituals of dying, and mitigates potential psychological harm precipitated by the trauma of family separation. With careful screening, education, pragmatic psychosocially oriented facilitation and teamwork, we can accommodate the very real needs of patients to not be alone, for families to fulfill their sense of responsibility and duty, and for staff to uphold the tenets of family-centered care. More than ever, it behooves us to facilitate loving relationships and genuine connections in our clinical worlds, as we continue to practice social distancing and isolation in our personal worlds. Dying alone, despite adhering to social distancing, should not be part of dying at all.

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Compliance with ethical standards

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References

- World Health Organization (2020) COVID-19 Dashboard. <https://covid19.who.int/>. Accessed 22 May 2020
- Truog RD, Mitchell C, Daley GQ (2020) The toughest triage—allocating ventilators in a pandemic. *N Engl J Med* 382:1973–1975. <https://doi.org/10.1056/NEJMp2005689>
- Sayed S (2020) The psychological toll of health care rationing should not be underestimated. *Opinion. Newsweek*. <https://www.newsweek.com/2020/04/24/psychological-toll-health-care-rationing-should-not-underestimated-opinion-1496321.html>
- Hill C, Knafl KA, Santacroce SJ (2018) Family-centered care from the perspective of parents of children cared for in a pediatric intensive care unit: an integrative review. *J Pediatr Nurs* 41:22–33
- Curley MAQ, Meyer EC, Scoppettuolo LA et al (2012) Parent presence during invasive procedures and resuscitation. *Am J Respir Crit Care Med* 186(11):1133–1139
- Curley MAQ (1997) Mutuality—an expression of nursing presence. *J Pediatr Nurs* 12(4):208–213
- (2020) Severe Outcomes Among Patients with Coronavirus Disease 2019 (COVID-19)—United States, February 12–March 16, 2020. *MMWR Morb Mortal Wkly Rep* 69:343–346. <https://doi.org/10.15585/mmwr.mm6912e2>
- Sethuraman N, Jeremiah SS, Ryo A (2020) Interpreting Diagnostic Tests for SARS-CoV-2. *JAMA*. 10.1001/jama.2020.8259. <https://jamanetwork.com/journals/jama/fullarticle/2765837>
- Gondi S, Beckman AL, Deveau N et al (2020) Personal protective equipment needs in the USA during the COVID-19 pandemic. *Lancet* 395(10237):e90–e91. [https://doi.org/10.1016/S0140-6736\(20\)31038-2](https://doi.org/10.1016/S0140-6736(20)31038-2)
- Lobb EA, Kristjanson LJ, Aoun SM, Monterosso L, Halkett GKB, Davies A (2010) Predictors of complicated grief: a systematic review of empirical studies. *Death Stud* 34(8):673–698
- World Health Organization (2020) Infection prevention and control during health care when novel coronavirus (nCoV) infection is suspected. [https://www.who.int/publications-detail/infection-prevention-and-control-during-health-care-when-novel-coronavirus-\(ncov\)-infection-is-suspected-20200125](https://www.who.int/publications-detail/infection-prevention-and-control-during-health-care-when-novel-coronavirus-(ncov)-infection-is-suspected-20200125)
- Wong SC-Y, Kwong RT-S, Wu TC et al (2020) Risk of nosocomial transmission of coronavirus disease 2019: an experience in a general ward setting in Hong Kong. *J Hosp Infect*. <https://doi.org/10.1016/j.jhin.2020.03.036>
- Back A, Tulsy JA, Arnold RM (2020) Communication skills in the age of COVID-19. *Ann Intern Med*. <https://annals.org/aim/fullarticle/2764314/communication-skills-age-covid-19>
- Brogen EG, Deatrick J, Ulrich C, Curley MAQ (2020) Defining a “good death” in the pediatric intensive care unit. *Am J Crit Care* 29(2):111–121
- Velasquez D, Mehrotra A (2020) Ensuring the growth of telehealth during COVID-19 does not exacerbate disparities in care. *Health Aff Blog*. <https://www.healthaffairs.org/doi/10.1377/hblog20200505.591306/full/>