

A PRACTICAL APPROACH TO HOSPITAL VISITATION DURING A PANDEMIC: RESPONDING WITH COMPASSION TO UNJUSTIFIED RESTRICTIONS

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During the COVID-19 pandemic, evidence-based resources have been sought to support decision-making and strategically inform hospitals' policies, procedures, and practices. While greatly emphasizing protection, most guiding documents have neglected to support and protect the psychosocial needs of frontline health care workers and patients and their families during provision of palliative and end-of-life care. Consequently, the stage has been set for increased anxiety, moral distress, and moral injury and extreme moral hazard. A family-centered approach to care has been unilaterally relinquished to a secondary and nonessential role during the current crisis. This phenomenon violates a foundational public health principle, namely, to apply the least restrictive means to achieve good for the many. Instead, there has been widespread adoption of utilitarian and paternalistic approaches. In many cases the foundational principles of palliative care have also been neglected. No circumstance, even a global public health emergency, should ever cause health care providers to deny their ethical obligations and human commitment to compassion. The lack of responsive protocols for family visitation, particularly at the end of life, is an important gap in the current recommendations for pandemic triage and contingency planning. A stepwise approach to hospital visitation using a tiered, standardized process for responding to emerging clinical circumstances and individual patients' needs should be considered, following the principle of proportionality. A contingency plan, based on epidemiological data, is the best strategy to refocus health care ethics in practice now and for the future. (*American Journal of Critical Care*. 2021;30:302-311)

Although it was once considered unthinkable, many hospitalized patients are now dying alone.¹ In response to the COVID-19 pandemic, hospitals worldwide have tightened their visitor policies following public health recommendations.² For example, in May 2020 at St Boniface Hospital in

Winnipeg, Canada, the family of a 66-year-old patient with cancer was prevented from being with her at the end of her life.³ This occurred despite the province of Manitoba's having one of the lowest COVID-19 caseloads in Canada at the time (290 cases, 7 deaths, and 35 723 tests performed as of May 21, 2020).⁴

These unprecedented circumstances have created a cascade of reactive changes in hospitals' delivery of care. Visitation restrictions have become a standard of pandemic protocols and are driven by a broadly utilitarian approach.^{5,6} In turn, these restrictions have led to changes in how health care workers care for people who are dying, with serious repercussions for families.⁷ During the pandemic, missed opportunities for families to be with gravely ill patients are a haunting reminder of how unilateral policies fail to respond



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compassionately, with the practice of restricted visitation already questioned during the severe acute respiratory syndrome (SARS) epidemic of 2002 to 2004.^{8,9} We suggest that the same psychosocial collateral damage described then is occurring again now, and on a much larger scale, because of policies that discount the value of family-centered care.¹

Patient- and family-centered care is touted as the hallmark of high-quality health care in hospitals,^{10,11} and compassion is considered an essential element of high-quality care.^{12,13} However, strict, one-size-fits-all policies that completely bar visitors or allow only 1 visitor (even at moments close to death) have become the norm and have rarely been questioned during the current pandemic.¹⁷ Hence, family-centered care became one of the pandemic’s first victims owing to a return to paternalistic approaches.⁶ In fact, these restrictions may not even be explicitly justified by research evidence.¹⁴ Adult patients are being treated uniformly (ie, left alone and isolated from family members), regardless of SARS-CoV-2 status. The approach in pediatric facilities has been to allow only 1 family member to visit per day.^{8,15}

Many health care workers initially agreed with increased visitor restrictions. Tensions grew as the role of asymptomatic carriers became clear.¹⁶ Health care workers’ compassion yielded to a dire need to

be protected from infected individuals who had not yet shown symptoms.¹⁷ Every visitor increased their risk of infection.¹⁸ As the pandemic progressed, health care workers witnessed how rules meant to protect played out. They identified the conflict between their patients’ need for compassion and their own need for protection.¹ Do constraints on visitation mean that the fiduciary obligation to provide patient- and family-centered care becomes supererogatory? No. The logistical challenges to visitation do not excuse us from fulfilling our obligations to patients and families; there is still something owed. Health care workers and hospital administrators owe transparency and rationale. They must investigate what can actually be done and explore what is safe to try. Leaders in health care need to create opportunities to explicate the ethical rationale for eliminating visitation.¹⁴

In this review, we aim to identify practical approaches to hospital visitation for patients in palliative or end-of-life care circumstances. We identify and examine foundational concepts, the current evidence, and special factors and provide an example of a responsive visitation protocol. We present a stepwise approach to decision-making for visitation and offer implementation guidelines. We advocate for a considered and compassionate approach to help fill the gaps in current best practice documents and enhance the quality of care during a pandemic. This approach may reduce triggers of anxiety,¹⁹ limit moral distress,^{20,21} and prevent moral injury.²² For patients, families, and health care workers, the current visitation restrictions were enacted with best interests in mind but have failed to protect.²³

Literature Search

In May 2020, we conducted an in-depth search of the MEDLINE, PubMed, Embase, Scopus, and Web of Science databases using the Medical Subject Headings terms *palliative care/end-of-life, moral hazard/injury, and advance directives/moral distress and pandemics/COVID-19*. We limited the search results to English-language articles published between 2015 and 2020. This review also draws on additional articles that were subsequently collected (eg, references from the reference lists of the articles found in the literature search, new publications, valuable research published before 2015, and current news media)

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Table 1
Foundational concepts

Concept	Description
Moral distress	Arises when a person, according to his or her own perception, is compelled (eg, by a system) to do something or participate in an act that he or she believes to be morally wrong. Its lasting effects, known as moral residue, can have a devastating impact on clinicians. ^{21,24-26}
Moral injury	Occurs as a result of moral distress and relates to being unable to provide high-quality care and healing. It may involve feelings of betrayal, guilt, shame, anger, and/or a sense of loss of one's moral integrity. ^{21,26,27}
Moral hazard	Occurs when those who are empowered to parse risk and fashion responses (decision makers) are not those who suffer its burdens (decision bearers). ²⁸ When intentionality is present and someone decides on risk while another bears the cost of the outcome, a place of moral hazard exists. ^{29,30}

and analyzed by consensus among the authors. The concepts of moral distress, moral injury, and moral hazard are described in Table 1.

Findings

Currently, the best available evidence for controlling the spread of SARS-CoV-2 includes frequent, thorough handwashing (hand sanitizing), physical distancing (maintaining a minimum distance of 1.8 m, or 6 feet), quarantine or isolation of contacts,³¹ and using an N95 respirator with a face shield when performing aerosol-generating procedures.^{17,32} These measures have been shown to be effective.^{31,33,34}

However, COVID-19 has presented unique challenges related to (1) understanding the prevalence of the virus, (2) recognizing the needs of distinct patient populations (eg, older adults, obstetric patients, and pediatric patients) with and without positive SARS-CoV-2 status when admitted to the hospital,¹⁸ and (3) responsibly allocating scarce resources.³⁵ Such circumstances create a place of moral hazard for health care workers and add to an already heavy psychological burden during the pandemic (eg, anxiety, reduced self-efficacy,³⁶ depression, anxiety, poor-quality sleep or insomnia).²³ These challenges are specifically relevant to decision-making during the pandemic.

Understanding Prevalence

Variations in prevalence of COVID-19 in different regions of the world, and even within a single country, are remarkable. In Canada, for instance, Ontario and Quebec have experienced a disproportionate number of cases and deaths compared with other large areas of the country.⁴ New York City, with a relatively dense population, saw a very high prevalence compared with other US cities. And the north of Italy was much more affected than the south, despite the country's relatively small size.³⁷

Testing

Polymerase chain reaction–based testing materials have been scarce, response times vary significantly,

and some brands lack sensitivity and specificity.³² Also, large-scale testing has been a worldwide problem, particularly in (already) underresourced communities.³⁸ Hence, adequate screening of health care workers, patients, and visitors with accurate and timely polymerase chain reaction testing has been difficult.^{39,40} The use of verbal screening (inquiring about recent travel, contacts, and current symptoms) became routine. Isolation of COVID-19–positive patients is usually discontinued once the patient is asymptomatic and/or after a set time limit (eg, 14 days)¹⁷; however, testing of asymptomatic individuals varies widely. These factors all affect isolation practices, policies, and health care workers' exposure protocols.¹⁸ Furthermore, recent studies indicate that health care workers are more likely to acquire COVID-19 from contacts in the community than from their workplaces.⁴¹

Different Patient Populations

Children have been largely spared from this pandemic, constituting only 1% to 5% of the total population testing positive,^{42,43} with just 2% requiring intensive care unit admissions.^{43,44} Despite the emergence of novel multisystem inflammatory syndrome,⁴⁵ the number of children hospitalized for severe COVID-19 remains small. Hence, the separation of parents who live in the same household from hospitalized children who are COVID-19 negative lacks support. In fact, the importance of parental presence for hospitalized children is undeniable.⁴⁶

Scarce Resources

Many hospitals have struggled to procure supplies, from sedatives and opioids to ventilators and personal protective equipment (PPE).^{47,48} Stockpiling supplies has been advocated as an essential component of any prepandemic preparation, although a worldwide event would inevitably bring shortages and competition between countries.³⁸ The scarcity of PPE has led to international conservation strategies, including visitation restrictions, even in communities seemingly unaffected by the pandemic with adequate surge resources.⁴⁹

Table 2
Personal experiences during COVID-19

Person	Direct quote	Context	Location
Spouse/family	For nearly 25 years, John had stood at Yaroslav's side, but in the end, he wasn't allowed to sit next to him for even a moment. "I may have gotten through this a little easier if I could have sat by him for just a second . . . I just needed to say something to him. I just needed to say, "Don't be scared." ⁵²	Mr Yaroslav Koporulin (patient) was the father of 4 children under 3 years old (2 sets of twins); lung cancer diagnosis; died alone; strict visiting hours of 3 PM to 7 PM only	Washington, District of Columbia, United States
ICU physician	My patient's wife arrives at the emergency department at 1:30 AM, despite having been told she would not be allowed to see her husband. I go to meet her, and we discuss her husband's continued decline. Unfortunately, in the middle of the conversation, a Code Blue rings from the overhead speaker for a patient in the ICU. I step away and find myself entering her husband's room, where CPR is already in progress. ⁵³	Dr Glen Wakam was unable to keep the usual promises to patients and their families because hospital policies do not allow visitors at this time.	Detroit, Michigan, United States
ICU physician	Now, walking around my ICU, it is far from a war zone. It is much more like a graveyard. Quiet, still, and empty. The crowds are gone. Medicine has bowed its head before COVID and dropped to its knees. Families, once welcomed and invited, are banned. ⁵⁴	In Dr Pradeep Ramachandran's ICU, all the beds are filled with patients on ventilators. A colleague weeps as they intubate a patient for the last available ventilator.	Boston, Massachusetts, United States
ICU physician	Older patients are not being resuscitated and die alone without appropriate palliative care, while the family is notified over the phone, often by a well-intentioned, exhausted, and emotionally depleted physician with no prior contact. ⁵⁵	Dr Mirco Nacoti and colleagues are forced to operate well below normally accepted standards of care, owing to hospital overcrowding and severe shortages of medical equipment, PPE, medicines, and other essential resources.	Lombardia region, Italy
Registered nurse	I cry for the parents, children, siblings, [and] spouses who cannot be with their loved ones who may be dying but can't have visitors because there is no visiting allowed. ⁵⁶	Health care workers feel that they are at their breaking point and the pandemic is only getting worse; nurses speak out anonymously for fear of reprisal.	Long Island, New York, United States
Anesthesiologist	What's very devastating for me is some people we know will not survive...and since they're not allowed to have visitors, I may be the last face they see and voice they hear ever as I put them to sleep (general anesthesia) prior to being on a ventilator. ⁵⁶	Dr Cory Deburghgraeve is working a 94-hour week and intubating patients with coronavirus. He tries to show extra compassion with patients through many layers of PPE.	Chicago, Illinois, United States

Abbreviations: CPR, cardiopulmonary resuscitation; ICU, intensive care unit; PPE, personal protective equipment.

Importance of Information and Communication

Throughout the pandemic, an abundance of conflicting information has been circulated via the media, causing confusion and uncertainty about how to stay safe.⁴⁹⁻⁵¹ Fears of the unknown, anxiety about risks, and uncertainty about liabilities are very real driving forces behind decision-making. However, hospital administrators generally are not the individuals who must bear witness to negative outcomes from one-size-fits-all protocols. Table 2 provides examples of personal experiences during COVID-19. Perhaps more than ever, evidence-based information is fundamental when creating and implementing practices that

protect the health and well-being of health care workers and the public.

During the SARS outbreak, it became very clear that frequent, transparent, and flexible hospital communication was invaluable.^{36,57} Communication about appropriate provision of supplies and equipment, particularly in the face of potential shortages, needs to be evidence-based and reassuring, including alternatives to protect patients and health care workers.^{10,32} To facilitate communication and decision-making, it has been recommended that a hospital (or group of hospitals) organize a command center to work with local or regional public health authorities. This group drafts an escalation plan of strategies, according to

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disease prevalence in their region or community, with predetermined, specific criteria (contingency levels) set for each stage of the pandemic.⁶ It is crucial that hospitals' measures align with these community plans and public health directives.

An important component of such contingency planning is proper consultation and communication.³⁶ First and foremost, a consultation with stakeholders, including frontline health care workers, is mandatory to establish trust and increase adherence. Finally, open and ongoing communication with patients and families is required, including broadly sharing visitor policies on traditional and social media alongside individualized information sharing at each facility (eg, via pamphlets, mobile applications, and/or use of navigators).⁵⁸ Essentially, institutions cannot expect busy frontline health care workers to be the primary source of information for patients and families.⁵⁹

A Precedent-Setting Example

One hospital yielded to the call to have visitors return to the bedside. At Seattle's Virginia Mason Medical Center, a new role of "support companion" was created to guide families and patients with COVID-19 at the end of life. The support companion acts as a designated person available to guide visitation. At Virginia Mason, registered nurses fulfill the support companion role to help visitors throughout the process, relieving frontline staff of this task. The availability of both PPE and staff allowed this institution to be flexible, responsive, and supportive of patients and loved ones as they said their final good-byes—a vital part of a "good death."⁶⁰

Stepwise Approach, Guidelines, and Questions

After reviewing the literature and considering the program described above, we devised a practical stepwise approach to enhance evidence-based decision-making to support visits for patients receiving palliative or end-of-life care (Table 3). It follows the ethical principle of proportionality, which demands that "the risks of compromising standards in a given instance should be weighed against the need to do so to optimize benefits to patients, caregivers, and the community."⁶¹ In contrast to utilitarianism, the

delivery of valuable goods should be the goal, including the best opportunities for patients to be well cared for while supporting health care workers' safety. Any allocation of resources needs to be checked by the question "Are we doing more harm than is needed?"^{6,14} Criteria for each step should be explicitly disclosed in advance to stakeholders to ensure fairness, maximize transparency, and build capacity for consistent decision-making.⁶² Visitation policies must have practical implementation guidelines (see Figure) and build in opportunities for regular reevaluation to guide appropriate goals of care.

Discussion

There is a general consensus that a pandemic brings extenuating circumstances to the usual modus operandi of an organization. This situation may require the use of international directives such as the Siracusa principle (which delineates situations when civil liberties may ethically be limited),⁶³ in which the collective good is held as the highest ethical standard. However, there is a need for creative contingency planning that includes a tiered, standardized approach for pandemic hospital visitation to avoid moral and psychological damage, which will continue to accumulate.²⁵ Early and responsive organizational action will reduce opportunities for hasty crisis-level reactions (without accounting for context and circumstances) and relieve pressure on individual clinicians. Such planning also helps to responsibly allocate resources,¹⁴ from critical care beds to complex therapies such as extracorporeal membrane oxygenation.^{64,65}

Maves et al³⁵ predicted that the first or subsequent waves of COVID-19 would see critical levels of demand for resources that might outstrip supply. Indeed, this has already occurred. Further, broadly restrictive visitation policies are depriving patients of an invaluable resource and denying families opportunities that cannot be replaced. Families of dying patients often have psychosocial needs similar to those expressed by health care workers (ie, hear me, protect me, prepare me, support me, and care for me),¹⁹ but under pandemic restrictions their needs may go unmet.⁶⁶ As dedicated health care workers, we share the common value of human connection at the end of life and recognize the need to involve

Table 3
Stepwise approach to decision-making for hospital visitation

All visitors	<ul style="list-style-type: none"> • Encourage technology for virtual visiting and request caregivers to shelter in place • Screen and limit entry of visitors with greeter (reception) desk, with preference given to legal substitute decision maker/medical power of attorney • No symptomatic visitors allowed • All visitors permitted are masked as potential asymptomatic carriers and provided education about hand hygiene and PPE use 			
Level based on surge state and prevalence	Level 1	Level 2	Level 3	Level 4
Surge state	Conventional: pending surge	Contingency: mild surge	Contingency: moderate surge	Crisis: major surge
Prevalence	<i>Low</i> prevalence in organization and/or community	<i>Moderate to high</i> prevalence in organization and/or community	<i>Moderate to high</i> prevalence in organization and/or community	<i>Very high</i> prevalence in organization and/or community
Patient populations: COVID not suspected or PCR-negative	<ul style="list-style-type: none"> • Physical distancing required—strategic positioning of visitor chairs in the patient’s room • Preference given to visitor(s) who can act as self-sufficient caregiver • Consider context of individual patient^a and organizational capacity within the current level; reassess when circumstances change 			
	Limit number for daily in-room visitor(s)	Limit number and amount of visitation time for daily in-room visitor(s)	Limit number (eg, <2), time, and permitted reasons ^b for daily in-room visitor(s)	Limit number (eg, 1), time, and permitted reasons ^b for in-room visitor per stay
Patient populations: persons under investigation or PCR-positive	<ul style="list-style-type: none"> • Physical distancing required: 1.8-m/6-foot perimeter marked around patient’s bed • Preference given to visitor(s) who can act as self-sufficient caregiver(s) • Must don droplet precaution PPE (eg, mask, face shield, gloves, and gown) • No visitation permitted during high-risk procedures • Consider context of individual patient^a and organizational capacity within the current level; reassess when circumstances change 			
	Limit number for daily in-room visitor(s), with HCW support companion to arrange time of visits, review risks, and help with donning and doffing PPE	Limit visitation time and only 1 in-room visitor daily for permitted reasons, ^b with HCW support companion to arrange time-limited visits (aimed to say good-bye), review risks, and help with donning and doffing PPE	Limit visitation time, only 1 in-room visitor daily, and limited number of visitors per stay, for permitted reasons ^b If possible, use HCW support companion to arrange 1 time-limited visit aimed to say good-bye, review risks, and help with donning and doffing PPE	Rare in-room visitors; virtual visit using technology or through glass Consider end-of-life unit
Scarce resources allocation	Resources such as PPE available; need to be conserved	Resources such as PPE limited; need to be reused and conserved	Resources such as PPE scarce; need to be reused/adapted and conserved Visitors may be asked to bring their own PPE	Resources such as PPE critically scarce; must be strategically allocated Visitors asked to bring their own PPE

Abbreviations: HCW, health care worker; PCR, polymerase chain reaction; PPE, personal protective equipment.

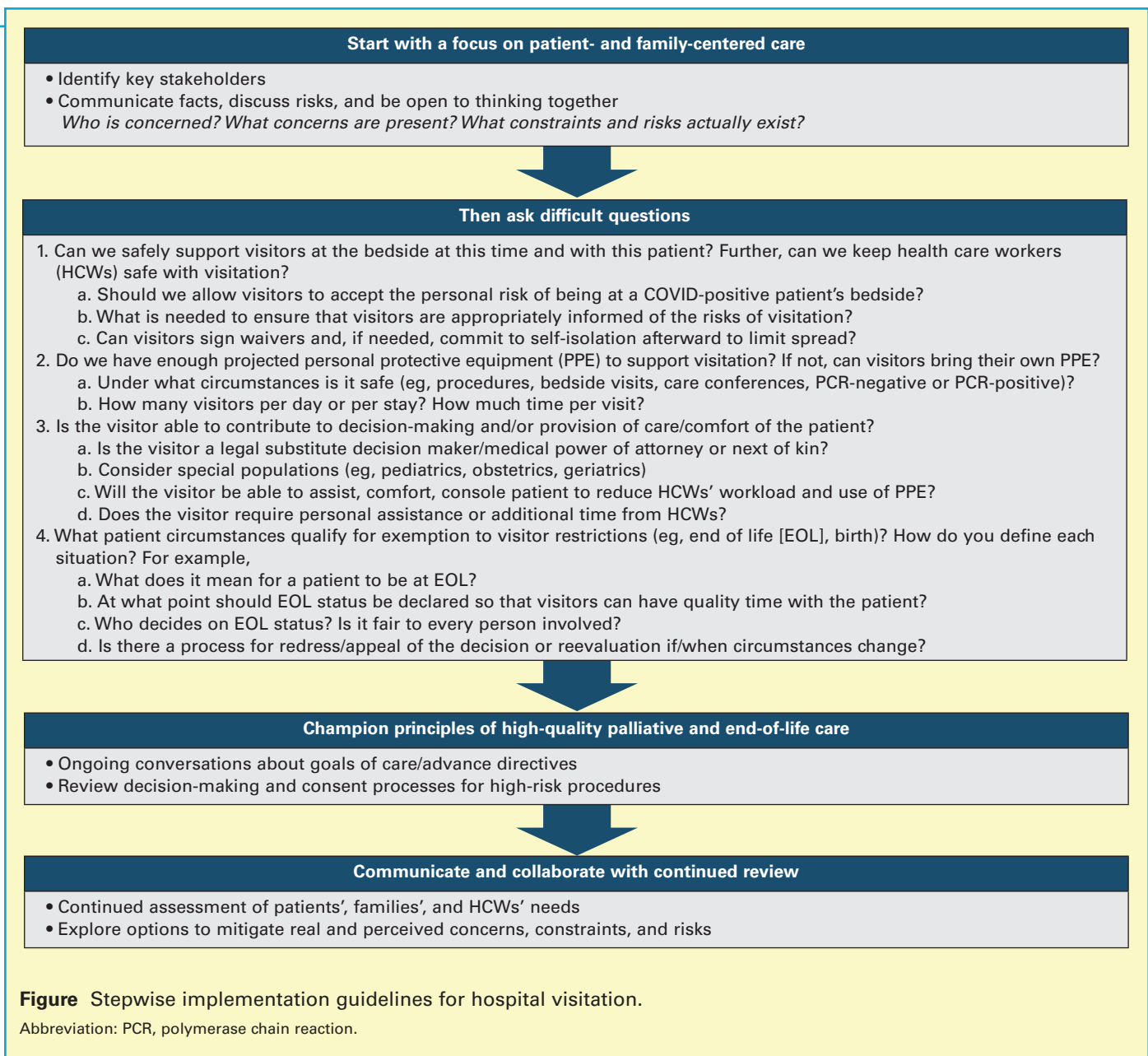
^a Examples of special patient population considerations: pediatrics, consider allowance for both parents, especially for infants/young children and those with developmental delays and autism spectrum disorder; obstetrics, consider allowance for 1 partner/support person, especially for high-risk perinatal circumstances that may require decision-making; geriatrics, consider allowance for 1 visitor especially for assisting with feeding, emotional support, mobilization, and/or facilitating communication.

^b Goals-of-care conversations, end-of-life circumstances, discontinuation of life-sustaining treatments, and so on.

family whenever possible as a baseline ethical obligation. Some hospitals have enlisted volunteers to accompany dying patients as an innovative approach.⁶⁷ It is clear that the strong ethical obligation to be

present with dying patients has been directly challenged during this pandemic.^{68,69}

Traditionally, we define a “good death” as one that is relatively free of unnecessary suffering for all



involved and consistent with patient wishes and goals (eg, clinical, ethical, cultural, spiritual).^{60,70,71} According to Schaepe and Ewers,⁷² having family at the bedside facilitates the sharing of information about the patient that is grounded in their intimate knowledge of the patient's needs and preferences. The presence of family at the end of life may require several visits, as the timing of a person's death remains difficult to predict. Thompson et al⁷³ reported that at the end of life, families usually engage in a range of rituals to comfort the dying patient and to start their own grieving process. Evidence from palliative care research shows that holding a dying loved one's hand, stroking their arm, or playing with their hair are all typical gestures.⁷⁴ These simple acts let the patient know

that they are valued and loved. Often, dying patients and their loved ones reconcile past wrongs, impart words of wisdom, and share last wishes.⁷³ Research indicates that when they cannot be at the bedside during the dying process, families often experience excessive feelings of guilt and failure, as death is a rite of passage that is important to witness in many cultures.⁷¹ Some authors have argued that witnessing patients dying alone brings taxing emotions to health care workers. Many who see this as inhumane take it upon themselves to fill the void.^{7,19} End-of-life care is the most often cited source of moral distress in nonpandemic situations, and health care workers' witnessing patients dying alone is a major contributor to moral distress experiences.^{1,69}

“ Visitors are ultimately part of the care team and an essential and irreplaceable aspect of a hospital’s pandemic triage algorithm. ”

During the SARS outbreak in 2003, measures were put in place to mitigate the psychosocial impact on health care workers.⁷⁵ Studies identified frequent and proper communication,^{58,69} without being unduly reassuring, as very helpful.^{57,76} Hospital-level leadership, infection prevention and control services, and other supervising bodies need to be transparent and flexible, acknowledge shared uncertainty, and provide clear evidence-based plans that will bolster health care workers’ trust, confidence, and sense of self-efficacy.⁷⁷ This information includes direction about hospital protocols, policies, and processes. It is very important for health care workers⁷⁸ and the public to know that proper protection from the virus is a priority, hence the limits to free visitation.⁵

Circumstances in which health care workers are unable to do their jobs effectively owing to limited resources are the second most cited source of moral distress among health care workers.^{79,80} During this pandemic, health care workers have “gone to war without ammunition”; the lack of proper PPE has sparked copious complaints and is one reason health care workers have approached the media to express their frustration.^{5,81} Another fundamental resource lacking for patients dying alone is proper palliative care (eg, health care worker training, availability of chaplains and social workers, medications to alleviate or manage symptoms).^{7,69,73} These circumstances have also been noted as triggers for moral distress among health care workers.²⁰

From an ethics perspective, all health care workers carry an obligation to explore the difficult questions surrounding end-of-life care, to implement a workable responsive approach, and, subsequently, to communicate it effectively. Whether an institution can support visitors at the bedside during the peak of a pandemic is ultimately specific to that institution. Explicit and transparent processes help health care workers, patients, and families understand the rationale for the choices made, even if they do not agree with them. Also, each plan must contain triggers to reevaluate previous guidelines, should conditions change.

Finally, visitors are ultimately part of the care team and an essential and irreplaceable aspect of a hospital’s pandemic triage algorithm. They are not

an unnecessary risk to safety. The costs of unfairly and unilaterally restricting visitation are simply too high. Again, the implementation of crisis standards of care should not change our obligation to maintain compassion. Turning to algorithms and crisis protocols that lack sensitivity to humanity and create emotional dissonance among frontline health care workers is neither safe nor ethically supportable. Such circumstances often lead to the need for work-arounds and place stakeholders in a position of moral hazard and at high risk for moral distress and moral injury.^{26,82} With the stepwise protocols for decision-making and implementation offered here, we hope to start conversations to discover new and feasible alternatives to a one-size-fits-all policy.

Conclusion

The pandemic resulted in broadly restrictive and often unfair protocols, largely owing to misinformation, trial and error, and crisis demands on resource conservation. Policies and procedures were devised with the best intentions at the time. However, we recommend that a robust evidence-based protocol for visitation, guided by ethical principles, be immediately incorporated into hospitals’ contingency plans.

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CE 1.0 Hour Category B

Notice to CE enrollees:

This article has been designated for CE contact hour(s). The evaluation demonstrates your knowledge of the following objectives:

1. Analyze the harms that restricted visitation during a pandemic brings to patients, their loved ones, and staff.
2. Identify and explore the practices and processes aimed to maintain safety with visitation.
3. Describe steps to fairly approach visitation restrictions to preserve staff's moral integrity and restore patient- and family-focused care.

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