

COVID-19 Caregiver Restrictions in Pediatrics

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Since the emergence of severe acute respiratory syndrome coronavirus 2, more than a million people have died worldwide. In the United States, hundreds of thousands of people have died of coronavirus disease (COVID-19)–related causes, and morbidity and mortality rates continue to climb as new epicenters develop across the nation.

At the start of the pandemic, health care systems urgently implemented policies to mitigate COVID-19 exposure risks to patients and staff. Caregiver restriction policies represented a key strategy for hospitals and clinics to limit exposure risks and conserve personal protective equipment.

Over the past year, policies that restrict or limit caregivers have impacted patients, families, and clinicians profoundly. Critically ill patients remain isolated from family members; many have died without the presence and support of loved ones. The grief and moral distress inherent to caregiver restriction policies are widely acknowledged; however, the psychosocial burden of suffering has largely been considered a necessary, if unintended, corollary of pandemic safety protocols.

As a pediatric oncologist and palliative care physician, I have seen caregiver restrictions impact patients and families across each stage of the illness trajectory: from diagnosis to disease progression, clinical deterioration, and end of life. Parents struggle to decide which caregiver stays with, and which separates from, a critically ill child who may not survive the hospitalization. Lone parents receive news that their child will die while their partner watches through a screen, unable to comfort one another. A mother cries every day, fearing that her infant will die without having a chance to know her father. A father misses the death of his child while awaiting his turn to be at the bedside. Already unbearable clinical situations become untenable.

Presently, we lack evidence to know if stringent caregiver restriction policies have decreased COVID-19 spread within health care systems. Several major pediatric health care systems in cities with high COVID-19 prevalence rates consistently permitted 2 caregivers at the bedside, with no reported outbreaks within their systems. Pragmatically, we cannot conclusively prove nor disprove the efficacy of strict caregiver restrictions in pediatric hospitals on the basis of anecdotal reports. In the coming months and years, however, we will have opportunities to evaluate whether choices made under conditions of profound uncertainty were justified. I hypothesize that forthcoming cost/benefit analyses that balance the perspectives of patients, families, and frontline clinicians against evidence of nosocomial COVID-19 spread within hospitals will suggest that the intended risk mitigation benefits did not outweigh the harms incurred by caregiver restrictions.

In the interim, we continue to face a spreading pandemic with no visible end point, and ongoing opportunities exist for pediatric health care organizations to explore alternatives to caregiver restrictions in the care of children with

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acute and chronic illnesses. In recent months, many pediatric hospitals have begun to revise and liberalize caregiver restrictions; however, many institutions continue to restrict parents and other caregivers from the bedside of critically ill children. As pandemic epicenters unfold, we must strive to protect patients, families, and health care workers; and at the same time, as pediatric clinicians, we have a moral imperative to align existing safety policies with the intrinsic mission of our field.

Rethinking caregiver visitation policies begins with a simple premise: that parents (or other primary caregivers) are essential for pediatric health care provision. Primary caregivers are the child's preeminent advocate; they know the child's medical history, warning signs, and needs better than any medical professional. As with essential medical personnel, hospital systems can and should undertake strategies (eg, symptom screening, universal masking, social distancing, use of protective personal equipment as needed) to decrease exposure risks while prioritizing the presence of essential caregivers.

In pediatrics, the wellbeing of the family unit is paramount. Pediatric clinicians are trained to optimize the physical and psychosocial health of the whole family unit, recognizing that the wellness of the caregiver often is closely related to the patient's wellness. We know that parents are at high risk for experiencing physical and psychological health problems in the setting of a child's progressive illness, even in optimal scenarios with unrestricted access to the bedside.¹ Policies that preclude families from supporting medically ill children during times of stress place caregivers at increased risk for significant and sustained negative psychosocial sequelae.^{2,3} Comparatively, caregivers who are allowed to support ill and dying patients at the bedside experience physiologic and psychosocial benefits.⁴

For these reasons and others, caregiver visitation policies that restrict parents from the bedside of an ill child pose moral and ethical challenges for frontline pediatric

clinicians.^{2,5} In recent months, increasing distress related to visitation policies has been reported by pediatric clinicians.^{2,3} Across centers, pediatric clinicians have been tasked with implementing caregiver restriction policies that they did not participate in developing and may not understand or endorse. When assessing policies, institutional leadership should partner with frontline medical and psychosocial clinicians, as well as patient and family representatives, to give voice to key stakeholders in exploring alternatives to strict restrictions.³ Potential action items for rethinking COVID-19 caregiver restrictions are summarized in Table 1.

Policies that permit exceptions to be granted on a case-by-case basis can help to balance quality care provision with safety precautions. However, one also must recognize that this process is frequently compromised by difficulties in predicting the timing of clinical deterioration. When >1 caregiver is not permitted at the bedside of a critically ill child, an absent parent risks losing the chance to create

memories, say goodbye, and provide comfort to a child at the time of death. The stakes are high, and there are no do-overs.

Additionally, as our country grapples with intersecting pandemics of COVID-19 and systemic social injustice, it is important to reflect on the ways that caregiver restrictions may disproportionately harm families with underrepresented minority backgrounds or lower socioeconomic statuses. Universal application of policies across all caregivers yields equal, but not necessarily equitable, care. A single mother with a hospitalized child and an infant at home, who lacks family support or the financial means to afford child care for the sibling, struggles with policies that restrict siblings from campus. Caregiver restrictions may inadvertently contribute to mistrust in the health care system and compound stress for families without the financial means to navigate these separations. Further research is needed to explore the unintended consequences of caregiver restriction policies on specific populations of patients and families.

TABLE 1 Key Principles and Action Items for Rethinking COVID-19 Caregiver Restrictions

Key Principles	Action Items
Parents (and other primary caregivers) play an essential role in the care of an ill child.	Instead of framing policies around "if" or "when" caregivers should be allowed to visit, refocus conversations around "how" caregivers can safely visit.
Prognostic uncertainty leads to challenges in predicting if or when a patient may clinically deteriorate or die.	Create standardized operating procedures that liberalize visitation for the family of patients with critical illness, worsening clinical trajectories, or those approaching end of life. Develop systems that empower frontline clinicians to make real-time modifications to restrictions during extenuating circumstances.
Frontline health care professionals experience moral distress when tasked with implementing policies that they did not develop.	Provide frequent and transparent communication to clinical staff about visitation policies. Proactively involve frontline health care workers in policy decision-making and implementation processes. Create forums and avenues that empower clinicians and staff to share their expertise and challenge existing policies as the pandemic evolves.
Caregiver restriction policies, when universally applied, may not be equitable for socioeconomically disadvantaged families, disproportionately affecting underrepresented minority families.	Build pathways for leadership to engage in bidirectional dialogue with underrepresented minority families; empower families to share their perspectives and recommendations with policy decision-makers. Systematically examine unintended impacts of caregiver restriction policies on socioeconomically disadvantaged families, with transparent disclosure of findings and discussion of proposed solutions.

Mitigating COVID-19 risk is a priority and responsibility that all clinicians share, and this obligation includes the implementation of strategies to guide safe visitation. In pediatrics, policies precluding the physical presence of primary caregivers at the bedside should be avoided whenever possible. Fortunately, ethical frameworks exist to balance pandemic safety precautions with provision of holistic, optimal care.⁵ Existing precedent from pediatric centers that allow 2 or more caregivers at the bedside offers a roadmap for health care administrators and clinicians charged with keeping patients, families, and health

care professionals safe during an ongoing pandemic.

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