Ethical Guidance on Family Caregiving, Support, and Visitation in Hospitals and Residential Health Care Facilities, Including During Public Health Emergencies: an American College of Physicians Position Paper

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ABSTRACT

Public health emergencies create challenges for the accommodation of visitors to hospitals and other care facilities. To mitigate the spread of COVID-19 early in the pandemic, health care institutions implemented severe visitor restrictions, many remaining in place more than 2 years, producing serious unintended harms. Visitor restrictions have been associated with social isolation and loneliness, worse physical and mental health outcomes, impaired or delayed decision-making, and dying alone. Patients with disabilities, communication challenges, and cognitive or psychiatric impairments are particularly vulnerable without caregiver pres-

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INTRODUCTION

Clinicians recognize the importance of patient relationships with, and caregiving by, family in hospitals, nursing homes, and long-term care (LTC) settings.[2,3] Although institutional visitor policies had become more flexible in response to

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While visitor restrictions aimed to achieve the critical societal goal of protecting public health, this aim was often allowed to override considerations of individual patient welfare and clinicians' ethical duties to patients, calling into question whether the appropriate balance of community versus individual interests was being struck. Meanwhile, evidence demonstrating that visitor restrictions were necessary to reduce nosocomial SARS-CoV-2 transmission was lacking.

This paper reviews the impact of visitor restrictions on hospitalized patients and LTC residents during the pandemic as a lens for considering more general ethical guidance regarding visitation and support. Given the significant harms caused by limiting family caregiver support, particularly for vulnerable patients, the American College of Physicians (ACP) maintains that visitor policies should be guided by ethics, evidence, and a strong presumption in favor of preserving opportunities for caregiver support/visitation, including during public health emergencies.

The terms family caregiver and loved ones are used interchangeably to denote anyone, defined by the patient, who provides "support and with whom the patient has a significant relationship."[9] Not all loved ones/caregivers are family members, nor does all caregiving and support involve medical needs. The terms LTC facilities and nursing homes are also used interchangeably, as are patient and resident. The concerns raised about nursing homes extend to other residential care facilities, e.g., long-term acute care, subacute rehabilitation, acute rehabilitation, and psychiatric facilities. Similar issues are raised by visitor restrictions in outpatient settings but are beyond this paper's scope.

METHODS

This paper was developed on behalf of the ACP Ethics, Professionalism and Human Rights Committee (EPHRC). Committee members abide by the ACP's conflict-of-interest policy and procedures; appointment to and procedures of the EPHRC are governed by the ACP bylaws. Following environmental assessment to determine the scope of issues and literature reviews, the EPHRC evaluated and discussed drafts of the paper; it was reviewed by the ACP Board of Governors, Board of Regents, Council of Early Career Physicians, Council of Resident/Fellow Members, Council of Student Members, and other committees and experts; and the paper was revised to incorporate comments from these groups and individuals. The ACP Board of Regents approved the paper on 23 July 2022.

OVERVIEW OF HOSPITAL AND NURSING HOME COVID-19 VISITOR RESTRICTIONS

In the US, hospitals take guidance from multiple entities, including the Centers for Disease Control (CDC), Centers for Medicare and Medicaid Services (CMS), American Hospital Association, Joint Commission, and state and local health boards. Hospitals have more discretion than nursing homes to revise visitation policies. During COVID-19, hospital policies have been variable but generally restrictive over long time periods, although some provided limited exceptions for end-of-life care, pediatrics, labor and delivery, and disabled individuals.[6,7] Hospitals and clinics sometimes eased visitor restrictions before LTC facilities, but many still enforce policies drastically limiting in-person caregivers, undermining patient- and family-centered care.

Nursing homes are largely regulated by CMS and subjected to oversight by state agencies and, sometimes, local health departments. They generally lack discretion to revise visitor restrictions. On March 13, 2020, CMS recommended immediately restricting all visitors, volunteers, and nonessential health care personnel, with limited exceptions for so-called compassionate care visits for actively dying patients.[10] CMS recognized that preventing visitors should be temporary. In May 2020, CMS issued phased-reopening recommendations for nursing homes,[11] but requirements were so strict most LTC facilities could not satisfy criteria for allowing visitors. Six months after the initial lockdown, CMS issued guidance recognizing that isolation imposes a physical, emotional, and mental health toll on LTC residents. New policies permitted visitors in facilities with no outbreaks, if community case numbers remained low.[12] These requirements remained difficult to achieve, which meant ongoing visitor restrictions for many nursing homes.

One year after CMS restricted visitor access to nursing homes, on March 10, 2021, CMS advised facilities to "allow indoor visitation at all times and for all residents (regardless of vaccination status)," except when residents had COVID-19 infections, were under quarantine, or if county positivity rate was $> 10\%$ and resident vaccination rate $< 70\%$.[13] The updated guidelines accounted for widespread vaccination against COVID-19. They clarified that compassionate care visits and visits required under federal disability-rights law should be permitted at all times, even during outbreaks. As case numbers swelled worldwide during summer 2021, many locales reinstated visitor restrictions ad hoc and not under CMS guidance.[14]

Not until November 2021, 20 months after the original restrictions, did revised CMS guidance remove nursing home visitor restrictions, stating "residents have the right to receive visitors at all times and make choices about aspects of their life in the facility that are significant to them."[15] However, when the Omicron variant swept across the world in December 2021, CMS offered a caveat: "there may be times when the scope and severity of an outbreak warrants the health department to intervene with the facility's operations."[16] CMS expected such interventions "to be extremely rare and only occur after the facility has been working open visitor policies while recognizing that future public health emergencies might necessitate temporary mitigation strategies.

UNINTENDED HARMS OF VISITOR RESTRICTIONS

Despite the language of visitor restrictions, loved ones and family of patients are not mere "visitors." They provide emotional comfort; support daily activities (e.g., feeding and mobility); meet important psychosocial needs (e.g., re-orientation to surroundings to limit delirium); facilitate communication; enhance continuity of care; advocate to address unmet needs; and assist in medical decision-making, among other roles.[2,3] Although most persons benefit from family involvement in care, those with high reliance on family caregivers are most harmed by visitor restrictions.

Some clinicians in overwhelmed heath care settings—battling staffing shortages and resource limitations—viewed the absence of visitors as reducing their workload. Many others—who regard family caregivers as crucial partners in care, complementing clinicians' efforts to attend to patients' needs and provide support—perceived their absence as harmful to patients and care teams and often advocated for easing visitor restrictions.[3,5,7–9]

The COVID-19 pandemic highlights the vital roles of family caregivers by illustrating harms exacerbated by their absence. Such unintended harms include the following.

Social Isolation and Loneliness Loneliness has dominated the pandemic experience for many, particularly for hospitalized patients and LTC residents prohibited from receiving visitors. Studies worldwide demonstrate social isolation's profound toll on physical and mental health. Social isolation/loneliness have been associated with cognitive and physical decline, anxiety/distress, depression, delirium, and behavioral disturbances among patients and LTC residents.[3,5,17–23] Social isolation increases risk for premature death as much or more than hypertension, obesity, or smoking.[24] Loved ones also suffer.[20,25] A multicenter study of physically distanced family members of critically ill COVID-19 patients highlighted their "profound suffering and psychological illness," including "substantial stress and PTSD in 63% of 330 family members at 3-month follow-up."[25] Families experienced overwhelming guilt, helplessness, decisional conflict due to suboptimal communication, yearning for physical connection, and fear patients would feel abandoned.[25]

Impaired or Delayed Medical Decision-making Beyond restricting vital relationships, comfort, caregiving, and patient advocacy, limiting family presence can affect clinical decision-making for all patients. Even patients with capacity often rely on trusted others to help assist with complex decision-making; those with impaired decision-making capacity must rely on surrogates. Patients lacking surrogates to speak for them, known as unbefriended or unrepresented patients, are particularly vulnerable. Ironically, during COVID-19, patients with willing and able advocates/surrogates were involuntarily "unfriended" or, to coin a word, *disrepresented* by not being able to have surrogates physically present. When denied in-person access, surrogates may not understand the patient's clinical circumstances and acute functional decline. This may delay fully informed medical decisions and prolong hospitalizations.[5]

Dying Alone An indelible tragedy of the pandemic is many people dying alone without loved ones' presence, human touch, or valued end-of-life rituals—typically regarded as a "bad" death and previously unimaginable on this scale.[26] In addition to harms suffered by those dying alone, families experienced poor bereavement, and many HCWs suffered profound emotional and moral distress in accompanying patients un0 -1.25 Td[le adv)ccom gs 8d onTJ gestures.[31,32] Other communication hurdles include limited English proficiency (LEP) and/or poor health literacy. LEP patients are particularly vulnerable to social isolation in unfamiliar health care settings, experiencing poor communication with non-language-concordant clinicians, and suffering worse health outcomes.[33] Family caregivers are inappropriate substitutes for medical interpreters; however, they often provide important emotional support and advocacy and facilitate decision-making.[33]

Patients with Significant Cognitive or Psychiatric Impairments Patients with cognitive deficits (e.g., due to dementia or delirium) rely on others for basic needs, advocacy, and medical decision-making.[5,23] Patients with mental health issues often rely on family caregivers for emotional support and recovery.[34]

Patients Undergoing Surgery or Procedures Post-operative patients denied in-person family caregivers experience medication delays, decreased mobility, social isolation, and inadequate consideration of discharge preferences/needs.[35]

Residents of Long-term Care Facilities LTC residents have borne the brunt of prolonged COVID-19 visitor restrictions. They spent more than 2 years in varying degrees of confinement and isolation, suffering separation from family and community support—not only denied visitors (including spouses), but often prohibited from leaving the facility despite regulations requiring they be allowed to leave.[8],[14] Many residents suffered intense loneliness and social isolation; potentially irreversible declines in cognition, function, and physical and mental health; and increased utilization of psychotropic medications and physical restraints.[17,21,22] Non-COVID-19 deaths also dramatically increased among nursing home residents, likely attributable to profound effects of social isolation among residents who often cannot comprehend or remember why their families appear to have abandoned them.[36] Despite alternative attempts to connect (e.g., video chats), many LTC residents suffer from sensory or cognitive impairments, making these interactions confusing and distressing for residents and loved ones.[20,36] Particularly for vulnerable populations, there is no substitute for face-to-face interaction, companionship, touch, and in-person support.

VISITOR RESTICTIONS' ROLE IN REDUCING COVID-19 TRANSMISSON

Visitor restrictions during public health emergencies should balance the aims of reducing disease spread and meeting individual patient needs. Early in the COVID-19 pandemic, before adequate infection prevention and control (IPC) measures could be ensured due to unknown modes of transmission, scarce PPE, and inadequate testing, this balance tipped in favor of preventing infection over patient needs for caregiver presence. Later, available epidemiological evidence supported shifting that balance toward less restrictive visitor policies.

Evidence shows that consistent use of recommended IPC measures prevents nosocomial spread of COVID-19 and other health care–associated respiratory viral infections (HA-RVIs), even when HCWs have high-risk patient exposures (e.g., exposure > 10 min during aerosol-generating procedures).[37] In one study conducted over an 8-month period, unprecedented levels of control over HA-RVIs (including SARS-CoV-2 and 16 common RVIs) were achieved, despite increased testing, using a bundle of IPC measures that intermittently included visitor restrictions. Such infection control was sustained, remaining unchanged as the number of visitors allowed per patient increased.[38]

Another study examining the effects of allowing visitors back into nursing homes found that visitors would not play a significant role in transmitting COVID-19 to residents or HCWs if visitors utilized appropriate IPC measures and were not from communities with a much higher local COVID-19 prevalence than the prevalence in HCWs' communities.[39] These findings acknowledge that HCWs—whether in hospitals or LTC facilities—are at risk for community-acquired infections and are more likely than visitors to spread infection due to prolonged contact with patients/residents and potential for spreading infection from one patient/resident to another during care.[39]

Vaccination further reduces such risks of transmitting/acquiring COVID-19. A post-COVID-vaccine study found that visitor restrictions were ineffective in reducing COVID-19 transmission, whereas vaccination achieved significant reductions in nosocomial COVID-19 infections.[40]

While limited, available evidence indicates that visitor restrictions play a negligible role in protecting patients/residents or HCWs when visitors comply with effective IPC measures (e.g., universal masking) for all in-person interactions,[3,38,39] particularly in contexts of high vaccine uptake.[40] Pragmatically, such evidence should guide efforts to better balance public health interests against the needs of individual patients/families. Any potential (yet unsubstantiated) benefits of visitor restrictions should be weighed against clearly demonstrated harms imposed by visitor restrictions in hospitals and LTC settings: social isolation and loneliness; patient, caregiver, and clinician distress; prolonged hospitalizations and inappropriate care; delayed/impaired decision-making; and patients/residents suffering and dying alone. Ethically, the presumption should be in favor of maintaining family in-person presence, limited only as deemed necessary based on available evidence.

POSITIONS

Position 1: Ethical principles and scientific evidence should guide development of health care facility visitation policies. Policymakers and administrators must consult with relevant stakeholders, including physicians and other health care team members, as part of this process before implementing policy

Under principles of medical ethics, clinicians should benefit and not harm patients, respect patient dignity and autonomy, and promote distributive justice in health care. Physicians have a duty to prioritize the patient's good, basing their counsel "on the interests of the individual patient, regardless of… the medical care delivery setting."[41] Visitation policies necessarily take factors beyond individual patients into consideration. They should do so by incorporating physician ethical responsibilities, including acting on the "the best available evidence in the biomedical literature"[41] and the public health ethical imperative to choose the least restrictive means necessary to achieve a critical community goal. Visitation policies should not undermine physicians' necessary commitment to, and advocacy for, individual patients. Physicians must be able to discharge their patient advocacy duty and be included in the development of visitation policies that directly affect their ability to provide optimal patient care. Community stakeholders representing the interests of patients and families should also be engaged in policy development when feasible.

Position 2: Visitation policies and those who implement them must recognize the value of loved ones/family caregivers to patients and include them as sources of continuity of care and supporters of patient autonomy. Good communication is essential

Family caregivers play crucial roles in the lives of patients, especially those living with vulnerabilities.[2] Physicians must respect and value caregivers as essential partners in patient care. Medical care should remain patient- and family-centered.[2,41,42] This duty always exists in medicine, but clinicians must take additional care to attend to this obligation when patients are isolated from their family/caretakers. Health institutions must ensure that clinicians are sufficiently supported in implementing their duties of care.[41]

Clinicians always have a duty to communicate clearly with patients/residents and their surrogates/caregivers, demonstrating respect for patient dignity and a commitment to beneficence and nonmaleficence; crisis and geographic separation amplify this responsibility. Strong communication respects patients' values and relationships, recognizing that autonomy is "set in a context of community relations."[43]

Physically distanced caregivers experience less mental anguish and decisional conflict when clinicians maintain consistent communication, foster continued connection with their loved ones (e.g., through videoconferencing), and demonstrate compassion.[25] Even palliative care family meetings for physician's responsibility "remains with the health and welfare of individual patients under the physician's care," although community well-being "must also be considered at a systems level including in institutional policies and other guidelines."[46]

Clinicians must be particularly attentive to patients who might need additional support. For patients with disabilities, physicians must ensure that a designated support person can be present, as required by disability-rights law. For vulnerable individuals without legally recognized disabilities, physicians should advocate to allow family caregivers to remain present. Furthermore, clinicians should advocate for expanded compassionate care visits, not limited to the dying, for those patients/residents needing family presence.

With these duties in mind, doctors must remain vigilant to prevent potential injustices that may arise from variable assessments of patients' needs for caregiver support. There must be an accessible, fair, and transparent appeals process for family caregivers to advocate for exemptions from visitation restrictions when needed.[3]

CONCLUSION

Visitation policies should recognize the important role of family caregivers in supporting and caring for patients and LTC residents. The COVID-19 pandemic provides a useful lens for examining visitor restrictions, illustrating the challenges a public health emergency can pose. Although intended to mitigate spread of illness and death, visitor restrictions resulted in unintended harms, especially for vulnerable populations.

Can lessons learned, supporting a strong presumption in favor of maintaining in-person family caregiver visitation whenever feasible, lead to more balanced visitor policies, including during public health emergencies? Policymakers must continually reassess the burdens and benefits of visitation policies and change course when available medical-scientific evidence shows that policies are overly burdensome for benefit produced.

Physicians must safeguard the dignity, values, welfare, and rights of their patients; help support and clearly communicate with family caregivers; and advocate for the best possible care. Always—particularly during public health emergencies—physicians and policymakers must focus on the needs of individual patients, especially the most vulnerable.

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REFERENCES