Healthcare Excellence Canada
Excellence en santé Canada

# Essential Together Evidence Brief Addendum

July 2023

## About Healthcare Excellence Canada

Healthcare Excellence Canada (HEC) works with partners to spread innovation, build capability, and catalyze policy change so that everyone in Canada has safe and high-quality healthcare. Through collaborations with patients, essential care partners and people working in healthcare, we turn proven innovations into lasting improvements in all dimensions of healthcare excellence.

HEC focuses on improving care of older adults, bringing care closer to home, and supporting pandemic recovery and resilience – with quality and safety embedded across all our efforts. We are committed to fostering inclusive, culturally safe, and equitable care through engagement with different groups, including patients and essential care partners, First Nations, Métis and Inuit, healthcare workers and more.

Launched in 2021, HEC brings together the Canadian Patient Safety Institute and Canadian Foundation for Healthcare Improvement. We are an independent, not-for-profit organization funded primarily by Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

150 Kent Street, Suite 200
Ottawa, Ontario, K1P 0E4, Canada
1-866-421-6933 | info@hec-esc.ca

## Social Media

Twitter | LinkedIn | Instagram | Facebook

Healthcare Excellence Canada honours the traditional territories upon which our staff and partners live, work and play. We recognize that the stewardship of the original inhabitants of these territories provides for the standard of living that we enjoy today. Learn more

# Contents

This evidence brief consists of publications since our last Evidence Brief, ranging from August 2021 through the first half of 2023. The initial evidence brief and subsequent addendum in 2021 provided a synopsis of the history and context of patient-family centered care, family presence policies, and related evidence to support these patient and family centred care (PFCC) practices and related HEC programming, and early emerging evidence as the COVID-19 pandemic was unfolding. This evidence brief continues to build on past Evidence Briefs with updated evidence on:

1. benefits of essential care partner presence
2. transmission of COVID-19 within healthcare settings
3. impacts of restrictive policies
4. potential role of technology

The evidence presented in this review continues to support earlier evidence noted in previous briefs. It adds further support not only for the benefits of essential care partner (ECP) presence and harms to restrictions, but also notes that ECPs are not significant vectors of transmission when appropriately trained with infection prevention and control (IPAC) procedures and personal protective equipment (PPE). This evidence review also points to technological innovations that emerged through COVID-19 in response to the restrictions.

## Benefits of essential care partner presence

Essential care partners fulfill crucial roles, including how they are able to provide emotional comfort, support daily activities, prevent delirium, and participate in medical decision-making, among other important responsibilities. [1,2] There is compelling evidence that the presence and engagement of patients in their care, and partnership with essential care partners have a positive impact on patient experience, safety, and health outcomes. [3,4] The benefits include cost savings, improved satisfaction with care for both patients and their families, enhanced management of chronic and acute illnesses, improved continuity of care, and a reduction in hospital readmissions.[3,4]

Recent research has continued to demonstrate that “visitor” policies that differentiate between the role of visitor and essential care partner, and accommodate the presence of essential care partners, have a positive impact to enhance communication and foster trust between families and care providers.[5] Moreover, these policies improve the accuracy and quality of information exchange related to diagnoses, care transitions, and discharge instructions, particularly in cases where patients and healthcare workers have language barriers.[5] Family members play a crucial role in communicating the need for escalated care and making shared decisions when a patient is unable to do so, often serving as patient advocates.[2,6-8] A recent study conducted by

Healthcare Excellence Canada and IMAGINE Citizen Network highlighted the importance of essential care partner support in advocacy and communication for patients, caregivers, and healthcare providers.[3] This support was particularly crucial for individuals such as children and youth with complex health issues, those facing severe illnesses, the elderly, patients with complex medical histories, and those who had experienced healthcare trauma in the past.[3]

Essential care partner presence was also found to motivate patients to continue necessary care, build trust in the care team, and ease acceptance of bad news, despite limited interactions due to PPE and time constraints. [7,9] During the pandemic, many patients, caregivers and healthcare providers advocated for easing visitor restrictions, recognizing family caregivers as essential partners in care. In recent studies involving healthcare staff in hospital settings, results have shown that the majority of staff believe essential care partners should be present to improve communication, help to save time for staff who are supporting communication, improve decision making, and prevent increased length of stay that resulted from restrictions. [10-12] From an equity perspective, these findings were noted to disproportionately impact older adults, individuals who do not speak English, and those with dementia, cognitive or physical impairments. [11, 13-15] These patient populations face barriers to quality care, including coordination and access issues, as well as understanding treatment-related information. [17,18] They often require caregiver support during hospitalization to overcome these challenges.[13–16,19,20] Family visitation was recently identified as one of only two modifiable risk factors related to delirium and leads to a decrease in delirium cases in the ICU by an observational study. [22] Reducing delirium incidents, which are common among acute and critically ill patients with COVID-19, has been widely cited as one of the key benefits in supporting the presence of family members. [3,23]

An unrestricted visiting policy is also important for optimizing end-of-life and grief experiences for patients, families, and providers.[22] The act of not allowing loved ones to be close during someone's final moments is unprecedented in most cultures and customs.[7,24] The physical presence of family members is particularly significant in protecting against "complicated grief," and reduces the risk of developing lingering psychological issues in loved ones of the patient. [7] Many healthcare providers also noted moral distress at having to enforce restrictive policies and are further discussed in section 3 below.

## Transmission of COVID-19 within healthcare institutions

Strict hospital visitor policies aimed to achieve three objectives: (1) preventing COVID-19 transmission from the community to healthcare settings to protect healthcare workers and patients; (2) preventing transmission from healthcare settings to the community to safeguard visitors; and (3) preserving personal protective equipment (PPE) due to supply concerns. While these visitor restrictions served the crucial goal of protecting public health, evidence supporting

the necessity of visitor restrictions to reduce nosocomial SARS-CoV-2 transmission seems to be lacking. [1] Existing research indicates that family/essential caregivers do not significantly contribute to the transmission of SARS-CoV-2. By providing appropriate access and training in infection prevention and control (IPAC), the safe inclusion of family/essential caregivers becomes feasible. Additionally, vaccination against SARS-CoV-2 provides family/essential caregivers with added protection and reduces their risk, especially when combined with ongoing IPAC measures.

Studies during the first wave of the pandemic showed that the risk of COVID-19 transmission from family/essential caregivers was low. A recent study of 9149 patients admitted to hospital in the United States from Mar. 7 to May 30, 2020 in the United States, found only 1.7% of patients had hospital-acquired COVID-19, and most were likely community-acquired cases identified late. Only one case was attributed to transmission from a presymptomatic visitor before restrictions were implemented. A study tracking nosocomial-associated respiratory viral infections from June to August 2020 in Singapore found no significant difference in infections when allowing one or two family/essential caregivers, with proper infection prevention measures in place. [2,5,25–27] Research further supports that following recommended infection prevention and control (IPC) measures can effectively prevent the nosocomial spread of COVID-19 and other health care-associated respiratory viral infections (HA-RVIs). During an 8-month study, the implementation of a bundle of IPC measures, including intermittent visitor restrictions, led to sustained infection control even as the number of visitors allowed per patient increased. [1]

A study published in 2021 using simulation models and observed data in Scotland, found that visitors would not significantly contribute to COVID-19 transmission in nursing homes if they followed IPC measures and came from communities with similar or lower COVID-19 prevalence than the care home's community. Moreover, visitors have limited interactions with a small number of staff and residents, making them less likely to cause transmissions. Stopping visits might not be very effective unless staff and their close contacts outside the care home are also shielded from the community, which is unlikely. [28] In a study following 2,884 health personnel in a pediatric hospital from April 2020 to November 2020, authors were able to demonstrate that allowing parents/caregivers to visit using a standardized visiting protocol, did not increase the rate of infections in health personnel and did not have a significant impact in spreading the infection to the children’s families. During the second period of the study, there was even a decrease in the percentage of COVID cases among health personnel. The authors proposed that parents/caregivers assisting with patient care might have undertaken certain procedures involving higher exposure, potentially reducing the infection risk for health personnel.[29–31] Additionally, as most children had underlying medical conditions, their parents/caregivers likely practiced more cautious handwashing and hygiene compared to others. These parents/caregivers were also trained in hand hygiene protocols to enter as visitors.[29]

## Impacts of restrictive family presence policies during COVID-19

Reports have widely documented patients' distress and trauma caused by the absence of family members during the pandemic. In one study, healthcare providers interviewed reported that patients were “wailing’ and being ‘visibly sad’ due to restrictions imposed on loved ones. [33] Patients who experienced visitation restrictions faced delays in care responses, medication management errors, more incidences of falls and sepsis, less understanding of their medical status, and increased anxiety due to hospitalization and separation from their families. For instance, in a 2021 study involving 315 caregivers/children, not having a caregiver presence was associated with higher rates of 7-day readmission, increased odds of receiving opiates for moderate to severe pain scores, and increased likelihood of experiencing an adverse event. [34] Anecdotally, physicians reported that when visitor restrictions are in place, patients avoid hospital stays and, if admitted, often request early discharge, leading to readmissions. Numerous examples were offered by providers where patients delayed or skipped medical care to avoid hospitalization.[11]

Visitation restrictions inevitably had adverse effects on families, leading to reduced involvement in care, delays in important care-related discussions, lower understanding of disease progression, and inadequate preparation for end-of-life decision-making. [32] According to the study by Wentlandt et al., healthcare providers believed that restrictions hindered caregivers' ability to assess patients' clinical status, preventing them from providing important context and information to the healthcare team, leading to struggles in making care decisions. [11] Caregivers participating in a HEC-supported research project about their personal experiences of caring for a loved one in LTC before and during the pandemic wrote “Being locked out and restricted from visiting our loved ones took a toll emotionally and was difficult. Media coverage of LTC homes in crisis only added to worry and concern for our loved ones.” [35] A multicenter study focusing on physically distanced family members of critically ill COVID-19 patients revealed their significant suffering and psychological distress. At the three-month follow-up, 63% of 330 family members reported substantial stress and post-traumatic stress disorder (PTSD). Families faced overwhelming guilt, feelings of helplessness, decisional conflicts arising from inadequate communication, a strong longing for physical connection, and fears that their loved ones would feel abandoned. [1,36]

Healthcare providers enforcing no-visitation policies also reported symptoms of PTSD, burnout, and intention to leave their jobs. Restricted visitation rules also contributed to an increase in violence directed at hospital workers during the pandemic. Providers voiced frustration at the physical separation rules imposed on patients and families. One provider stated to researchers

that there were: “Ridiculous rules with visitation and not letting families come because they may unknowingly transmit the virus. But it didn't make sense. Especially if you're telling me if I have all the right PPE, I can go assess the patient. Why can't a family member, if they're provided with the right PPE, why can't they even go in and say, goodbye?.”[33]

Restricted visitation policies beyond the initial COVID-19 crisis response suggests that decision makers may not have fully considered the risks of restricted visitation to patients, families, and staff in comparison to the risk of COVID-19 transmission.[32]

## Potential role for technology

An HEC-supported paper by Gallant et al., [37] highlighted suggestions about how technological and virtual innovations hold great potential for enhancing essential care partner presence in LTC homes. This is in line with other evidence, which supports that virtual visits can reduce anxiety in caregivers [21]

The experience of visitor restrictions during COVID-19 and the clear need for essential care partner presence has led to the development of innovations to support alternative ways of visiting. One study describes the development of local ‘environment’ films. Pre-recorded films describing the ICU environment, alongside noises and equipment, were available for families to view, allowing contextualization and visualization of how care was being delivered. [38] Another innovation, “Family Glass Cabin” (FGC) offers a safe solution to overcome social distance and allows direct contact between individuals with ABI (Acquired Brain Injury) and their caregivers. The FGC has shown positive effects in stimulating functional recovery in patients and reducing anxiety and burden in caregivers. Initial data suggest that having a caregiver physically present (mediated by the FGC) enhances communication and interpersonal abilities, leading to improved cognitive and sensory-motor outcomes for patients with ABI. Moreover, the FGC provides an emotional and social experience not only for patients but also for caregivers, promoting their psychological well-being. By the end of the experiment, caregivers experienced a significant reduction in emotional burden and anxiety symptoms. [39] Another innovation, “Inpatient Video Navigator" gives providers the ability to get help from navigators to educate families and patients on setting up telehealth meetings with clinicians and social video visits during the patient's hospital stay.  The program also provides tablets for patients to access media content in their native language and can enhance engagement with online newspapers, entertainment, and TV stations featuring current events. The study noted that nevertheless, hospitals must exercise caution to ensure that these interventions do not replace medical interpretation services, and that virtual presence of loved ones should not be relied upon as ad hoc interpreters.[40]

In circumstances where the physical presence of family cannot be achieved, technology can serve as a tool to help overcome isolation and loneliness. However, issues of equity and accessibility must be considered when implementing technological innovations.[33] Using technology cannot replace the need for physical presence of essential care partners in many cases, but can assist. Additionally, using technology might feel less personal, so providers will need to develop skills to communicate effectively. [38] Futhermore, not everyone has access to devices required to support virtual visits and tablet programs sponsored by organizations will likely be required to ensure equitable access. [33]

## Endnotes


1. Dugdale LS, Esbensen KL, Sulmasy LS, for the ACP Ethics P and HRC. 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. *J Gen Intern Med*. 2023;38(8):1986-1993. doi:10.1007/s11606-023-08070-1
2. Munshi L, Odutayo A, Evans G, Keresteci M. Impact of Hospital Visitor Restrictions during the COVID-19 Pandemic. Ontario COVID-19 Science Advisory Table. doi:10.47326/ocsat.2021.02.31.1.0
3. Montesanti S, MacKean G, Fitzpatrick KM, Fancott C. Family caregivers as essential partners in care: examining the impacts of restrictive acute care visiting policies during the COVID-19 pandemic in Canada. *BMC Health Serv Res*. 2023;23:320. doi:10.1186/s12913-023-09248-3
4. Canadian Foundation for Healthcare Improvement. MUCH MORE THAN JUST A VISITOR: An Executive Summary of Policies in Canadian Acute Care Hospitals. Published online 2020. https://www.cfhi-fcass.ca/docs/default-source/itr/tools-and-resources/better_together_executive-summary_en.pdf
5. Munshi L, Evans G, Razak F. The case for relaxing no-visitor policies in hospitals during the ongoing COVID-19 pandemic. *CMAJ Can Med Assoc J*. 2021;193(4):E135-E137. doi:10.1503/cmaj.202636
6. Fiest KM, Krewulak KD, Hiploylee C, et al. An environmental scan of visitation policies in Canadian intensive care units during the first wave of the COVID-19 pandemic. *Can J Anaesth*. 2021;68(10):1474-1484. doi:10.1007/s12630-021-02049-4
7. Mistraletti G, Giannini A, Gristina G, et al. Why and how to open intensive care units to family visits during the pandemic. *Crit Care*. 2021;25(1):191. doi:10.1186/s13054-021-03608-3
8. Cuevas E. No Visitors Allowed. *JAMA Neurol*. 2021;78(4):381-382. doi:10.1001/jamaneurol.2021.0050

9. Kotfis K, Williams Roberson S, Wilson JE, Dabrowski W, Pun BT, Ely EW. COVID-19: ICU delirium management during SARS-CoV-2 pandemic. *Crit Care*. 2020;24:176. doi:10.1186/s13054-020-02882-x
10. Gilmour J. 974 Parent/carer presence on medical ward rounds: opinions of parents/carers and healthcare staff in a tertiary paediatric critical care unit. *Arch Dis Child*. 2022;107(Suppl 2):A363-A364. doi:10.1136/archdischild-2022-rcpch.587
11. Wentlandt K, Wolofsky KT, Weiss A, et al. Physician perceptions of restrictive visitor policies during the COVID-19 pandemic: a qualitative study. *CMAJ Open*. 2023;11(1):E110-E117. doi:10.9778/cmajo.20220048
12. Azad TD, Al-Kawaz MN, Turnbull AE, Rivera-Lara L. Coronavirus Disease 2019 Policy Restricting Family Presence May Have Delayed End-of-Life Decisions for Critically Ill Patients. *Crit Care Med*. 2021;49(10):e1037-e1039. doi:10.1097/CCM.0000000000005044
13. Aroos R, Wong BLL, Merchant RA. Delayed health consequences of COVID-19 lockdown in an older adult. *Age Ageing*. 2021;50(3):673-675. doi:10.1093/ageing/afab052
14. Lo AX, Wedel LK, Liu SW, et al. COVID-19 hospital and emergency department visitor policies in the United States: Impact on persons with cognitive or physical impairment or receiving end-of-life care. *J Am Coll Emerg Physicians Open*. 2022;3(1):e12622. doi:10.1002/emp2.12622
15. Brown EE, Kumar S, Rajji TK, Pollock BG, Mulsant BH. Anticipating and Mitigating the Impact of the COVID-19 Pandemic on Alzheimer's Disease and Related Dementias. *Am J Geriatr Psychiatry*. 2020;28(7):712-721. doi:10.1016/j.jagp.2020.04.010
16. Selick A, Durbin J, Casson I, Lee J, Lunsky Y. Barriers and facilitators to improving health care for adults with intellectual and developmental disabilities: what do staff tell us? *Health Promot Chronic Dis Prev Can*. 2018;38(10). doi:10.24095/hpcdp.38.10.01
17. Arora KS, Mauch JT, Gibson KS. Labor and Delivery Visitor Policies During the COVID-19 Pandemic: Balancing Risks and Benefits. *JAMA*. 2020;323(24):2468-2469. doi:10.1001/jama.2020.7563
18. Castelpietra G, Colli C, Tossut D, et al. The impact of Covid-19 pandemic on community-oriented mental health services: The experience of Friuli Venezia Giulia region, Italy. *Health Policy Technol*. 2021;10(1):143-150. doi:10.1016/j.hlpt.2020.12.002
19. Gil R, Arroyo-Anlló EM. Alzheimer's Disease and Face Masks in Times of COVID-19. *J Alzheimers Dis*. 2021;79(1):9-14. doi:10.3233/JAD-201233
20. Schlögl M, A. Jones C. Maintaining Our Humanity Through the Mask: Mindful Communication During COVID-19. *J Am Geriatr Soc*. 2020;68(5):E12-E13. doi:10.1111/jgs.16488

21. Rose L, Cook A, Onwumere J, et al. Psychological distress and morbidity of family members experiencing virtual visiting in intensive care during COVID-19: an observational cohort study. *Intensive Care Med*. 2022;48(9):1156-1164. doi:10.1007/s00134-022-06824-9
22. Wu Y, Wang G, Zhang Z, et al. Efficacy and safety of unrestricted visiting policy for critically ill patients: a meta-analysis. *Crit Care*. 2022;26(1):267. doi:10.1186/s13054-022-04129-3
23. Hart JL, Taylor SP. Family Presence for Critically Ill Patients During a Pandemic. *Chest*. 2021;160(2):549-557. doi:10.1016/j.chest.2021.05.003
24. Wakam GK, Montgomery JR, E BB. Not Dying Alone — Modern Compassionate Care in the Covid-19 Pandemic. *N Engl J Med*. 2020;382(24). doi:10.1056/NEJMp2007781
25. Cattelan J, Castellano S, Merdji H, et al. Psychological effects of remote-only communication among reference persons of ICU patients during COVID-19 pandemic. *J Intensive Care*. 2021;9:5. doi:10.1186/s40560-020-00520-w
26. Wee LE, Conceicao EP, Sim JXY, Aung MK, Venkatachalam I. The impact of visitor restrictions on health care-associated respiratory viral infections during the COVID-19 pandemic: Experience of a tertiary hospital in Singapore. *Am J Infect Control*. 2021;49(1):134-135. doi:10.1016/j.ajic.2020.11.006
27. Norton A, Wilson T, Geller G, Gross MS. Impact of Hospital Visitor Restrictions on Racial Disparities in Obstetrics. *Health Equity*. 2020;4(1):505-508. doi:10.1089/heq.2020.0073
28. Nguyen LKN, Howick S, McLafferty D, et al. Impact of visitation and cohorting policies to shield residents from covid-19 spread in care homes: an agent-based model. *Am J Infect Control*. 2021;49(9):1105-1112. doi:10.1016/j.ajic.2021.07.001
29. De la Rosa-Zamboni D, Adame-Vivanco MJ, Luque-Coqui M, et al. Allowing access to parents/caregivers into COVID-19 hospitalization areas does not increase infections among health personnel in a pediatric hospital. *Front Pediatr*. 2022;10:896083. doi:10.3389/fped.2022.896083
30. Li H, Wang Y, Ji M, et al. Transmission Routes Analysis of SARS-CoV-2: A Systematic Review and Case Report. *Front Cell Dev Biol*. 2020;8:618. doi:10.3389/fcell.2020.00618
31. Kutti-Sridharan G, Vegunta R, Vegunta R, Mohan BP, Rokkam VRP. SARS-CoV2 in Different Body Fluids, Risks of Transmission, and Preventing COVID-19: A Comprehensive Evidence-Based Review. *Int J Prev Med*. 2020;11:97. doi:10.4103/ijpvm.IJPVM_255_20
32. Marmo S, Milner KA. From Open to Closed: COVID-19 Restrictions on Previously Unrestricted Visitation Policies in Adult Intensive Care Units. *Am J Crit Care*. 2023;32(1):31-41. doi:10.4037/ajcc2023365

33. Wasilewski MB, Szigeti Z, Sheppard CL, et al. Infection prevention and control across the continuum of COVID-19 care: A qualitative study of patients', caregivers' and providers' experiences. *Health Expect Int J Public Particip Health Care Health Policy*. 2022;25(5):2431-2439. doi:10.1111/hex.13558
34. Lin K, White MJ, Holliday KM, Parnell LS, Parente VM. Protective and Unequal? Caregiver Presence During Pediatric Hospitalizations. *Hosp Pediatr*. 2022;13(1):e1-e5. doi:10.1542/hpeds.2022-006590
35. Johnston P, Keatings M, and Monk A.. Experiences of Essential Care Partners during the COVID-19 Pandemic. *Healthc Q*. 2022;25(Special Issue). Accessed June 26, 2023. https://www.longwoods.com/content/26979/healthcare-quarterly/experiences-of-essential-care-partners-during-the-covid-19-pandemic
36. Hochendoner SJ, Amass TH, Curtis JR, et al. Voices from the Pandemic: A Qualitative Study of Family Experiences and Suggestions regarding the Care of Critically Ill Patients. *Ann Am Thorac Soc*. 19(4):614-624. doi:10.1513/AnnalsATS.202105-629OC
37. Gallant NL, Hardy MS, Beogo I, et al. Improving Family Presence in Long-Term Care during the COVID-19 Pandemic. *Healthc Q*. 2022;25(Special Issue). Accessed June 26, 2023. https://www.longwoods.com/content/26980/healthcare-quarterly/improving-family-presence-in-long-term-care-during-the-covid-19-pandemic
38. McPeake J, Kentish-Barnes N, Banse E, et al. Clinician perceptions of the impact of ICU family visiting restrictions during the COVID-19 pandemic: an international investigation. *Crit Care*. 2023;27(1):33. doi:10.1186/s13054-023-04318-8
39. De Luca R, Rifici C, Pollicino P, et al. Is the "Family Glass Cabin" Useful to Safely Allow Inpatient–Caregiver Interaction in the COVID-19 Era? A Pilot Study on Severe Acquired Brain Injury. *J Clin Med*. 2022;11(6):1623. doi:10.3390/jcm11061623
40. Kucirek NK, Thomas NJ, Norman JS, et al. Stories from COVID-19 Reveal Hospitalized Patients with Limited English Proficiency Have Always Been Uniquely Prone to Social Isolation. *J Gen Intern Med*. 2021;36(3):786-789. doi:10.1007/s11606-020-06383-z
41. Giannitrapani KF, McCaa MD, Maheta BJ, Raspi IG, Shreve ST, Lorenz KA. Serious illness care quality during COVID-19: Identifying improvement opportunities in narrative reports from a National Bereaved Family Survey. *Palliat Med*. Published online May 17, 2023:02692163231175693. doi:10.1177/02692163231175693