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EVIDENCE BRIEF ADDENDUM: ESSENTIAL CARE PARTNERS EMERGING EVIDENCE

Healthcare Excellence Canada

INTRODUCTION

Essential care partners (often informal family caregivers) are estimated to provide over 66.5 billion dollars' worth of care annually in Canada,[1] yet during the COVID-19 pandemic, early and tight blanket visitor restrictions limited the ability of caregivers to provide supportive care in health and care facilities[1]. These restrictions failed to differentiate between the role of visitors and essential care partners. The initial Evidence Brief[2] dated November 2020, provided a synopsis of growing evidence regarding the presence of essential care partners in four key areas:

- Benefits of family caregiver presence
- Changes in family presence policies in hospitals across Canada
- Transmission of COVID-19 in hospitals and long-term care
- The impact of restrictive visiting policies on patients[2], caregivers, and healthcare providers.

Throughout the COVID-19 pandemic, this body of evidence continues to grow. This 'Evidence Brief Addendum' adds to the initial 'Evidence Brief' by providing an updated synopsis of evidence regarding the presence of essential care partners that has emerged between the fall of 2020 and July 2021. The benefits of essential care partner presence have been well-established. This Addendum focuses on the following three key areas:

- **Caregiver presence policies that have continued to change throughout the COVID-19 pandemic across Canada:** Increased understanding of COVID-19, notable impacts of restrictive policies on patients, and community transmission rates influenced the ongoing changes to provincial and territorial directives related to visitor policies throughout the pandemic. More recent directives indicate that a more balanced approach to enable the physical presence of caregivers. However, implementation of these directives remains inconsistent within provinces, territories and regions, even in times of reducing COVID-19 prevalence and increasing vaccine uptake.
- **Transmission of COVID-19 in hospitals and long-term care:** Numerous studies conducted through the pandemic are consistent with pre-pandemic literature, which demonstrates family presence does not increase rates of COVID-19 transmission when supported and highlights the success of infection and prevention control measures that support safety and limits transmission in health and care settings.
- **Impact of restrictive visiting policies during COVID-19 in hospitals and long-term care:** There is a significant amount of evidence that highlights the multitude of risks to the care, safety, and outcomes of patients, as well as impact on families, health and care providers, and the health system.

1 Health and care organizations refer to any setting where a person receives healthcare or care including hospitals, long term care/nursing homes/advanced care homes, and other congregate care settings.

2 Patient refers to anyone receiving healthcare or care in any setting. This can include patients, clients, healthcare users and those living in congregate care/long-term care/nursing homes/advanced care homes.

Caregiver Presence Policies

The COVID-19 pandemic created major changes throughout the world, including substantial shifts in healthcare policy and practice in Canada. Fear regarding transmission of COVID-19, particularly in the initial stages of the pandemic, resulted in significant changes to visitor policies in many health and care facilities and did not differentiate visitors from essential care partners, prohibiting essential care partners from having access to patients.[3]

Wave one: In an environmental scan conducted in Spring 2020 of publicly available provincial and territorial directives, it was evident that guidance had been led by provincial/ territorial pandemic task forces and command tables. The resultant blanket visitor restrictions failed to distinguish between a visitor and that of a family member and/or caregiver who actively participates and partners in patient care – an essential care partner. The majority of directives were highly restrictive, with a few notable exceptions in paediatrics, birthing mothers, and end-of-life care. Further nuancing of these directives for the most part did not consider medically vulnerable populations (including those with cognitive impairment) and caused significant distress to patients. Media reports throughout wave one highlighted many instances of patients dying alone without support of their loved ones, and the emotional and morale anguish experienced by caregivers and healthcare providers.

Wave two: By the Fall of 2020, there began to be public calls to recognize the multitude of risks because of the restrictive visiting policies and for a more balanced approach to enable the safe re-integration of essential care partners.[4-6] Another environmental scan of publicly available provincial/territorial directives showed a move to allowing some essential care partners to be physically present and noted the importance of including them in infection prevention and control measures.[7-9] However, in most cases, essential care partners were allowed in a very limited capacity (i.e., only for certain patients in specific circumstances), with limited numbers (e.g., 1-2 essential care partners only, with only one allowed to be present at a time, and/ or during limited times during the day). The definition of what was 'essential' was mostly left up to the facilities to define, and in some cases, individual managers on units within facilities, creating inconsistencies in how provincial/territorial policy directives were operationalized.

Wave three: A third environmental scan of directives was conducted in March 2021 and showed many provinces moving to a regional approach. Colours or levels were assigned to areas based on COVID-19 prevalence and essential care partner policies varied depending on the assigned level, considering regional variations of community transmission. In areas with less prevalence, there may be two or more essential care partners allowed, while in areas with higher prevalence, restrictions continued with allowances made for certain patients and circumstances, such as end-of-life. The language has started to shift to differentiate between visitor and essential care partner, and there is recognition of the unintended harm experienced by patients in earlier waves with blanket restrictions. However, inconsistency of application of provincial/ territorial directives has continued, with variation within and across regions.

Where We Are Now: A recent environmental scan of policies was conducted in July 2021 and showed minimal changes to policies in hospitals, where limited numbers of essential care partners are permitted entry. There has been a significant shift in policies allowing both essential care partners and general visitors into long term care facilities. The high rates of vaccination in long-term care facilities among residents and their essential care partners has provided a level of protection against transmission to enable these changes[10] Vaccinations have been prioritized for long-term care worldwide, and the efficacy for both infection and transmission are strong. As a result, governments around the world have lifted many of the initial restrictions.[10-14] In general, COVID-19 vaccines have been shown to be highly effective and have been a key enabler to support family presence and remove restrictions.[15,16]

In some provinces, high rates of vaccination have resulted in allowing more essential care partners access within hospitals. Health and care facilities are being encouraged to consider vaccination status during requests for exemptions to the visitor restrictions. However, even with increasing rates of vaccination, and provincial policies that allow entry of essential care partners in both hospitals and long-term care facilities, there remain ongoing inconsistencies within regions and within facilities on how policies are implemented.[17-19]

Transmission of COVID-19 in hospitals and long-term care

It is difficult to fully understand and study transmission specific to the presence of essential care partners because most studies conducted during COVID-19 are confounded by multiple changes to infection prevention and control procedures occurring at the same time as visitor restrictions.[20,21] However, the evidence does not substantiate family members or designated support people as vectors of transmission.[20,22] Multiple reviews and briefs are calling for reintegration of essential care partners that highlight this lack of evidence of increased transmission, along with the numerous harms associated with blanket visitor restrictions.[10,23,24]

Models and studies have found that patient segregation, population size in long-term care, cohorting, and universal masking have been key factors to reduce transmission in health and care facilities, rather than restricting visitors.[25,26] In particular, studies in Singapore designed to assess changes in transmission due to visitor restrictions found that when restrictions were removed for essential care partner, there was no increase in COVID-19 transmission. Up to five essential care partners were allowed to be physically present and maintained all other precautions,[25,27] indicating that with proper infection control measures essential care partners could be safely present within health and care facilities.[27,28]

Impacts of restrictive visiting policies during COVID-19 in hospitals and long-term care

The negative impact of restrictive policies was known prior to COVID-19 due to lessons learned in past pandemics such as severe acute respiratory syndrome (SARS) in 2003. Sadly, many of the same harms have been highlighted in the literature emerging throughout COVID-19, and particularly in the early days of the pandemic.[2] Over the past six months, there has been an increasing body of evidence that demonstrates how visitor restrictions, including restrictions on essential care partners, have had negative consequences for patients and caregivers, as well as healthcare providers, and the health system in general.

Patients: Recent studies of the impact of visitor restrictions on patients during COVID-19 have shown negative impacts on patients' physical and mental health, experience of care, and safety. In terms of physical health, studies have shown a reduction in physical abilities and nutritional intake, increased pain and symptoms, and increased agitation and aggression.[29] For newborns, especially those in the neonatal intensive care unit (NICU), breastfeeding has been negatively impacted, with many mothers being unable to breastfeed since they could not be present with their babies.[16,30] Mental health has been negatively impacted, with studies indicating increased psychological and emotional distress, and anxiety.[29,31,32] Increased rates of cognitive decline and delirium have also been shown both in older people living in long term care[29] and in patients of all ages in hospital.[33] Negative experience has been measured through patient experience surveys and a reduction in satisfaction and experience has also been shown.[15,29,34] Additionally, Non-COVID-19 patients have had longer stays in the ICU since visitor restrictions have led to delays in decision making regarding treatments before death.[15,35] Patient safety has also been negatively impacted with studies showing increased rates of falls and sepsis.[34] Additionally, processes known to improve outcomes have been negatively impacted with restrictions leading to poorer sharing of information, communication and decision making,[15,35-37] and negative impacts to medication reconciliation.[38]

Caregivers: Recent literature highlights the impact on caregiver health, experience, and increased difficulties with transitions in care. Caregivers have reported increased psychological and emotional distress and anxiety,[29,31,32] as well as increased social isolation.[30] Visitor restrictions have resulted in poor experiences of grief since many loved ones passed away without family present.[15] Other poor experiences include reduction in family support,[32,37] and negatively impacted parental bonding with newborns.[16,29,30] Poor communication with caregivers and an increased need for communication has been reported.[29,34,37,39] Transitions in care, already a noted area of concern, has been further disrupted with a lack of preparedness for discharge that has been compounded with caregivers' lack of confidence and competence to provide care for patients at home.[39]

Healthcare Providers: Healthcare providers have also been negatively impacted by visitor restrictions, notably on their health and well-being as well as on their experience of providing care. Healthcare providers have experienced secondary trauma,[15] as well as increased psychological and emotional distress, anxiety and depression.[16,29,31,40] because of having to implement policies that contradict what they know and understand of person-centred care. Visitor restrictions have resulted in new tasks and added to their workload. Examples include needing time to learn new technology for virtual visits, increasing social support to patients, and more time needed to communicate with families.[29] Studies have found that job satisfaction of nurses has decreased because of restrictions on visitors and essential care partners.[34]

Health System: Recent studies have indicated that visitor restrictions have also had negative consequences on the health system, including reduced ICU capacity because of increased use by COVID-19 patients, causing undo strain on an already stressed system.[15,35] There has been increased difficulty in accessing informed consent for clinical research.[41] Additionally, visitor restrictions have magnified health disparities and further negatively impacted health equity.[30,37,42,43]

Conclusion

As the COVID-19 pandemic has evolved, the essential role of essential care partners in the care of patients has become abundantly clear, as have the negative consequences because of blanket visitor restrictions.

Numerous resources have been developed by several organizations, including HEC's published Policy Guidance that offers seven specific elements that are intended to guide new policy to safely reintegrate family caregivers as essential partners in care.[4] HEC has also worked with partners to develop the Essential Together program to support health and care facilities to implement this policy guidance. Through learning opportunities, resources and tools, and coaching support, facilities are supported to distinguish between general visitors from essential care partners, engage patients in the development of policies and processes for family caregiver presence, and implement practices and processes that welcome and support essential care partners to safely participate as part of the care team. The National Institute on Ageing recently published a guidance document considering the widespread vaccinations in long-term care homes across Canada that provides recommended policies for the safe re-entry of family caregivers and general visitors.[10]

The need for a balanced approach to manage the limited risk of transmission and unintended harm of restrictive policies is now clear. Thankfully, reductions in COVID-19 and increasing uptake of effective vaccines, have resulted in less restrictive policies that enable the safe re-entry of essential care partners in some facilities. Although provincial and territorial directives have shifted with the changing contexts of the pandemic, the implementation of these policies at the facility level has not been consistent. There remains room for improvement to consistently welcome the safe presence of essential care partners. As we plan for the recovery phase, the system has the opportunity to demonstrate its resilience and learn from the lessons of this pandemic to build policies together with patients and essential care partners and ensure blanket restrictions are never used again. In times of crisis or not, essential care partners play a critical role in the care of patients. They are not visitors, and as we have seen through this pandemic, can learn and adhere to safety protocols that enable their safe presence to provide supportive care.

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