EVIDENCE BRIEF:
Caregivers as Essential Care Partners

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Canadian Foundation for Healthcare Improvement
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cpsi icsp
Canadian Patient Safety Institute
Institut canadien pour la sécurité des patients

The newly amalgamated organization that brings together the Canadian Foundation for Healthcare Improvement and the Canadian Patient Safety Institute works with partners to share proven healthcare innovations and best practices in patient safety and healthcare quality. Working together with patients and other partners, we can deliver lasting improvement in patient experience, work life of healthcare providers, value for money and the health of everyone in Canada. The organization is a not-for-profit charity funded by Health Canada. The views expressed herein do not necessarily represent the views of Health Canada. Visit cfhi-fcass.ca and patientsafetyinstitute.ca for more information.

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INTRODUCTION

During the COVID-19 pandemic, early and tight blanket restrictions were placed on "visitors" in healthcare institutions, including acute care and rehabilitation hospitals, long-term care homes, and in other residential congregate care settings. Well into the first year of the pandemic, emerging evidence demonstrates the significant impact such restrictions have had on the quality of life and physical and emotional/psychological well-being of many people – including patients/residents/clients,* families, caregivers, and providers. There is also emerging evidence that demonstrates significant impact on patient safety, quality of care and outcomes.

Previous work led by the Canadian Foundation for Healthcare Improvement (CFHI) as part of the Better Together program and campaign supported the development and implementation of open family presence policies across Canada.

Open family presence policies support the presence of family caregivers, designated by patients, to be at the patient beside without any time restrictions.[1,2]

Blanket visitor restrictions refer to visiting restrictions that extend to all "visitors" entering a facility usually without exemptions, including essential care partners.[3,4]

As a newly amalgamated organization, CFHI and Canadian Patient Safety Institute (CPSI) are launching new programming to support healthcare facilities, including hospitals, long term care and other congregate care organizations, to implement policy guidance to safely reintegrate the presence of caregivers as essential care partners during this time of pandemic and beyond.

This evidence brief provides a synopsis of growing evidence regarding the presence of caregivers as essential care partners. Evidence is presented in the following four key areas:

1. **Benefits of family caregiver presence**: Highlights the growing body of evidence that demonstrates improvements in patient safety, patient experience, patient outcomes and patient care with presence of essential care partners across a range of institutional care settings.
2. **Better Together**: family caregiver presence policies in hospitals across Canada. Results of previous CFHI programming in Better Together demonstrate shifts in family presence policies in hospitals across Canada over the past 5 years; changes in family presence policies are also noted during COVID-19 in hospitals and long-term care settings.
3. **Transmission of COVID-19 in hospitals and long-term care**: Reports on the transmission of COVID-19 within facilities during this time of pandemic.
4. **Impacts of restrictive visiting policies during COVID-19 in hospitals and long-term care**: Emerging evidence highlights the multitude of risks noted to patient care, patient safety and patient outcomes, as well as impacts on families

* This document is meant to reflect many settings where people receive care, including healthcare facilities, long-term care and other congregate care settings. For the purposes of this report, "patient" also includes clients and residents.

The adoption and implementation of family and caregiver presence policies is rooted in an underlying philosophy of patient- and family-centred and partnered care within an organization. Patient- and family- centred care has been a longstanding pillar of quality patient care, as noted in the seminal report Crossing the Quality Chasm by the Institute of Medicine in 2001.[5] A 2014 Commonwealth report positioned quality care as care that is effective, safe, coordinated and patient-centered where care delivered meets the needs and preferences of patients.[6]

The Institute for Patient- and Family-Centered Care (IPFCC) highlights the important role that family members caregivers and other support people play in the care of patients. IPFCC describe patient- and family-centred care (PFCC) is an approach to all processes of care that are grounded in mutually beneficial partnerships between patients, families and healthcare providers. Moreover, this means recognizing the importance of family and caregiver presence and their participation in the care, quality and safety of patients.[7,8]

In Canada, we have seen shifts toward patient-centred philosophies in care, as noted in existing reports from Saskatchewan's Patient First Review Commissioner's Report to the Saskatchewan Minister of Health;[9] Patients First: Action Plan for Healthcare, Patient Declaration of Values,[10,11] and the People's Health Care Act in Ontario; Alberta Health Services Department of Engagement and Patient Experience framework,[12] and British Columbia's Primary Healthcare Charter,[13] all which have underscored the significance of "patient as partners," supporting the transformational shift into more PFCC practices and the need for new infrastructure to support this philosophy of care. Additionally, support for family presence practices over the past 20 years has been recognized by many influential organizations including those that supported CFHI's Better Together campaign (such as the Canadian College of Health Leaders, IMAGINE Citizens and the Registered Nurses Association of Ontario) as well as various pan-Canadian health organizations and provincial quality councils, indicating a positive shift towards and support for more accommodating visiting policies and overall PFCC practices.[14] The emergence and ongoing threat of the COVID-19 pandemic has challenged the ability of many healthcare facilities to balance their philosophies and practices of PFCC with safety and infection prevention and control considerations during this time of crisis.

1. Family Caregiver Presence: Differentiating Roles and Benefits

Family caregiver presence policies as part of PFCC: Differentiating visitors from family caregivers

Developing and implementing policies that support the integration of families and caregivers into patient care can be understood as a practical approach to operationalizing PFCC. Creating accommodating visiting policies (or family presence policies) enables families and caregivers as essential care partners to be present and engaged during the care process and ensure care is in accordance with patient's preferences.[15] Essential care partners are a constant in a patient's life and often know them better than the healthcare providers. To facilitate the change towards PFCC, a cultural shift is required in how families and caregivers are perceived; that is of being "more than just a visitor" but rather as essential care partners who are key players in the quality, safety and experience of patient care. This distinction between visitors and essential care partners who are identified by patients is a key feature of family presence policies that are more accommodating and open to essential care partners. According to a 2015 CFHI survey, 90 percent of healthcare professionals are in support of family presence policies, when provided with definitions that help to differentiate visitors from family caregivers as essential partners in care.[16]

Family caregiver/family caregivers may include relatives and non-relatives as defined by the patients.[17,18]

Visitors play an important social role for patients, however, do not engage as active partners in care.[19,20]

Essential care partners are identified and designated by patients, or by their substitute decision maker or power of attorney. They play a significant role in providing physical, psychological and emotional support, including support in decision making, care coordination, and continuity of care. Essential care partners can include family members, close friends, caregivers, or any person identified by the patient.[21,22]

Patient and family centred care/partnered care is an approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients and families.[23,24]

Families and caregivers, as essential care partners, take on many roles as part of the care team, such as:

- Support communication and continuity of care with patients and healthcare providers and staff, including providing essential medical information for patients who are unable to advocate on their own behalf. This is critical for ensuring care is responsive to patient's needs/preferences and helps to enhance trust between patients and their circle of care.
- Assist in mobility issues and ensure comfort/promote healing
- Support hygiene, toileting and other daily life activities
- Social and psychological support to reduce patient anxiety and enhance emotional wellbeing
- Ensure accountability and adherence to best practices of providers including infectious disease protocols by acting as a reminder (e.g., hand hygiene, medication regimes).

Benefits of Family Presence Policies

The presence and participation of family caregivers in healthcare and long-term care facilities has been described as a potential transformative lever for improving PFCC and other quality domains in healthcare.[25,26,27]

Studies have demonstrated the benefits yielded from family presence policies without introducing added risk. This includes improved satisfaction, quality of information shared and additional positive outcomes for patients, families, and healthcare providers.[28,29,30,31,32] Several studies have indicated that hospitals who have greater family presence policies often report lower readmission rates, improved medication adherence, reduced patient falls and sustained cognitive function among senior patients.[33] According to a 2014 American study, hospitals that were examined for adopting family presence policies reported a reduction in the incidence of patient falls by 35 percent and injuries sustained by falls by 62 percent.[34] A study performed by the U.S. Health and Human Services department measured patient safety and found that hospitals with family presence policies had reduced readmission rates by 17.5 percent over a six-year course, and a nine percent reduction in the rate of harm over two years.[35] Further, some studies have reported patient anxiety and dissatisfaction to have decreased with the introduction of family caregivers in patient care processes.[36,37,38]

Similarly, the evidence to-date in the long-term care sector also demonstrates the valuable role of families and caregivers. These essential care partners support the work of staff but more importantly have been shown to positively influence the quality of life of residents and the quality of care they received. Family and caregiver presence have been associated with improving the physical and psychological well-being of residents; aiding in care management, reducing costs and protecting the physical and cultural safety of residents (among other outcomes).[39,40,41] Family and caregiver involvement is particularly critical for residents with culturally diverse needs and preferences and residents with complex conditions. It has been reported that residents who receive linguistic and ethno-specific care are more likely to see improvements to their physical and mental wellbeing such as decreased rates of depression, reduced social isolation and lowered risk of falls and hospitalization.[42] Similar outcomes have been also been identified in dementia care settings. Results from a 2007 randomized controlled study involving 20 long-term care homes found that facilities that received an intervention program-designed to improve communication and cooperation between families, residents and staff — reported reduced behavioural symptoms among residents, improved communication and care involvement, fewer conflicts between staff and families, and reduced rates of depression among staff. Conversely, the control group noted an increase in staff burnout.[43]

While there are many benefits and increasing support of PFCC, challenges to the full integration of PFCC practices in healthcare systems have been noted with reports indicating the continued use of practices that do not align with PFCC principles (for example refusal to include family at bedside rounds).[44] Healthcare providers who are often proponents of family presence have also shared patient safety concerns regarding the presence of families or caregivers during care, and the possibility of families becoming barriers to care delivery.[45,46] Such concerns remain unfounded in the existing literature that indicates family and caregivers do not negatively influence the health outcomes of patients.[47,48,49,50,51] For example, a 2007 observational study conducted on 252 American hospitals with 41,568 adults who suffered from cardiac arrest found that resuscitation quality, interventions, and system errors did not differ between hospitals with family presence policies and those without family presences policies, suggesting family presence does not lead to poor outcomes and a disruption in care.[52]

Other concerns raised with family presence relate to patient privacy and confidentiality and possible infectious disease transmission. However, professional organizations including the American Association of Critical-Care Nurses have offered safeguards and strategies for healthcare providers to use in order to protect patient privacy and confidentiality.[53] The College of Nurses of Ontario has provided a set of ethical practice standards and possible resolutions for ethical conflicts related to patient privacy and confidentiality for healthcare providers to consider when balancing patient and family needs.[54] Moreover, a 2014 review that explored the evidence around barriers

to family presence policies noted that family presence and flexible visitation does not cause additional harm in the form of infectious disease transmission,[55,56] rather harms can be introduced through poor procurement, distribution and training of personal protective equipment (PPE) and other infection prevention and control (IPAC) protocols along with other organizational factors such as disproportionate patient to staff ratio in healthcare and long-term care facilities.[57]

Education on the benefits of family presence for healthcare leaders, providers, patients, families and caregivers is recommended as increased knowledge and awareness has been noted to be a facilitator of changing attitudes and beliefs toward family presence, and to reduce the risk of conflict between providers and governing institutions that are responsible for implementing family presence policies.[58,59]

2. Better Together: Family presence policies in hospitals across Canada (2015-2020)

In 2015, CFHI, in partnership with the IPFCC, launched the Better Together campaign, to support the development and implementation of family presence policies in hospitals across North America. Family and caregiver policies reinforce the creation of supportive environments for PFCC practices.

Prior to the start of the campaign, CFHI commissioned a baseline study called "Much More Than Just a Visit: A Review of Visiting Policies in Select Canadian Acute Care Hospitals" to identify the prevalence of family presence policies in hospitals. The methodology was adapted from a 2012 study of posted visiting hour policies in the state of New York, US. Between February and April 2015, 114 eligible acute-care hospitals across Canada were reviewed (55 large community hospital, 55 teaching hospital, two medium-sized community hospital, and one small hospital) to determine how accommodating their visiting policies were for family members caregivers and visitors. Reviewers assessed the usefulness of visiting policies that were available on the hospital websites, and their openness, restrictiveness and general flexibility to accommodate individual patients and their family/care partners.[†] Data was validated by telephoning hospitals to confirm information shared on websites.

Results in 2015

Based on information provided on hospital websites, 104 out of the 114 hospitals clearly communicated their visiting hours. In communicating visiting hours, hospitals focused on the hours of operation and differences in visiting policy application for family members and other visitors. Of the 114 hospitals, 36 hospitals received a score of seven to 10 on the visiting hour openness and notification of flexibility, indicating they had "accommodating visiting policies." Thirty of the 36 hospitals that scored between eight and 10 were considered to have "very accommodating visiting policies." Based on the findings, there was room for positive development in the work of family presence in Canada. In addition to the Better Together Campaign with IPFCC, CFHI developed further programming, with an e-collaborative to support healthcare organizations to develop and implement family presence policies. The e-collaborative offered learning opportunities, peer-to-peer and coaching support and resources to encourage changes to policy by working with patients, families and caregivers as part of the improvement teams. CFHI also hosted a policy roundtable, with government representatives from most provinces and territories and patient and family partners to collaborate and discuss ideas for enhancing the spread of family presence policies across regions, provinces and territories beyond individual healthcare organizations.

Results in Early 2020 (Pre-Pandemic)

CFHI commissioned researchers in early 2020 to conduct a follow-up study of family presence policies across Canadian hospitals with a goal to determine changes in acute care hospitals across Canada over the course of five years since the launch of the Better Together campaign. It is important to note the 2020 review was performed in January and February 2020, a month before COVID-19 was declared a pandemic. This follow up study was in line with the initial Better Together program of work which focused on acute care hospitals across Canada. This is an important noted limitation, as these results do not reflect long-term care and other congregate care settings.

† Accommodating refers to the extent to which a hospital's visiting policy accommodates visits by a patient's family or caregivers to the hospital. Availability and usefulness indicate whether the hospital has a dedicated web page where its visiting policy is described; and, if so, how useful this information is for prospective visitors.

Following the same methodology used in the baseline study, between January and February 2020, 118 eligible acute-care hospitals across Canada were reviewed (55 large community hospitals, 59 teaching hospitals, two medium sized hospitals, one community acute care hospital, and one small hospital). The selected hospitals were closely matched with hospitals included in the 2015 report. Reviewers assessed visiting policies that were available on the hospital websites, and their openness, restrictiveness and general flexibility to accommodate individual patients and their family/care partners. Data was validated by telephoning hospitals to confirm information shared on websites.

Based on information provided on hospital websites, in 2020 114 of the 118 hospitals (98%) clearly communicated their visiting hours compared to 104 out of the 114 hospitals (92.5%) noted in the 2015 results. Hospitals focused on communicating the hours of operation and differences in visiting policy application for family members and other visitors. In early 2020 there were 80 hospitals that allowed overnight visitors, compared to 20 hospitals in the 2015 study in all domains of comparison, there was significant improvements in open family presence across Canada from 2015 to 2020. The overall scores out of 10 on openness of policies increased from 4.64 to 7.43 and on usefulness of information from 5.29 to 6.81. Such improvements indicated changes to acceptance and recognition of the valued role family caregivers bring to the health system. They also indicated appreciation of the role of family caregivers among health care teams through the acceptance and adoption of a philosophy of PFCC and associated practices. See Appendix A for comparison of hospitals scores in 2020 and 2015.

Early Results During COVID-19 (March 2020)

In the early months of the pandemic, significant shifts occurred in the ability of family caregivers to be present with their loved ones in any healthcare institution. CFHI commissioned researchers to re-evaluate the visiting policies of a sub-set of the 118 surveyed hospitals across Canada. All 35 hospitals in this subset had implemented new COVID-19 visiting policies. Most of these hospitals opted to suspend visitation; however, some hospitals allowed for limited visitor access for patients in special circumstances (such as end of life). Three hospitals did not indicate any changes to their visiting policies.

Two significant findings were noted in this follow up study:

1. The immediate and severe restrictions on “visiting” policies across all healthcare sectors that did not differentiate between a visitor and a caregiver as an essential care partner
2. The apparent fragility of patient and family-centred and partnered policies and practices that did not appear to be fully embedded in these surveyed healthcare organizations, as evidenced by the swift restrictions put on essential care partners and visitors.

The rapid response in the early days of the pandemic that was carried out in many healthcare settings including long-term care,[60,61] indicated a singular focus on the risk of transmission of COVID-19, important in the initial response to the pandemic. As the pandemic and blanket visitor restrictions continue, the emergence of unintended risks and harms to the quality of life, quality of care, patient, family caregiver and provider physical and emotional/psychological well-being of patients has become evident. A more balanced approach is needed to enable the physical presence of essential care partners.

Results During COVID-19 (October 2020)

As the COVID-19 pandemic continues to evolve with many regions entering their second wave of the pandemic, hospitals and other healthcare settings have begun to adjust their family presence policies to adapt to the rapidly changing landscape. The same research team conducted an additional review of the 35 hospitals from the March 2020 study, to examine whether family presence policies had changed since the spring. Findings from the study indicated that 28 of the 35 hospitals had made amendments to their COVID-19 visiting policies. Overall, most of these changes recognized the importance of essential caregivers/support people by supporting the presence of designated essential caregivers/support people during patient care processes. The remaining seven hospitals did not make changes to their policies from March 2020.

Federal/Provincial/Territorial Directives for Family Presence and Visitation in Long-Term Care Settings

The Better Together focused on the hospital sector only. To examine family presence policies in long-term care settings across Canada, a scan was conducted of publicly available sources of federal, provincial and territorial guidance and directives in October 2020. At this time, more than six months after the pandemic had been declared, most policies outlined in the scan appeared to have loosened their restrictions and supported the presence of one or two essential caregiver(s) under certain restrictions/ circumstances. In the time before this scan was conducted, media and social media reports would suggest that most, if not all, long-term facilities applied blanket visitor restrictions. In addition, evidence of the detrimental impacts to residents, caregivers and providers would also suggest that blanket restrictions have been applied during some periods of COVID-19 and policies have been subject to change as the pandemic evolves.

3. Transmission of COVID-19 within Healthcare Institutions

COVID-19 has shown that high transmission through non-hospitalized family clusters appears as one of the most common forms of spread in the early days of the pandemic. This transmission appeared to occur through close contact, saliva transmission and casual contact/simple prolonged proximity through the family clusters.[62,63,64,65] Two systematic review that examined the risk transmission of COVID-19 in hospitals and long-term care facilities. The studies found the proportion of nosocomial infections in patients with COVID-19 to be 44 percent during the early stages of the pandemic. For long-term care facilities, greater variability existed, with incidence rates reported to be between zero to 72 percent among residents and 1.5 to 64 percent among staff.[66]

There are various routes of transmission that are particularly relevant to considerations regarding family caregivers. In past outbreaks, poor implementation of IPAC measures along with other public health controls in healthcare settings have been reported to be a primary factor for infectious disease transmission among visiting family caregivers.[67,68] A scan performed by the Research, Analysis, and Evaluation Branch of the Ministry of Health in Ontario, noted findings from recent studies in the United States, Spain and South Korea demonstrated the overall risk of hospital-acquired COVID-19 infection to be low, noting the spread of COVID-19 as being not indicative of family caregiver presence but rather a result of poor implementation and adherence of public health measures.[69,70,71] This evidence scan and other studies have emphasized that infectious disease spread can be controlled through rigorous application of enhanced hand hygiene, training and education around PPE use and IPAC controls, screening, barrier precautions, use of alternative communication modalities and reducing the number of visitors and/or length of visits, when absolutely necessary.[72,73,74,75,76,77]

Similarly, research findings from long-term care facilities align with evidence emerging from acute healthcare settings regarding transmission. A recent rapid review published by the National Collaboration Centre for Methods and Tools examined mitigation strategies and risk factors associated with COVID-19 outbreaks in long-term care facilities. The review indicated no evidence to support restrictive visitor policies reduce outbreaks and mortality within long-term care settings.[78] Incidence of infection in surrounding community was noted as being a risk factor with the quality of evidence being moderate. Risk factors that received low quality of evidence included individual-level factors (for example age, gender, racial/ethnic minority status) and organizational level characteristics (such as poor staffing levels and sick leave policies), facility quality, facility size/density; and non-for-profit status. It is important to note that the evidence was unclear on whether large facility size (number of residents), resident to staff ratio or density of residents was a driving factor for transmission.[79] Interventions that were described as having the potential to decrease COVID-19 transmission included active screening of residents, staff and visitors, cohorting and voluntary staff self-confinement, adherence of IPAC protocols, physical distancing and occupancy limits for small areas, infection control audits, and the use of technological tools (such as contact tracing apps).[80] Limited evidence has been reported in other reviews and studies that have examined the rates of COVID-19 transmission attributed to family caregivers and visitor presence in long-term care facilities.[81,82,83] In particular, a study in the Netherlands described no new cases of COVID-19 for long-term care homes that had reopened with essential caregiver visiting policies in place; however authors noted results to be interpreted with caution due to the limited time frame of the study and confounding factors.[84]

Despite minimal published evidence regarding family and caregiver transmission of COVID-19 in healthcare facilities, there are documented concerns from healthcare staff regarding infectious disease transmission. According to an evidence report published by the CADTH on best practices to support staff during the COVID-19 pandemic, staff expressed concerns around the fear of infection due to limited PPE and/or poor adherence to IPAC measures.[85] Findings from the CADTH report reaffirmed previously mentioned recommendations for preventing outbreaks in facilities which included adequate supplies of PPE, sufficient IPAC training for staff, residents and families/caregivers and appropriate staffing ratios. These key strategies can subsequently remedy some fears expressed by staff with respect to risk of transmission.[86]

Specific to COVID-19, prevention and mitigation strategies to interrupt transmission should be broad in scope to control possible modes of transmission.[87] Guidance issued surrounding essential visitors, which include family caregivers as essential care partners, indicates that family caregivers should either provide their own, or be provided with appropriate PPE in some circumstances, receive donning and doffing training from trained staff as well as proper hand hygiene education, and be actively screened.[88,89,90,91,92] Approximately one third of family caregivers already carry out technical aspects of care, and there is capacity to learn and carry out IPAC procedures as necessary.[93] Continued considerations to support family caregivers during the ongoing COVID-19 pandemic include their engagement in ongoing discussions around PPE, as well as provision of guidance from trained healthcare professionals. Patients and family caregivers should be engaged in the current and future organizational pandemic planning, immediate and ongoing IPAC and PPE training, and inclusion in PPE census and procurement.[94,95]

Recommendations surrounding visitor restrictions are meant to be practical and include family caregivers, with guidance adapted by each healthcare facility and based on patient needs.[96,97,98,99] It is crucial to mitigate the impacts of blanket visitor restrictions and isolation while also balancing the need for patient and family-centred care, only imposing isolation for patients where precautions are appropriate.[100,101] The Toronto Region COVID-19 Hospital Operations Table developed a guidance document for healthcare facilities that features a list of recommendations to guide the re-integration of "essential visitors" (essential care partners) and associated operational needs. The document channels a similar call to action, in that an equitable, flexible, locally-based and evidence-informed approach to visitor restrictions during a time of COVID-19 must be employed in order to appropriately balance the risk of COVID-19 transmission with the irreversible harms to the health and well-being of patients and their families.[102] The Ontario Long-term Care COVID-19 Commission has also developed a set of evidence-informed recommendations that focus on:

1. Increasing staffing, which also includes recognizing the important roles essential caregivers/support persons play in providing care for their loved ones;
2. Strengthening healthcare sector relationships and collaboration;
3. Improving IPAC measures.[103]

Across Canada, provinces and territories have adopted various strategies that adhere to IPAC precautions and training for family caregivers.

Such evidence points to the ability to have safe re-entry of caregivers as essential care partners in care, and the need for visitation policies to be developed and implemented in a way that balances risk of infectious disease transmission, and the promotion of PFCC.[104] It is important to note that most of the findings reported in this brief have been curated from peer-reviewed and grey literature. Internal case reports from healthcare facilities may indicate cases where families, caregivers, and/or staff have been vectors of transmission. Nevertheless, leveraging evidence-informed recommendations as described above are recognized as effective mitigation strategies.[105,106,107,108,109]

4. Impacts of Restrictive Family Presence Policies on Patients, Families, Caregivers, and Providers During COVID-19

Restrictive family presence policies have been linked to a myriad of harmful effects on patient, family, caregivers and providers. Research has shown that patients, particularly those in medically vulnerable situations (e.g. intensive care units or older adult patients), are more likely to experience medical error, costly non-essential care, physical and/or emotional harm, social isolation and inconsistencies in care when families and caregivers are restricted from participating in care.[110,111] Moreover, restricted access also means families are unable to receive assurance that their loved one is receiving quality care that meets their loved one's preferences and needs. Studies have shown families subjected to these circumstances often report higher levels of stress and anxiety.[112] The emotional hardships felt by patients and family caregivers as a result of restricted policies are also felt by healthcare providers and staff. For example, reports have indicated hospital staff experiencing gaps in acquiring necessary information when family caregivers have been restricted entry into healthcare facilities.[113,114] These issues have been exacerbated by the COVID-19 pandemic as healthcare providers and staff struggle to fill the role of essential family caregivers.

Lessons learned from past outbreaks, such as the 2003 Severe Acute Respiratory Syndrome (SARS) outbreak, has indicated that restricting "visitors," specifically essential family caregivers, from entering the healthcare facilities can result in negative outcomes for patients, families and caregivers. A study that looked at the experience of children hospitalized for SARS, their parents and healthcare providers, reported social isolation as being a dominant theme, with several participants indicating they had experienced severe emotional distress, communication difficulties and alteration to their professional and parental role due to restricted family presences and severe IPAC controls.[115]

Evidence during the COVID-19 pandemic is only just emerging regarding the impact restrictive family presence policies are having on patients, families, caregivers and providers, particularly from the early days when most healthcare facilities adopted blanket zero visitor policies with the hope to reduce disease transmission. According to a Dutch study, residents of long-term care homes were negatively impacted once stern COVID-19 measures, including visitor restrictions, were enforced. Researchers reported higher rates of loneliness, depression, mood and behavioral issues among residents.[116]

The evidence appears to support anecdotal reports from patients, families, caregivers and healthcare providers that have outlined the challenges they have endured including psychological and moral distress, mental health issues, the worsening of health conditions, concerns for patient safety, communication lapses, and the ability of families/caregivers to provide care and support of their loved ones.[117,118,119,120] A recent report published by the Office of the Seniors Advocate British Columbia, examining the impact of visitor restriction on long-term and assisted living, shared several personal stories of residents and families who have experienced the harsh realities of restricted visiting. Many expressed experiencing feelings of helplessness, guilt, confusion, isolation, and frustration; with one participant expressing how their loved one felt as though "her family had given up on her."[121]

Healthcare staff have expressed concerns around safety and staff burnout as a consequence of poor pandemic preparedness planning in healthcare facilities. In a cross-sectional study by Verbeek et al., lifting visitor restrictions in long-term care facilities was supported by residents, families/caregivers, and staff. As facilities begin to reopen, it is imperative the concerns of healthcare staff are addressed as staff also play a crucial role in the quality of care and infection control of healthcare facilities. Key sources of evidence have identified strategies to address staff concerns around safety and burnout. These strategies include sufficient PPE and resources, adequate staffing levels, proper IPAC protocol training for staff, patients/residents, and families/caregivers, access to IPAC specialty teams and relevant medical staff, proper usage of screening protocols, and policies/incentives to reduce work between facilities and suitable enforcement of sick leaves.[122] Further, integrating the voices and experiences of

patients and family caregivers into existing and future COVID-19 response and recovery work is essential to ensure the needs of patients, families and caregivers are addressed.[123]

Currently, the amalgamated organization of CFHI and CPSI is working with a research team from the University of Alberta to further explore impacts of restrictive family presence policies on patients, caregivers and providers in healthcare settings, to add to the evidence base that has been generated during this time of COVID-19.[124] Preliminary data analysis has identified similar themes to those noted previously, related to psychological and moral distress, poor communication around patient needs, and for many patients and family members, it is detrimental to their healthcare experiences and outcomes. Although some healthcare facilities have begun to integrate elements of family presence into their policies, ongoing restrictions continue to create great hardship for many. Patients' desires and need – with respect to having essential care partners present to support them in during their healthcare stay (ambulatory or inpatient) – varies considerably, with many contributing factors. For instance, patients with complex and/or rare medical conditions, and those who have experienced some healthcare trauma, often have a greater need for family support. Some family caregivers and patients noted there is no "one-size-fits-all" family presence policy that will address all patient needs. In addition, providers also expressed high levels of psychological stress and moral distress adhering to visitation policy guidelines, describing anxiety because they could not provide the best care in a way that was patient-and-family centred. Providers expressed some confusion due to a lack of communication and directive on visitation policies. They also described the need to adapt quickly to new policies and directives, contributing to heightened stress for some. See Appendix B for a summary of key themes that emerged across individual interviews.

CONCLUSION

As the COVID-19 pandemic evolves, jurisdictions and institutions are looking for evidence-informed guidance to assist with the reintegration of family and caregiver presences in healthcare settings. Recommendations have been developed by several organizations, including CFHI's Re-Integration of Family Caregivers as Essential Partners in Care in a Time of COVID-19 report that offers seven specific steps that are intended to guide new policy for reintegrating family caregivers as essential partners in care.[125] The National Institute on Ageing recently published a guidance document that offers recommended policies for re-opening long-term care facilities in Canada with specific policies set for family caregivers and general visitors.[126]

CFHI and CPSI hosted a policy lab to co-develop policy guidance, offering a balanced approach for the safe re-integration of essential care partners into healthcare facilities. The newly amalgamated organization is now launching a program, called Essential Together, to support hospitals, long-term care, and other residential congregate care settings to implement this policy guidance. Through learning opportunities, resources and tools, and coaching support organizations will be supported to distinguish between general visitors from essential care partners, engage patients, family and caregivers 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.

APPENDIX A

Much More Than a Visitor: Policies in Canadian Acute Care Hospitals (2020)

Table 1. Count of hospitals by province/territory

Province/Territory	Count of Hospitals 2015	Count of Hospitals 2020
Alberta	13	13
British Columbia	20	23
Manitoba	6	6
New Brunswick	4	4
Newfoundland and Labrador	2	2
Northwest Territories	1	1
Nova Scotia	3	3
Nunavut	1	1
Ontario	41	42
Prince Edward Island	1	1
Quebec	15	15
Saskatchewan	6	6
Yukon	1	1
Total	**114**	**118**

Table 3. Count of Scores for Usefulness of Website Information on Visiting Policy

Score for openness of visiting policy	Count of hospitals 2015	Total (%) 2015	Count of hospitals 2020	Total (%) 2020
10	2	5 (4.39)	20	74 (62.71)
9	3		54	
8	25	31 (27.19)	6	12 (10.17)
7	6		6	
6	8	19 (16.67)	2	8 (6.78)
5	11		6	
4	17	28 (24.56)	5	15 (12.71)
3	11		10	
2	11	31 (27.19)	2	9 (7.63)
1	13		5	
0	7		2	
Total	**114**	**Total**	**118**	

Table 3. Count of Scores for Usefulness of Website Information on Visiting Policy

Score for Usefulness of Website Information	Count of hospitals 2015	Total (%) 2015	Count of Hospitals 2020	Total (%) 2020
10	0	3 (2.63)	5	25 (21.19)
9	3		20	
8	17	36 (31.58)	30	52 (44.07)
7	19		22	
6	20	33 (28.95)	17	21 (17.80)
5	13		4	
4	11	34 (29.82)	6	16 (13.56)
3	23		10	
2	3	8 (7.02)	1	4 (3.39)
1	3		1	
0	2			
Total	**114**	**Total**	**118**	

APPENDIX B

Family Caregivers as Essential Care Partners: Examining the Impacts of Restrictive Acute Care Visiting Policies During the Covid-19 Pandemic in Canada

Caregiver and Patient Interviews: Preliminary Themes

Theme	Description
Impact on the patient	
Physical comfort	• Patients described relying on their family members to provide physical comfort (e.g., helping to move them to a more comfortable position, adjust their pillows, getting fresh water); they felt badly ringing the call bell for these needs and many avoided doing so.
Emotional state (stress, fear, loneliness, etc.)	• Many patients described the intense loneliness and fear they felt spending days, weeks and sometimes months in hospital without any human contact with people who loved and cared for them. • Having someone sit with them and hold their hand, stroke them, hug them, is described as so important – and something that cannot be done via a phone or iPad.
Mental and cognitive health (anxiety, depression, delirium, dementia, etc.)	• The separation from loved ones created huge anxiety for some, and particularly when the patient had a rare and/or complex medical condition. • With over extended inpatient stays this separation also led to withdrawal, depression, and increasing confusion and dementia symptoms. (For example pre-school child in hospital for months with only Mom allowed to stay, became withdrawn and close relationship they had with father and sibling was diminished. • One patient described having a prolonged experience with delirium, which began when they were in ICU, which they felt would not have been as prolonged if they could have had some family members present.
Communication with the healthcare team	• Patients with rare and/or complex conditions, those with cognitive impairment and in particular, those who are very ill and/or on lots of pain medication described challenges with communicating with healthcare providers during hospital stays and appointments.
Safety	• Patients had falls in hospital (for instance when they needed to get up to go to the washroom) and didn't want to ring the call bell yet again or because of some cognitive impairment got up on their own and fell. • Problems with communication at discharge created potential unsafe situations (for instance patient arrived home with incorrect prescription). • Patient with rare condition had to call spouse to come and collect her post-op, as she felt unheard creating a potentially unsafe situation.
Concern about accessing need healthcare	• Patients and their family members spoke about being afraid and sometimes incredibly anxious about the need to return to the hospital for treatment or care; with some actively avoiding doing so.

Theme	Description
Impact on family member/caregiver, and other family	
Emotional state (stress, fear, loneliness, guilt, etc.)	• Family members also described the stress, fear and loneliness they experienced being separated from those they loved. Some described how guilty they felt not being able to be there for their loved one at such a difficult time (e.g., family members described sitting in their car and crying after dropping their loved ones off at the ER; others described waiting for hours to hear what had happened to their family member dropped off at the ER, or post-op. Did they survive?).
Mental health (anxiety, depression, etc.)	• In particular, when the hospital visits were repeated or an inpatient stay long, family members described having difficulty dealing with the ongoing stress and anxiety, as a result of their worry about how their family member was doing in part due to the often lack-of-communication both with their family member and healthcare professionals.
Communication with the healthcare team	• Communication with members of the healthcare team caring for loved one was often challenging. It could be difficult to reach busy healthcare providers. This contributed to worry and fear; as was a particular concern when the patient was unable to communicate by phone.
Communication with other family members	• Some spoke of the extra burden they had to assume in sharing what information communicated by healthcare professionals with others in the family (such as a Mom communicating with Dad re infant son's post-op recovery).
Caring for family member at home post discharge	• Poor communication throughout hospital stay, including at discharge, created some difficulties in following up and providing appropriate care at home. In some cases, family members had to do considerable running around and telephone calling, in order to get appropriate supplies and medications.
Potential increased risk of COVID contagion	• There were a number of situations where family members felt they were potentially increasing their risk of being exposed to COVID-19 as a result of hospital policies (e.g., not being allowed to bring a sibling to hospital appointments with child, leaving parent with decision re whether to leave sibling with a babysitter who was not following any COVID-19 public health protocols).
Impact on healthcare providers	
Healthcare providers are 'run off their feet'	• Many felt that healthcare providers were simply too busy, being "run off their feet" due to a combination of factors, including adhering to safety protocols and the absence of family members to help support the patient.
Healthcare providers need to work around policies to meet their patients and families' needs	• Some described healthcare providers needing to "work around" the visiting policies in place, in order to support their patients and families the way they wanted to (for example a specialist going to a side entrance of a children's hospital to bring in father, as she felt it was important that he be there in-person to discuss plans for upcoming urgent surgery on his infant son).

Theme	Description
Key principles underlying family presence policies during a pandemic	
Virtual presence is not helpful, or even possible, for many	• For some patients, connecting with family only via the phone or iPad is either impossible or does not work well (especially for patients who are either physically or cognitively unable to use such a device). • Sometimes it is very difficult to get other family member on the phone quickly enough (as healthcare providers are often in a hurry and cannot wait for this to happen).
Balance risk of COVID contagion and other potential harms as a result of restricting family presence	• There is clearly a need to weigh the impacts of restricted family presence policies with the risk of COVID-19 contamination. • Family members describe being extremely careful not to put their loved ones (the patient) at risk, nor anyone else in the facility. They wondered how they pose any increased risk, particularly given that they are wearing a mask at all times in hospital and wash their hands frequently.
Flexibility	• There is no "one-size-fits-all" family presence policy that will address all needs. • Any policies or guidance need to have enough inherent flexibility to trust healthcare providers, patients, families and caregivers to develop something that will work for a particular patient and family in a particular context.
Supporting family members/ caregivers to be safely present	• If healthcare organizations believe in and actively practice patient- and family- centred care, then the golden rule should be to start by asking the patient what kind of family/caregiver support they need while in the healthcare facility and then try to support that happening as safely as possible. Otherwise, there will always be cracks through which patients, family and caregivers will fall, and unintended harm will occur.

Healthcare Provider Interviews

Theme *Subtheme*	**Description**
Lack of Directives	Providers expressed a lack of communication and directive for visitation policies. For some, visitation policies have been changing regularly requiring health providers to consistently try to adapt to new policy changes.
Transition of care	Providers described difficulties with continuity of care for patients. As patients transition from one healthcare facility to another (for example hospice or different acute care hospital), they expressed concern regarding not knowing what the visitation policies and practices at other facilities were and couldn't inform the patient accordingly.
Moral Distress	Providers expressing a high level of moral distress from following visitation policy guidelines despite feeling that it is not the best care they could provide and is not patient-centred.
Risk of rule breaking	Providers expressing a high level of moral distress resulting from adhering to visitation policy guidelines, despite feeling this was not the best care they could provide and is not patient-centred.
Considerations of leaving the job	Providers commented on how they contemplated disregarding visitation policy practices at their hospital. This would risk their job but felt a moral imperative to provide patient-and-family centred care.
Mental Health	Providers described impacts to their emotional and mental health during the pandemic and from their experience enforcing visitation policies.
Adaptations to provider workflow	Providers shared how they have had to adapt their workflow and practices within their unit due to restrictive visitation policies during the pandemic.
Added responsibility among providers	Providers expressed that the role of enforcing visitation policies and dealing with the consequences resulting from the visitation policies has been an extra responsibility.
Use of technology	Administering and supporting the use of technology for patients to connect with loved ones and for providers to give updates to family members and caregivers
Designated position (e.g., implementing and monitoring visitation policies)	Providers suggested a solution to support and better handle restrictive visitation policies that were introduced during the pandemic would be to have a designated position to support the change. This position could be outsourced.
Volunteers	Providers suggested the use of volunteers for this designated position.

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