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## Restricted family presence for hospitalized surgical patients during the COVID-19 pandemic: How hospital care providers and families navigated ethical tensions and experiences of institutional betrayal



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### ABSTRACT

Early in the COVID-19 pandemic restricted family presence in hospitals was a widespread public health intervention to preserve critical resources and mitigate the virus's spread. In this study, we explore the experiences of surgical care providers and family members of hospitalized surgical patients during the period of highly restricted visiting (March 2020 to April 2021) in a large Canadian academic hospital. Thirty-four interviews were completed with hospital providers, family members and members of the hospital's visitor task force. To understand hospital providers' experiences, we highlight the ethical tensions produced by the biomedical and public health ethics frameworks that converged during COVID-19 in hospital providers' bedside practice. Providers grappled with mixed feelings in support of and against restricted visiting, while simultaneously experiencing gaps in resources and care and acting as patient gatekeepers. To understand family members' experiences of communication and care, we use the theory of institutional betrayal to interpret the negative impacts of episodic and systemic communication failures during restricted visiting. Family members of the most vulnerable patients (and patients) experienced short- and long-term effects including anxiety, fear, and refusal of further care. Our analysis draws attention to the complex ways that hospital care providers and families of hospitalized surgical patients sought to establish and reconfigure how trust and patient-centeredness could be achieved under these unprecedented conditions. Practical learnings from this study suggest that if family presence in hospitals must be limited in the future, dedicated personnel for communication and emotional support for patients, families and staff must be prioritized.

### 1. Introduction

When the COVID-19 pandemic was declared, restricted visitor presence in healthcare settings was a widespread public health intervention implemented to manage physical distancing, preserve resources and mitigate the virus's spread (Fancott et al., 2021; Jaswaney et al., 2021; Munshi, Evans, & Razak, 2021; Weiner et al., 2021). In Canada and elsewhere, most acute care settings strictly limited access only to individuals requiring essential inpatient or outpatient care. For COVID-positive and non-COVID patients, accompaniment inside

hospitals by a caregiver, family member or any support person was, in most cases, completely prohibited.

From the outset, there was clear recognition that restrictions on hospital visitors introduced during the pandemic challenged fundamental concepts that have long been central to most hospitals' mission and values (Dokken, Johnson, & Markwell, 2021; Voo, Lederman, & Kaur, 2020). For the last 20 years, person- and family-centered care (also called patient-centered, client-centered or personalized care) has been the dominant approach in healthcare. Person- and family-centered care promotes partnership, respect and collaboration with patients and

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families in planning and delivering their care, and has become synonymous with high quality care (Institute of Medicine (US) Committee on Quality of Health Care in America, 2001). In the hospital setting, it is enacted through patient and family engagement in quality and safety initiatives; shared decision-making approaches in treatment; and, importantly, flexible or open visiting policies (Barry & Edgman-Levitan, 2012; Ontario Hospital Association, 2021; Hurst, Griffiths, Hunt, & Martinez, 2019; NEJM Catalyst, 2017). During the early pandemic months, the implementation of restrictive measures that prohibited most visitors in the hospital made it more difficult, if not impossible for some, to maintain the open communication and engagement practices that have firmly embedded the person- and family-centered paradigm in clinical settings. Ongoing, though less stringent, restrictions to visitor presence have continued to the present.

In the beginning of the pandemic, when less was known about the virus's etiology and transmission routes, restrictive visiting policies sought to balance the risks and benefits of hospital visiting to patients, families and hospital staff (Arora, Mauch, & Gibson, 2020; Munshi et al., 2021; Virani et al., 2020). However, shortly after these policies were enacted, reports surfaced describing hospitalized patients' fear, loneliness, and isolation (Annear, 2020; Goldman, 2020; Munshi, Odutayo, et al., 2021; Vais, 2021). Beyond patients' suffering, family members described negative and even harmful experiences resulting from significant barriers to collaborating with care providers (Bronsther, 2020; Kucirek et al., 2021), and communicating with and caring for loved ones in intensive care (Andrist, Clarke, & Harding, 2020; Hochendoner et al., 2022; Kentish-Barnes et al., 2021). Many hospital providers also reported significant psychological burden and moral distress due to visitor restrictions (Annear, 2020; Goldman, 2020; Moss et al., 2021; Munshi et al., 2021; Munshi, Odutayo, et al., 2021; Vais, 2021). This moral distress was particularly reported among clinicians caring for very sick and dying patients who, they felt, suffered deeply in the absence of in-person family comfort and support (Azoulay et al., 2020; Jones-Bonfiglio, Nortjé, Webster, & Garros, 2021; Wendlandt, Kime, & Carson, 2022).

For hospitalized surgical patients, family and other support persons – collectively called “care partners” – the absence of visitors posed significant challenges. This is because care partners often provide important non-medical care that is needed to optimize a person's in-hospital recovery (Eskes, Schreuder, Vermeulen, Nieveen van Dijkum, & Chaboyer, 2019; Schreuder, Eskes, van Langen, van Dieren, & Nieveen van Dijkum, 2019; Yun et al., 2020). For example, helping with tasks at the bedside, personal hygiene, eating, or drinking. It also involves supportive emotional care, assistance getting in and out of bed, and advocating for a patient's care plan. Under ordinary circumstances, care partners could be present at the bedside to communicate routinely with the health care team. Under restricted visitor measures, however, communication between patients and their care partners, and care partners and care providers, shifted to virtual care modalities (telephone and/or video calls). Care partner absence at the bedside thus left a notable gap in resources and care for both patients and their health care teams. This gap has not yet been explored from the perspectives of care partners or hospital care providers.

This research was conducted to understand the impact of restricted visiting on care partners and care providers of hospitalized surgical patients in a large Canadian academic hospital during the early months of the COVID-19 pandemic. While quantitative approaches have effectively begun to describe the health outcomes among patients, care partners and providers (Amass et al., 2022), there has been little theoretically informed qualitative research to interpret care partner and provider experiences. We specifically focused on surgical patients who were expected to have a minimum of one-night hospital stay. Previously, surgical patients have reported the importance of emotional support during hospitalization as well poor communication and care coordination (Gottlieb Conn et al., 2018). Thus, care partner presence for these patients is critical. In this article, we draw on principles of public health and

biomedical ethics, and the theory of institutional betrayal (Smith & Freyd, 2014), to explore how care partners and providers experienced visitor restrictions, how they navigated the challenges that were presented, and how doing so impacted their relationships to one another, the institution, and the healthcare system. We aim to offer a transferable theoretical perspective on the impact of restricted visiting that moves beyond a descriptive summary of its local and immediate consequences for individuals, to also account for the broader social effects that visitor restrictions in hospitals during COVID-19 produced.

## 1.1. Theoretical approach

### 1.1.1. Public health and biomedical ethics

Several reports have already described the unprecedented ethical dilemmas that COVID-19 presented in hospitals, from the allocation of personal protective equipment to the rationing of ventilators, and the prioritization and cancellation of scheduled surgeries (Allinson, 2020; Chase, 2020; Demeter, 2021; Dunham, Rieder, & Humbyrd, 2020; Gostin, Friedman, & Wetter, 2020; Voo, Lederman, & Kaur, 2020). Most agree that in implementing pandemic control measures, policymakers and healthcare professionals have had to carefully weigh the risks and benefits to individual and public health. These considerations have been complicated by the divergent operational underpinnings of biomedical and public health ethics frameworks that co-exist in the healthcare system and that have converged during COVID-19 in the bedside practice of many hospital providers. In their everyday clinical work, hospital providers' ethical orientation is typically focused on the individual patient, an approach guided by the biomedical ethics framework described by Beauchamp and Childress over 40 years ago (Beauchamp & Childress, 2001). The framework's four principles – autonomy, beneficence, non-maleficence, and justice – prioritize individual patient interests and health by way of respecting patient choices, acting in patients' best interest, preventing patient harm, and ensuring fairness and equality in patient care (Kenny et al., 2010). This approach foregrounds what is the morally right thing to do for the individual patient, as well as providers' obligations toward patients who are under their care (Demeter, 2021). For example, research to understand the rise in patient demand for aggressive and clinically unnecessary contralateral prophylactic mastectomy (CPM) among women with early stage breast cancer illustrates how surgeons actively navigate these ethical obligations directly at the point-of-care to respect individuals' right to choose treatment (i.e., CPM), but also to prevent undue harm (Schmocker, Conn, Kennedy, Zhong, & Wright, 2019).

By comparison, the public health ethics framework is a utilitarian one that prioritizes collective interests and actions on behalf of the greater good. From this perspective, decisions are made to benefit the majority or many persons, while preserving access to resources in ways that benefit the system and society. Public health ethics frameworks guide public health programs such as cancer screening and surveillance which aim to reduce morbidity and mortality at a population level (Canadian Task Force on Preventive Health Care, 2013; Mokdad et al., 2017). The global response to the COVID-19 pandemic has been largely guided by public health ethics frameworks, such as the one set out in Canada, to support policymakers in ethical deliberations that impact the public's safety and wellbeing (Government of Canada, 2021). The Canadian framework is underpinned by the core values of trust and justice: briefly, that trust is foundational and must exist between persons, organizations and government via transparent decision-making and communication; and, that all persons must be treated equitably based on need and without discrimination. Public health ethics have guided the development of regional and organizational approaches to real world pandemic decision-making in hospitals, including rationing medical equipment, access to non-urgent surgery, and family presence at the bedside (Bardon, 2021; Macleod, Mezher, & Hasan, 2020; Robert et al., 2020; White & Lo, 2020). The experiences of hospital providers in navigating the tensions of co-existing public health and biomedical ethics frameworks through the

implementation of visitor restrictions have not yet been explored.

1.1.2. Institutional betrayal theory

In addition to considering the tension between biomedical and public health ethics frameworks, our study also draws on the theoretical concept of institutional betrayal, coined by Smith and Freyd as institutional action or inaction that intensifies the impact of a traumatic experience (Smith & Freyd, 2014). Institutional betrayal may be experienced by someone when an institution that they trust and depend on for safety and wellbeing fails to protect them from harm, and fails to respond effectively when such harm is disclosed (Smith & Freyd, 2014). Originally developed to understand institutions' roles in peoples' experiences of traumatic harassment, abuse and psychological distress, institutional betrayal has been more recently used to understand unexpected negative experiences in healthcare (Smith, 2017). Examples of institutional betrayal in the medical context might include a patient who experiences harm from a treatment or lack of treatment, and the institution fails to do anything in response. In the United States (US), veterans living with medically unexplained illness after the Gulf War have described experiences consistent with institutional betrayal in health care providers' lack of validation of the existence of their illness and their need for medical intervention (Bloeser et al., 2021). Among Canadians living with chronic disease who have reported negative healthcare experiences, provider and system-level factors, such as poor communication and provider shortages, have been found to contribute to the experience of institutional betrayal (Tamaian, Klest, & Mutschler, 2017). During COVID-19, institutional betrayal has been described among those living in neglected long-term and complex care settings, and among care providers who have been inadequately supported in their safety and wellbeing at work (Klest, Smith, May, McCall-Hosenfeld, & Tamaian, 2020). In the current study, we use the concept of institutional betrayal to think through care partners' narratives of post-operative communication and care during the period of restricted visiting and consider the factors that either mitigated or contributed to experiences of institutional betrayal. In our discussion we explore the potential health and social consequences of these experiences for patients, care partners, and providers.

2. Methods

2.1. Study design and setting

We conducted a qualitative study rooted in an interpretivist ethnographic approach (Sobo, 2009). The study was conducted in a large (1300 inpatient beds) publicly funded Canadian academic hospital in Toronto, Ontario.

Following guidance from the provincial government and Toronto Region COVID-19 Hospital Operations Table, on March 19, 2020, the hospital restricted all visiting (with rare exceptions only). Guidelines put forth by the regional governance table were not prescriptive but aimed to support the standardization of hospital-based policies throughout

Toronto, and intended to inform, rather than limit, the ability for local contextualized decision-making. In the study's hospital, an adapted visitor policy and visitor response guideline were created by the hospital's inter-professional visitors task force, comprised of senior hospital administrators, practice leaders, physicians, risk assessors, an ethicist and patient experience advisors. The guideline delimited phases of restricted visiting from zero to three with recommended levels of organizational response from high to low based on the presence of COVID-19 in the province, community, and hospital; availability of personal protective equipment; overall patient and provider volumes in the hospital; ability of individuals in the building to physically distance; and upholding the hospital's values of person-centered care.

During the study period, the hospital's pandemic response began at the strictest level prohibiting all patient visitation (March–July 2020) (Fig. 1. Visitor restrictions timeline). In July 2020, restrictions transitioned to a high-level category whereby one visitor could see a surgical inpatient daily for 2 h if they had been hospitalized for more than three days. From end of August to mid-October 2020, the hospital moved to an intermediate level whereby two visitors were permitted, one per day, for a 2-h visit. As COVID-19 community transmission increased in October 2020, visiting for surgical inpatients was again limited to patients with hospital stays of three or more days, and visits for 2 h daily. Finally, in January 2021, with continued rising rates of COVID-19, visits were further limited to one visitor per patient, visiting for a maximum of 2 h, twice per week. By end of April 2021, the response returned to a very high level whereby inpatients were limited to one visitor twice per week, after a minimum hospital stay of 14 days. Notably, when the response level transitioned from strictest to high-level, enhanced access was permitted for the sickest and dying patients. Unit managers were empowered in these circumstances to allow one-time compassionate visits. Outside of these criteria, care teams could initiate formal appeals for more frequent or longer family visits, at their discretion. Information about visitor restrictions was posted publicly on the hospital's website, recorded in the hospital's main telephone line greeting, and communicated to patients and families by hospital workers during pre-admission appointments.

Study data were collected from November 2020 to August 2021, reflecting participants' experiences from March 2020 to April 2021. Importantly, during this period, COVID-19 vaccines were not yet available to the public and were limited in distribution to hospital workers. Three 36-bed post-operative surgical units were included in the study, each one staffed by a manager, a team of interprofessional health care professionals and registered nurses. Surgical teams rounded daily on the units. Typical nurse-to-patient assignment was one nurse to four or five patients. Nurse and other healthcare worker shortages have been reported in the province for the last two decades and were only worsened in hospitals during the pandemic (RNAO, 2022; Weikle, 2021). Consistent with previous reports, some nurses, social workers, and other health care staff were internally redeployed to manage COVID-19 patient surges and monitor newly implemented safety measures in non-COVID units (Cadge

Date	Mar 21–Jul 8, 2020	Jul 9–Aug 23, 2020	Aug 24–Oct 8, 2020	Oct 9–Jan 11, 2021	Jan 12–Apr 25, 2021	Apr 26–Jun 10, 2021
Number of Visitors	No visiting	1 visitor	2 visitors	1 visitor	1 visitor	1 visitor
Frequency of Visit	n/a	Daily	1 per day	Daily	Twice per week	Twice per week
Length of Visit	n/a	2 hours	2 hours	2 hours	2 hours	2 hours
Duration of Hospital Stay	n/a	after 3 days	after 3 days	after 3 days	after 3 days	after 14 days

Fig. 1. Timeline of visitor restrictions during study period.

et al., 2021). Participating units experienced historical challenges with staff shortages as well as more episodic challenges during the study period due to increased workload and provider absenteeism.

## 2.2. Participants

We purposively sampled eligible care partners of adult patients undergoing elective (scheduled) or acute care (emergency) general surgery and general surgical oncology procedures after March 19, 2020. Procedures represented ranged from low risk (e.g. gallbladder removal) to high risk (e.g., major liver resection for metastatic cancer). Patients were first approached by a care team member for permission to invite their care partner to the research. With patient permission, we contacted eligible care partners. We sought out care partners of varied patient types (i.e., a maximum variation sample) including older adults, those who spoke English as a second language, and those who experienced cognitive, speech or other impairments (Sobo, 2009). We included individuals who were admitted to the hospital during the different phases of restricted visiting and who had varied lengths of hospital stay. Hospital care providers for general surgery and general surgical oncology inpatients were also purposively sampled reflecting different professional perspectives and experiences with post-operative care and communication roles. In addition to care partners and providers, we selected members of the hospital's visitors' task force to participate.

## 2.3. Data collection and analysis

Semi-structured telephone interviews were conducted by the primary author, a medical anthropologist and embedded scientist in the division of general surgery at the study's hospital. Interview guides were tailored to the different participant types. They were developed collaboratively by the study team, comprised of a social scientist, four surgeon-scientists, a research director, a patient equity manager, a nurse-researcher, a hospital executive, and a patient's care partner. The care partner joined the study team at conception and was neither a study participant nor was their family member admitted for a general surgical diagnosis. Interview questions explored participants' understandings and views on restricted hospital visiting during the pandemic and their personal and professional experiences with post-operative care and communication throughout the study period. Interviews lasted on average 30 min, were recorded and transcribed. After five care partner interviews, the primary author and family member (TM) on the study team independently reviewed and coded transcripts and met to discuss early insights or omissions. The same procedure was followed after three provider interviews between the primary author and one surgeon-scientist (BH). With minor phrasing adjustments, interviews subsequently continued iteratively with inductive coding after each interview by the primary author. After ten care partners and ten providers had been interviewed, the full research team met to conduct an interim analysis regarding emergent study findings and direction. Transcripts were coded on an ongoing basis first descriptively, and then theoretically drawing on ethical frameworks and the theory of institutional betrayal. Preliminary findings were also discussed with the hospital's patient experience advisors whose professional roles were to receive patient and family feedback and respond to requests for permission to visit. Final theoretical analysis was presented to the study team for discussion. Data collection stopped when the authors determined there to be sufficient data redundancy and a point of theoretical saturation had been achieved. Nvivo12 software was used for data organization.

## 2.4. Research ethics

The study was approved by the research ethics board where the study took place. Participants provided either written or verbal informed consent prior to being interviewed.

## 3. Findings

Thirty-four participants were interviewed: 17 hospital providers and 17 care partners. Providers were surgeons, nurses, social workers, spiritual care practitioners, administrators and task force members with one to 29 years of experience working at the hospital. All care partners were family members (hereafter referred to as family members), who were patients' spouses, adult children and siblings. Participant characteristics are detailed in Table 1. Quotes have been de-identified to protect participant anonymity.

First, we present findings of hospital providers' experiences, charting these from March 2020 onward. In the second section, family members' experiences are described.

### 3.1. "You're always trying to balance": hospital providers' experiences

#### 3.1.1. Pandemic onset: mixed feelings

The effort to balance the safety and needs of patients, families and staff was an overarching narrative of hospital providers' early pandemic work experiences when the first wave of cases in the province appeared. From January to July 2020, when no visiting was allowed, many providers felt the tight restrictions were "draconian" (Administrator) and "radical," (Nurse), however, they also supported the policy and viewed it as necessary during a time of tremendous uncertainty about the virus's transmission and how best to protect hospitalized patients and staff. "I initially thought, 'okay, this is what needs to be done to prevent the transmission of the virus,'" explained one surgeon. "And I think all around me everyone was on the same page because it was a new virus, and we didn't have a lot of understanding and the cases were going up."

Following widespread recommendations to shift to virtual care,

**Table 1**  
Participant characteristics.

<b>CARE PROVIDERS</b>	<b>N = 17</b>
Role	
Surgeon	4
Nurse	3
Social Worker	3
Spiritual Care Practitioner	2
Administrator	3
Task Force Member	2
<b>FAMILY MEMBERS</b>	<b>N = 17</b>
Gender	
Male	4
Female	13
Age	
35-54	6
55-74	9
≥75	2
<b>PATIENTS</b>	<b>N = 17</b>
Gender	
Male	13
Female	4
Age	
35-54	2
55-74	10
≥75	5
Visitor restrictions	
No visiting	10
Limited visiting	7
Length of Stay	
≤3	3
4-10	9
10-15	3
≥16	2

surgeons communicated pre-operatively by telephone with patients and families who had scheduled procedures. They had the impression that most were grateful for the opportunity to have their surgery and accepting of the fact that visitors would not be allowed. According to a senior surgeon, *“There was nobody that I spoke to that wasn't aware that we were in the midst of a global pandemic and that drastic measures needed to be taken.”* Following surgery, staff used unit-based iPads, patients' personal mobile phones and, occasionally, their own mobile phones to connect patients with families and to provide bedside updates. Despite knowing about the visiting policy prior to admission, families were found by staff to need lots of emotional support. In recalling how they approached post-operative communication with families during this time, nurses, social workers, and unit managers drew on the public health rationale to remind family members, who were often upset and frustrated, why the policy was in place. A nurse described her empathetic approach to family care, stating, *“I would always say, ‘I hope you understand, with the virus, we're not only protecting the patient but you as well and the staff so that we can continue to do what we're doing.’ Obviously, some family members would be angry for not being able to come in but by reiterating to them its importance, and giving them the time, not brushing them off, it made it easier.”*

Most providers emphasized having had mixed feelings about the visiting restrictions that, while offering protection from COVID-19, potentially impacted patients' and families' ability to cope with their diagnoses and treatments, and to participate in urgent decision-making if needed. A nurse expressed deep empathy for their situations, explaining, *“These families are dealing with a big horrendous event in their lives. Somebody is threatened or could die from surgery. I don't even know how I would react if it was my family member. I would want to be there”.* During this time, patients were observed by staff on the unit to have much lower mood, wandering minds, and difficulties sleeping. Though some supportive care could be given to and from family members by phone, many providers felt this did not compare to being in-person. A spiritual care practitioner, whose role was to provide emotional support at the bedside, characterized the psychological cruelty of the situation and forewarned of potential harms for patients and families, stating, *“I really felt for families who found it so difficult and absolutely understanding. I think it's inhuman in many ways. So the risk of the virus spreading is so high that you have to let go of the benefits of having family members present. But there is a cost to that, it just doesn't happen at no cost. No, it's a very real cost to that.”*

With the first wave of COVID cases, unit staff also experienced significant impact on their own work and wellbeing. A social worker described the *“dual stress”* of protecting oneself from possible COVID exposure and *“the time and hardship”* of adapting one's practice to virtually include family. Patient assessments required more time and staff were challenged to engage the perspectives and preferences of non-English speaking patients more than ever. Planning and executing discharge were felt by social workers to be less optimal without in-person family engagement. And, without family able to accommodate food preferences, nurses and managers felt that post-operative nutrition for some was compromised. Phone calls from family members looking for updates from the unit nursing stations were, in the beginning, constant and time consuming. A nurse described the added time spent at each patient's bedside helping patients and family connect, giving updates and increased emotional support to minimize the calls to the nursing station, stating, *“I figured, I have to make a change, I have to take the time to explain. It took 30 min, but it was the easiest way to communicate with them. At the end of the day, you just had to accept that this was part of your workload. I'm providing one-to-one care, but I have five patients to take care of. And I had to divide myself evenly. You had to give a lot of time to each patient, and I realized that I am now their family member.”* To this end, she noted, while communicating with one patient and family, four other families could be calling the unit for her. One manager described how family absence created bottlenecks in several care processes simultaneously, with the added pressure of impromptu telephone communication, as follows: *“The families play such an important role in understanding what the patient's background is and what their needs are going forward and whatever*

*environment they are going to. It was hard to move patients through the system. It increased a lot of complaints from families about not being informed about what was going on and definitely increased workload not only because nurses were then having to do bedside tasks, but also just the number of phone calls that we would get from family members was overwhelming.”*

At the time of being interviewed for this study, providers reflected on this period as one of uncertainty and heavy demand, but also one where there was a strong sense of blanket protection for patients, families, and themselves. This sense of security was short-lived, however, as one surgeon explained, because the impacts on patients, families, and staff would become significant. In drawing attention to the mounting ethical tensions that providers encountered, he explained how restricted visiting impeded the provision of quality, patient-centered care that was the cornerstone of his surgical practice, stating, *“In the early days of the pandemic, I was thinking this is a good way to protect patients' families and make sure that people aren't exposed by trying to come in and see their loved ones. So, initially I was really focusing on the good public health parts of the policy. But when we tried to work around that and actually provide patient care, holistic patient care, it quickly became apparent there were a lot of barriers.”*

### 3.1.2. After the first wave of cases: pushing the limits

In July 2020 (the second half of the first wave in PROVINCE), the total restriction on visiting was lifted and patients hospitalized for three days or longer were able to receive a daily 2-h visit from one designated person. Patients could identify their authorized care partner whose name was entered electronically to an approved visitor portal. Screening personnel at the hospital's entrance then granted access to approved individuals who would receive the daily, coloured sticker pass to enter the building. This change to the visiting restrictions was mostly welcomed by surgical care providers who very much wanted family members to return. However, the new visiting parameters also introduced new challenges anchored in frontline providers' unforeseen roles in negotiating the new visiting limits with families in their units.

One of the major difficulties encountered at this time related to the inconsistency in rules across the hospital, between and even within units. Though the policy itself was firm, there was leeway at the unit-level to allow more visiting based on perceived patient and family circumstances. Unit managers held influence over this decision; some managers were found to be more flexible than others toward increased visiting which was viewed positively by many staff. While this was a deliberate decision on the part of the task force in recognizing that different patient populations required different considerations, surgical patients and families moving from and to the intensive care unit (ICU) would encounter stricter rules as their conditions improved which was sometimes difficult to understand. A task force member described the rationale behind this decision while acknowledging the potential challenges with perceptions of equitable care, stating, *“We did give enhanced access for areas where patients were the sickest or were dying or had a life altering situation. It's more challenging to implement and it can contribute to that feeling of unclear or differential standard, but there was an underlying rationale and we certainly tried to do our best to communicate to patients and families that it's going to be revisited when you move units, as you get better, for example from ICU to ward. But of course, if you're in that position of having your access curtailed that's not going to be well received generally, regardless of the rationale.”*

Frontline providers therefore described a shift in family members' behaviours when visiting was allowed but limited on the ward. As one unit manager explained, *“Once things started to loosen up a little bit there was a lot more pushing and less understanding for what the rules are.”* While for many families the one-visitor, 2-h limit worked well (particularly for those who had a smooth recovery and foreseeable discharge), for others it was experienced as too restrictive. In addition to the increased number of phone calls from family members needing updates on patient care, nurses and social workers found themselves fielding long and stressful phone calls with family members wishing to negotiate for more time or more visitors. They developed team-based strategies to manage those

families who were most persistent by calling the unit at different times of the day hoping to get different answers from different staff. A nurse described the added pressures staff experienced in response to family requests to escalate their particular case, stating, “At first, we were happy to explain the policy to them, but then it became a burden. They put a lot of pressure on us by asking what they can do, who they can ask, can they speak to the manager, and explaining every reason why they should be there in person.”

Many providers would generously listen to family members “plead their case” for permission to visit more. “I honestly don't think there was a conversation that I had without talking about the visitor policy,” one social worker explained, “and each family will describe why this is a unique situation and why their loved one needs more than one designated visitor and because it's this specific reason but, we always have to go back to what the current policy is.” Despite the widely held view that many hospitalized patients would benefit from at least a one-time compassionate visit, most providers tried to uphold the new restrictions as best they could, making exceptions only for those who met the criteria set out by the task force. This included a patient actively dying, a patient who had lost a family member of their own, or a patient truly needing family support to advance their medical care. Still, nurses in particular described a number of scenarios where they found themselves having to make difficult decisions whether to bend or enforce the visiting limits with families already on the units. For example, some family members were viewed to willfully ignore the 2-h limit. In one unit, gentle reminders were used, including signs on patient doors and overhead speaker announcements that prompted all family members to respect the time, without singling anyone out. Nevertheless, some family members would not comply. Some would stay for extended periods; others would leave but return later. According to staff, some family members, not on the approved list, would lie about their names to hospital screeners only to be discovered once in the patient room. In some cases, those not approved for visiting would find a sticker visitor pass in the trash outside the hospital and use it to get past the front door. Frontline providers struggled in these situations, knowing that visits helped their patients' recoveries, but all the while worried about possible COVID exposure and equity in access to family support. In the tensest situations, they called hospital security to support their efforts to ask families to leave; other times they did nothing. Neither decision was easy, as one nurse explained, “I had a difficult situation where I had to involve security because the family member wouldn't leave. And she thought we were abusing her. We understand how important it is to see your family but at the same time we also have to enforce the policy.”

The distress providers experienced navigating the visitor restrictions on the unit was considerable as they contended with what was in the patients' and others' best interests. They personally struggled to reconcile their roles as patient advocates and patient gatekeepers, and in the absence of face-to-face communication with families, many believed trust was difficult if not impossible to establish. The family member claim of patient mistreatment described by the nurse above was evidence that family members were losing trust in nurses' care. A junior surgeon explained, “I'm invisible to them and they're invisible to me. I find there's a little bit more distrust because people are not there in person. They can't see what's happening and they're frustrated. And so you kind of erode trust in the relationship with the healthcare team.” Other staff described how critical relational components of trust-building were disrupted by family members' absence. A different nurse, for example, described how nurse-family trust-building was thwarted by restricting visiting such that family members could not themselves experience the care, stating, “In normal times, the family comes in, and I don't want to use the word mistrust but there is always hope, and they come with some anxiety and hope that their relatives will have the amount of care that they need. When they see and experience it, there's a level of comfort and it builds relationships, and it helps the nurses. But now that is taken away.” Trust in the hospital more broadly was also perceived to be compromised. A task force member questioned the foundations for family members' expressed fears of inadequate care when appealing for extending visiting, as follows, “[Families] actually fear that their family member will not get the best care if they aren't there. And that to

me is fascinating because this is a fantastic hospital. Our reputation is tremendous and accurate, like we provide amazing care, and our outcomes are amazing. And yet, what we hear from patients and families is that they are worried, that their loved one won't get the proper care. People say, ‘Well, the nurses aren't calling me back and doctors aren't calling back and so I don't know what's happening.’ Basically, I don't know that my family member is getting the care they need. That's what we hear.”

Some staff felt that family members lacked appreciation for what they were going through trying to protect their own loved ones and themselves. A unit manager explained, “It seemed at times they didn't care that we were trying to protect them, and that they didn't care about our safety.” While trying to remain compassionate yet practical, complicated ethical decision-making ensued oftentimes straining family-provider relations. To illustrate this, an administrator recounted the following example,

“We have a patient who has been here for six years. He is completely unconscious, no connection to his family at all. But the family really had become almost part of the unit, like dad was very, very involved and the family were here every single day, 10 hours a day, 365 days a year, for six years. And he wasn't able to visit. So he would somehow get a visitor's sticker off one of the poles in the parking lot and put it on his shirt and sneak in. The patient was in a private room so he would go in and he would close the door. He would come in for short visits. Eventually they had to get security and the police in to have him removed because he was doing this every day. We almost had to take them to court. And the moral distress that that caused the unit and the father it was awful. And, interestingly enough, the father got COVID and when visiting, brought COVID into the unit and took out all kinds of staff with COVID before there was the vaccine which just reinforced that he shouldn't have been there.”

This scenario highlighted the ethical tensions providers faced when in the position to decide between individual and collective patient-family and staff needs, and the potential cascading effects and health outcomes for patients, staff and the hospital. While staff in this example did not formally authorize the family visit, this illustrates the lived tension between empathy and enforcement that they experienced daily even with family members who were well known to them as part of the patient's care team. Moreover, this illustrates the intensity of some family members' experiences of needing to be there regardless of having a prior trusting relationship with the unit staff, their repeated requests not to visit and the active threat of COVID-19 transmission.

### 3.2. “I was never part of the equation”: family members' experiences

Most family members expressed support for restricted visiting despite many concerns that they held about the emotional and physical needs of their loved ones. Participants interviewed were almost evenly split between those who were and were not able to visit post-operatively. Among those who visited or were able to speak directly with their loved one, communication with care teams was generally viewed as good, particularly for those whose recoveries were uncomplicated. However, among the 10 participants who were completely restricted from visiting, seven described experiences consistent with institutional betrayal either in whole or in part. While these participants varied in many ways (by hospital length of stay, patient diagnosis, patient health status, familiarity with the team and hospital, prior experience with the healthcare system), they held in common a view that significant and unresolved communication failures with the hospital team greatly impacted the patient-centeredness and quality of care. When these occurred, family members described a range of perceived physical and mental health impacts, both short- and long-term. In the experience of one spouse, compounded unresolved communication failures over a prolonged hospitalization during restricted visiting were believed to result in the patient's untimely death and poor-quality end of life. Below we explore these participants' views on the factors that helped or hindered their communication and care experiences.

### 3.2.1. Daily verbal updates

The inability to access daily verbal updates about their loved ones post-operatively was the most described communication problem under visiting restrictions. While almost all participants spoke directly with their surgeons after the operation and considered the surgical care to be top-notch, many recounted difficulties thereafter getting information by telephone. Some reported not being able to speak with the patient's nurse, while others reported not being able to connect with anyone. Even when able to speak with the patient, those with hearing or visual impairments were found not able to fully update their family as COVID-issued face masks and shields made it difficult for patients to both recognize and understand staff at the bedside. One participant, whose spouse was not able to communicate with the team in English, explained, *"My husband's English is not good enough to understand everything they asked him, like if they asked how's your pain, he would just say 'okay'. If he needed more tests, he wanted to know why but he couldn't ask, and nobody explained it to me."* With understanding for the pressures that hospital staff faced, participants described an overarching sense of frustration, alienation, and helplessness when they could not get a verbal update. The spouse of a patient who had had a post-operative complication explained how, in her experience, staff appeared to de-prioritize calls from family coming into the nursing station. As a result, she experienced a lack of compassion and broken trust in care. She explained, *"Calling the nursing station was clearly not an option because I got the impression that they didn't like the intrusion. And talking with [patient] was next to impossible until the day before he got out when I could finally get clear texts and phone calls from him. I just needed some way to know that somebody is looking after him. But when I called, I was put on hold, and nobody came to the phone. And that just added to the stress because now I'm thinking, 'okay, nobody even cares about him'."*

Concerns were thus exacerbated when in addition to being unable to speak with a nurse, participants were unable to speak or text with patients directly from their own phones. This was the case for several patients who were physically weak post-operatively, or who experienced in-hospital complications or grief. In these circumstances, when no visiting was allowed and no verbal updates were available, family members described the hospital experience as *"traumatic"* and *"inhuman"* in light of their perceived inability to comfort, intervene or advocate. These experiences highlighted the sense that being there in-person was felt by some family members to be, not only supportive, but life-or-death situations. For example, the son of a patient who was operated on urgently explained that he would have done anything to be at his father's side because his father was already in crisis grieving the recent loss of his mother. He stated, *"Some of the context for this was that his wife died about ten days before his emergency surgery. So, he was in crisis anyway and very much grieving. He had some really unpleasant experiences with tubes down the nose which caused him a lot of bleeding and choking on his own blood which he found really distressing, and it was really hard to hear about that. We only heard those things from him later on. I don't remember getting any report on that from the healthcare team."*

Considering the pressures they recognized at the unit-level, some participants sought alternate ways to access verbal updates, for example, calling the surgeon's office directly and using contacts from clinical research studies. When they led to an update, these efforts reportedly alleviated stress and provided reassurance. Some family members described other attempts to work around the visiting rules to ensure some care oversight, such as trying to hire a private nurse and appealing for a policy exemption. These strategies reflected pushing the limits of restricted visiting, as experienced by frontline providers, but in ways that were not necessarily observable to them. Some such strategies were successful, while others were not. For example, the wife of a newly admitted patient who was screened at the hospital entrance reported, *"You couldn't sweet-talk your way in because I did try."* This occurred when visiting was limited to those in-hospital for a minimum of 3-days, which her husband had not yet achieved. Another participant, the son of an elective surgery patient, described *"cheating the rules"* by knowingly visiting longer than the prescribed 2 h daily; this participant

subsequently advocated for permission to increase their visiting, citing concerns about communication due to language barriers and lack of trust in personalized care due to staff shortages.

### 3.2.2. Systemic failures and complications

Some participants recounted intensely negative experiences during restricted visiting that were characterized by multiple episodes of failed communications (prolonged absence of information) around unexpected medical complications, and inability to advocate such that they reported significant effects on their own and their loved ones' wellbeing after hospitalization. These experiences of more systemic failures were often compounded by patient vulnerabilities, such as impaired hearing or vision, as well as the experience that the onus was entirely on the family to make communication happen. During the time when visiting was permitted, several family members experienced lengthy approval delays such that they were not allowed to enter the hospital until several days after they had expected to. The wife of one patient spoke about her frustrating attempts calling the unit to get on the visitor list during the first week of her husband's complicated admission after an urgent cancer surgery, explaining, *"I was told that I would be allowed to visit. I would have to call the unit to get my permission. And I would be allowed to visit every couple of days. That never happened. I called and I waited, waited all day, every day to get a call to see if I could come in. And many days, I never got a call, even though I would have called in the morning. I called in every morning that could I be put on the visitor list."*

In one instance, the wife of a patient who was called to come into the hospital by the patient's physician (while the patient underwent a risky procedure) was denied access by the screeners because the visit had not been entered to the portal: *"They said, 'Well, the doctor didn't have any authority to tell you that you could come for a visit.'"* Participants reported that these breakdowns in the communication chain contributed to both patient and family stress and led to increased phone calls to the units on the part of family members to sort out hospital access.

Breakdowns in communication with the units around patient care events exacerbated these experiences. For example, a patient's wife explained that after an undisclosed incident whereby her husband became dehydrated, a conversation with him suggested to her that he was confused and possibly in distress. After contacting the unit, the participant described perceived inadequate and worrisome follow up, which were compounded by the effects of a major cancer diagnosis and sub-optimal communication about his care. *"It was pretty traumatic," she explained. "Just actually being in shock of going through that invasive surgery, being given that diagnosis. If I had been there the day that some of those plugs that weren't plugged in, maybe it wouldn't have been so traumatic for him. Because I could have been watching, right? Like, somebody could have been seeing him not feeling well."* Another wife-participant echoed this view, stating, *"They were having shortage of staff problems then. And I could have helped him. I could have helped with his care if they'd let me in there."* These situations reinforced for family the imperative of being there to provide some tangible, concrete care and its importance over any warnings about potential COVID-19 spread. And though they expressed gratitude for the opportunity to have surgery during the pandemic (as mentioned earlier by a surgeon), this gratitude was at odds with the distress they experienced from restricted visiting. For instance, as a result of their hospital experience, a patient's wife described several ongoing psychological symptoms for herself and her husband:

*"We're very thankful that during COVID he was able to have surgery and that doesn't go unnoticed. However, I think it's going to have some pretty long-lasting post traumatic effects. I had to bring him back to our local hospital and that brought everything back when I had to drop him on the doorstep again. I had a panic attack and meltdown, which I'm a very strong person. That's never happened to me. I just don't know how much more of this I can take and I can't even imagine what he was feeling, feeling unwell and having that whole situation happen again with nobody with*



him. He's been having some nightmares. I've been having some dreams. We're dealing with some stuff right now. It's challenging."

Psychological symptoms, such as anxiety and fear of subsequent re-hospitalization, were described by several participants. Some explained that the experience had been so traumatic for the patient that they would likely refuse follow-up cancer surgery if it meant another hospitalization during COVID. The wife of one patient spoke about the immediate and long-term emotional and medical consequences of the hospitalization experience, stating, "I knew that because of COVID there would be no visitors allowed. But in my husband's situation, there was no information about him. No one called us to update, and it was difficult to get help. He had to wait for a long time until somebody would come to help him at the bedside. My husband and I, we just cried on the phone. We felt so helpless. And my husband says, next time, he would rather stay home, even if he needs another surgery. It was a very, very painful and scary experience." Another wife explained similarly how, after her husband's experience, his acceptance of future care was also in question.

"He could not wait to get out of the hospital because he didn't feel safe there. He didn't feel comfortable there. He wanted to be with people that he knew. My fear now is the cancer has come back so there will be more surgery. And now he's terrified of this experience again. My fear right now is that he's going to forego the surgery and the treatment and just let it take its course to avoid the trauma that he had that time. I'm pretty sure we're going to be going through this again, but my fear is he's going to say, 'Forget it. I will just take my chances'."

These experiences of significant communication failures and the associated distress of restricted visiting for patients experiencing complications led family members to describe the overarching sense that they were not part of the equation of patient care during a time when they believed they were needed most.

#### 4. Discussion

Restricted family presence in hospitals during COVID-19 produced significant unintended effects on two deeply embedded social constructs in our healthcare system: trust and patient-centeredness. In foregrounding the ethical tensions that providers experienced in providing hospital care in the absence of family, and the communication-based betrayals that families experienced in light of restricted visiting, our study draws attention to the complex and contested ways that providers and families sought to understand and reconfigure how trust and patient-centeredness might be achieved under these unprecedented conditions.

Both the public health and biomedical ethics approaches to patient care foreground the role of trust. Trust is a multifaceted and complex construct that is a foundational ethical value in healthcare. In public health, trust in healthcare systems and organizations is instilled through the establishment of accessible, safe, evidence-based quality care which contributes to building one dimension of trust: institutional trust (Arakelyan et al., 2021). Institutional trust relies to some extent on an organization's reputation vis-à-vis transparent performance indicators and health outcomes. On the ground, in hospitals and other medical settings, it is another dimension of trust – interpersonal trust – that is developed. Interpersonal trust between patients-families and providers is not necessarily linked to health outcomes the way institutional trust is; rather, it is a relational type of trust affected more by perceived motivations and intentions usually conveyed through communication practices and behaviours, and perceptions of reliability and technical competence (Arakelyan et al., 2021; Blödt, Müller-Nordhorn, Seifert, & Holmberg, 2021; Hall, Dugan, Zheng, & Mishra, 2001). Healthcare encounters are characterized by many different types of interrelated trust, which may be established, broken, and re-established continuously over time (Smith, 2017). Indeed, trust researchers argue that institutional and interpersonal trust are inherently linked, as care experiences and relations between providers and patients-families not only affect the

relational aspects of trust but can in some circumstances influence the stability of institutional trust as well.

Findings from our study illustrate how hospital providers in this acute care setting found themselves in a position where they had to simultaneously navigate both institutional and interpersonal trust with family members who were restricted from visiting. While they sought to maintain family members' confidence in the public health approach by way of upholding a policy to protect patients and society, many experienced and described a significant erosion of trust at the interpersonal level whereby new and existing patient-family relationships and positive communication practices were either fractured or obstructed. Front line providers became responsible for explaining and reiterating continuously to family members the public health rationale for restricted visiting, which became a de facto communication priority. When visiting restrictions loosened on the units, they became responsible for enforcing them despite feeling conflicted about their value. They were subsequently challenged by workloads and time constraints to engage with families about individual patient care and to meaningfully connect and build a trusting interpersonal relationship. While some family members expressed a sustained trust in the system and hospital care, many who were not able to access information about their loved one expressed a loss of interpersonal trust through expressions of increased anxiety, discomfort, and fear that they were not being provided with the best, or even adequate, care. Among patients and families who experienced seemingly insurmountable communication barriers that were perceived to directly impact patient care, patients' plans to subsequently refuse to seek additional care reflected a deeper loss of institutional trust and sense of betrayal. This finding is consistent with Smith's theorization of the relationship between trust and institutional betrayal, whereby negative medical experiences left unaddressed by institutions are posited contributors to refusal of further, though much needed, treatment (Smith, 2017). The potential health consequences of this betrayal could be significant for some surgical oncology patients in this study who described a preference to avoid additional hospital care while restrictions were in place, and may also impact on future health care encounters of all affected patients.

This analysis also reveals the impact of restricted family presence policies on the disruption of person- and family-centered care vis-à-vis communication practices and processes. An abundance of literature has emerged on this topic since public safety measures have been in place, most of which endorses a sensitive and essential prioritization of virtual communication modalities to keep families informed and in the circle of care (Burke, Hampel, Gholson, Zhang, & Ruffkhar, 2021; Hugelius, Harada, & Marutani, 2021). While acceptance and adaptation to remote family engagement was a goal of early pandemic hospital care, a significant learning was that structured and predictable processes for families to communicate with patients and providers were also urgently needed (Ashana & Cox, 2021; Hart, Turnbull, Oppenheim, & Courtright, 2020). Our analysis suggests that establishing these structures and processes for pushing information out to families by a designated communicator should be a priority for communication systems to preserve both interpersonal and institutional trust. In the absence of specific communication processes that were centered around proactively pushing information out to family, and designated personnel to ensure family members' close engagement in care, many family members and healthcare providers in our study suffered. Our findings illustrate how family members of the most vulnerable hospitalized patients, some of whom experienced complications, or were unable to advocate for themselves, had the most intensely negative experiences of being disengaged and perceptions of being disregarded for their roles in patient care. This was exacerbated by their experiences of constantly having to reach out for information, and perceptions of receiving little or no emotional support when doing so. While in pre-pandemic times these circumstances would have signalled the need for more intensive person- and family-centered strategies, in times of restricted visiting, providers' abilities to identify and meet these needs were significantly limited. Strategies to address this have since

been described in the literature demonstrating how interpersonal and institutional trust can be preserved. During its first wave of COVID cases, a Dutch hospital recruited non-ICU medical specialists (oncologists, anesthesiologists, neurologists, geriatricians, pediatricians) to provide daily medical updates about ICU patients to families and found positive impacts offering a sense of transparency and certainty in communication as well as needed emotional support (Klop et al., 2021). An Italian hospital similarly recruited physicians and psychologists to be a daily primary contact for families of COVID-positive patients (Carletto et al., 2021). The redeployment of nurses who were unable to provide bedside care as family communication leads was also an effective family support strategy in a US hospital (Donohue-Ryan & DeLuca, 2021). These studies highlight the effectiveness of systematic, proactive and frequent communication structures and process characterized by reliability and consistency, and which are tailored to patient and family circumstance. Our analysis suggests that interpersonal trust may be maintained when family members are contacted and updated daily by someone who becomes known to the family as the point of contact and has reliable information about the patient. Coordinated implementation and accountability for proactive family communication across the organization are needed to strengthen trust beyond this at the institutional level (Hart et al., 2020).

The ethical tension presented by restricted hospital visiting may be diminished but not resolved by improved communication systems. Thoughtful and continuous consideration and contemplation of the risks and benefits of restricted visiting should include reflections on patient and family experiences and outcomes, such as the ones described in our study, to illuminate situations where proportionality may be in question; that is, where the harm restricted visiting has (or will) cause outweighs the good that is intended. The interpretation of harm should include both the patient and family medical and psychological needs, in the short or long term, and the availability and use of protective measures such as PPE, vaccinations and testing. As data emerges on the effects of restricted visiting for post-operative surgical patients and others (Iness et al., 2022), we must re-visit and adjust our understanding of balance between public health and family-centered care.

#### 4.1. Limitations

Our analysis has limitations. Study participants were recruited from the general surgery program of one Canadian hospital which limits variability in the experiences they shared. While hospitals following similar guidelines may find the experiences here resonate, study findings may not be transferable to those where structured communication and care processes were implemented early in the pandemic. With respect to our sample, it is possible that family members who had more positive hospital experiences did not express interest in this study, however, some participants with shorter hospital stays and uncomplicated recoveries reported positive communication and care, as noted. This study aimed to capture the experiences of a diverse sample of hospital providers and care partners with shared experience of implemented visitor restrictions in one clinical setting. In-depth analysis of the unique experiences of subgroup participant samples, such as surgeons or nurses, was not conducted but may offer further elaboration on this subject. Patient perspectives would also provide an additional lens on the impact of restricted visiting.

#### 5. Conclusion

Hospital providers and families of hospitalized surgical patients have faced what were once unthinkable circumstances, navigating the risks and benefits of family presence during the COVID-19 pandemic. Through the lens of ethical tensions and the theory of institutional betrayal, this analysis has illustrated how their communication and care experiences impacted the establishment and continuity of trust and person- and family-centered care. While the effects of restricted visiting on myriad

health outcomes may never be fully known, continued exploration and elaboration of the experience of restricted visits on providers, patients and families is needed. Learnings from this study suggest that if family presence must be limited in the future, dedicated personnel for communication updates and emotional support for patients, families and staff must be prioritized.

#### Author contributions

The study was conceived by LGC in collaboration with NGC, LdP, JH, LL, TM, RT, FCW, BH. Data were collected by LGC. Data were analysed by LGC in discussion with all authors. All authors provided input to study interpretation. The manuscript was drafted by LGC. All authors critically reviewed the manuscript prior to submission.

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#### Declaration of interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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