**Characterizing family engagement practices in intensive care**

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MSc Thesis

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**Abstract**

**Background:** Family engagement is increasingly recognized as a key component of patient care, especially in intensive care settings. Involving family members in patient care may enhance patient and family outcomes and improve overall care quality. As a result, professional societies support the routine provision of family engagement policies and practices in intensive care settings. However, the actual practices and impact of family engagement in intensive care remain underexplored.

**Objectives:** The overarching aim was to investigate family engagement practices in intensive care. The specific aims were to (1) systematically observe and describe how family members engage in the care of patients within a cardiovascular intensive care unit (CVICU) and (2) explore the relationship between family presence and patient outcomes.

**Methods:** A comprehensive literature search was performed to explore the role of family engagement in ICUs and key engagement domains were defined. The "Direct Observation of Family Engagement Practice in a Cardiovascular Intensive Care Unit" study involved methodical observation to capture and characterize family engagement practices in a CVICU. Observations focused on documenting instances of family presence and participation in patient care activities across multiple sessions.

**Results:** Over a two-month period from October to December 2022, 104 patients were observed, with family present for a majority (59%) of patients. Family engagement was primarily through communication (100%), active family presence (59%), and direct involvement in care tasks (57%). Family presence was associated with reduced 30-day hospital readmission rates but not CVICU or hospital length of stay.

**Conclusions:** By observing family engagement practices in an intensive care setting, the study highlights the various forms of engagement activities that families actively participate in. A relationship between family presence during intensive care stay and patient outcomes was identified. Further research is needed to assess the causal effects of family engagement on patient outcomes, understand the mechanisms behind these effects, and develop standardized tools to measure and improve family engagement activities in ICU settings.

**Résumé**

**Contexte**: La participation des familles devient de plus en plus un élément essentiel dans les soins prodigués aux patients, particulièrement dans le cadre de soins intensifs. La participation des familles pourrait améliorer les conséquences pour les patients et les familles, ainsi que la qualité globale des soins. Par conséquent, les organisations professionnelles encouragent la mise en place systématique de politiques et de pratiques d'implication de la famille dans le cadre des soins intensifs. Néanmoins, les pratiques actuelles et l'impact de l'implication de la famille dans les soins intensifs demeurent insuffisamment explorés.

**Objectifs:** L'objectif général était d'étudier les pratiques d'engagement familial dans les soins intensifs. Les objectifs spécifiques étaient (1) d'observer et de décrire de manière systématique la façon dont les membres de la famille participent aux soins des patients dans le cadre des unités de soins intensifs cardiovasculaires (USIC) et (2) d'explorer la relation entre la présence de la famille et les conséquences pour les patients.

**Méthodes:** Une recherche documentaire exhaustive a été effectuée pour explorer le rôle de l'engagement des familles dans les unités de soins intensifs et les domaines principaux de l'engagement ont été définis. L'étude « Direct Observation of Family Engagement Practice in a Cardiovascular Intensive Care Unit » (Observation directe des pratiques d'engagement familial dans une USIC) a consisté d'une observation méthodique pour capturer et caractériser les pratiques d'engagement familial dans une USIC. Les observations visaient à documenter la présence et la participation des familles aux activités de soins des patients au cours de plusieurs sessions.

**Résultats:** Au cours d'une période de deux mois, entre octobre et décembre 2022, 104 patients ont été observés et la famille était présente pour la majorité (59%) entre eux. L'engagement de la

famille s'est principalement manifesté sous la forme de communication (100 %), d'une présence active (59%) et d'une participation directe aux tâches de soins des patients (57%). La présence de la famille a été associée à une réduction des réadmissions à l'hôpital à 30 jours, mais non à une réduction de la durée de séjour à l'USIC ou à l'hôpital.

**Conclusions:** En observant les pratiques d'engagement de la famille dans le cadre de soins intensifs, cette étude illustre les différentes formes d'activités d'engagement auxquelles la famille participe activement. Une association entre la présence de la famille pendant le séjour en soins intensifs et les conséquences pour le patient a été identifiée. D'autres recherches sont nécessaires pour déterminer les effets causaux de l'engagement familial sur les conséquences pour les patients, comprendre les mécanismes à l'origine de ces effets, et développer des instruments standards permettant la mesure et l'amélioration des activités d'engagement familial dans le cadre des soins intensifs.

**Contribution of Authors**

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Thesis candidate. Performed literature review. Wrote data collection forms, and other study-related documents. Co-developed study design and methodology. Obtained data and assisted in data analysis. Wrote initial manuscripts for the quality improvement study. Presented findings to Master's Thesis Committee, Maurice McGregor Cardiovascular Research Day, McGill University's High Value Healthcare Symposium, and the Canadian Cardiovascular Society's Vascular conference. Wrote thesis document.

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**List of Tables and Figures**

**List of Abbreviations**

| Abbreviation | Definition |
|---|---|
| CVICU | Cardiovascular Intensive Care Unit |
| ER | Emergency Room |
| FCC | Family-Centred Care |
| FST | Family Systems Theory |
| ICU | Intensive Care Unit |
| JGH | Jewish General Hospital |
| PCC | Patient-Centred Care |
| PFCC | Patient- and Family-Centred Care |
| QI | Quality Improvement |
| STROBE | Strengthening the Reporting of Observational Studies in Epidemiology |
| USIC | Unité de Soins Intensifs Cardiovasculaires |

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## Introduction

Hospitalization in an Intensive Care Unit (ICU) is an overwhelming and stressful experience for patients and their families due to the nature of critical illness, the care environment, and the uncertainty surrounding the patient's condition.[1] In such circumstances, families often feel overwhelmed, powerless, and struggle to understand their loved one's condition and treatment plan.[2] This can exacerbate their stress and emotional burden, which may lead to lasting psychological symptoms, such as depression, anxiety and post-traumatic stress.[3]

Engaging families in critical care delivery has emerged as a vital and effective strategy to improve experiences and outcomes for both patients and their families.[4,5] A patient- and family-centred care approach, which has been promoted by medical professional societies, health care organizations, and governmental agencies, emphasizes the importance of engaging patients and families in care.[6-10] Family engagement may include the active involvement of family members in delivering health care services, such as aiding in daily patient care activities, providing emotional support, and participating in communication with healthcare providers.[5,11,12] This approach underscores the collaborative partnership among healthcare providers, patients, and their families, acknowledging the pivotal role that families play in supporting the patient's health and well-being.[12,13] The term 'family' is broadly defined to include anyone whom the patient wants involved in their care and may involve biological, legal, or other connections.[5]

Patient- and family-centred care interventions in the ICU are associated with improvements in patient and family satisfaction, family mental health, and resource utilization, such as decreased ICU length of stay.[4] However, despite evidence supporting the benefits of family engagement in ICU care, a critical gap remains in understanding actual family engagement practice in the ICU setting. While surveys have provided insights into policies and

general practices across ICUs, scant data on how family members are actively involved in patient care remains.[4,14] Understanding the various ways in which families participate in care – whether through decision-making processes, communication with healthcare teams, or direct involvement in daily caregiving activities – is essential to optimize their role in the ICU. Observing and documenting these interactions may provide actionable insights into how families are currently engaging in the ICU, highlighting areas for strengthening practices and identifying gaps in involvement. Furthermore, there is limited knowledge about the impact of the family's role on patient outcomes.[15]

Thus, the objective of this thesis was to explore the specific ways in which families participate in care in a cardiovascular intensive care unit (CVICU). In addition, this thesis will also explore the potential impact of family engagement on patient outcomes.

## Chapter 1: Literature Review

### 1.1 Overview and Rationale

This literature review endeavours to provide an understanding of family engagement in ICU care, its' theoretical underpinnings, current practices, and impact on patient and family outcomes. The review will comprehensively examine family engagement in critical care, exploring the various elements that contribute to its effective implementation and measurement. It will begin with an exploration of the theoretical frameworks and models that support family engagement and patient- and family-centred care. The review will then describe the current practices of family engagement in critical care, detailing the strategies and approaches that healthcare providers use to integrate families into the care process and the impact of family engagement on patient and family outcomes. Finally, known barriers and facilitators to family

engagement in ICU care will be described, identifying the obstacles that hinder effective family participation, and highlighting factors that promote and encourage family involvement.

### 1.2 Theoretical Frameworks and Current Practices of Family Engagement in Critical Care

Patient-Centred Care (PCC) is a fundamental approach to healthcare delivery that personalizes medical treatment and support services to the specific needs, preferences, and values of each patient.[16] This approach endeavours to foster a collaborative and respectful environment for patients and healthcare providers.[17] This involves a paradigm shift that moves away from traditional paternalistic models of care. Instead, it aims to empower patients to actively participate in their own care decisions, ensuring their preferences and values are at the heart of the care they receive.[16,18] The benefits of PCC include improved patient outcomes, greater adherence to treatment plans, increased patient satisfaction, reduced healthcare costs, and more efficient use of healthcare resources.[16,19]

However, PCC may overlook the broader systemic impacts highlighted by Family Systems Theory (FST), which emphasizes the interconnectedness of family dynamics and their influence on various aspects of patient care and outcomes.[20] Family Systems Theory was developed in the mid-20$^{th}$ century as a basis for understanding the shaping of healthcare environments by familial interactions and their impact on those same interactions.[21] FST highlights how family members interact with each other and with other systems.[20,22] It defines a family as an interconnected group of interdependent individuals within a larger network of interacting parts.[20] This theory suggests that changes in one family member may have ripple effects on the entire system, affecting the dynamics and functioning of the family as a whole.[21,22] By applying FST principles, healthcare providers can gain a better understanding of how each family member's actions, roles, and relationships impact the overall family system.[20,23] This

understanding is crucial in critical care settings, where patient outcomes may be influenced by familial support and dynamics.[24] Recognizing and leveraging the principles of FST enables healthcare teams to adopt collaborative approaches that support both patients and their families, thereby enhancing overall care quality and patient and family satisfaction in critical care environments.[20,23,24]

This gap highlights the need for Family-Centred Care (FCC), which extends the focus beyond individual patients to include their families in the care process.[25] FCC represents an evolution beyond PCC, recognizing that healthcare decisions and outcomes are deeply intertwined with family dynamics and support systems.[25,26] Family-centred care is a healthcare approach that prioritizes and respects the unique needs and values of each family.[27] Healthcare providers can gain a better understanding of the broader context in which patients exist and receive care by involving families in the care process. This collaborative approach aims not only to enhance decision-making and communication but also to improve patient and family satisfaction, and ultimately achieve better health outcomes.[28]

Building upon the foundations of both PCC and FCC, Patient- and Family-Centred Care (PFCC) integrates the preferences, values, and needs of both patients and their families into every aspect of care delivery.[29] This approach ensures that care is tailored to meet medical needs while also addressing the emotional, social, and practical aspects of patient and family well-being.[12,30] The four concepts that lie at the heart of PFCC include: (1) Dignity and Respect, (2) Information Sharing, (3) Participation, and (4) Collaboration.[31] The Dignity and Respect domain involves the healthcare team prioritizing and integrating patient and family beliefs, values, and opinions into the care they receive.[31] To achieve this, the care team must build relationships, personalize care, and respect the patient and family's time.[31] Actual practices of Dignity and

Respect may include minimizing wait times, being attentive, expressing empathy, fostering personal connections, practicing cultural competence, and ensuring open communication channels with patients and their families.[30] The Information Sharing domain entails healthcare providers delivering thorough and impartial information to patients and families in a supportive manner, empowering them to actively engage in care and decision-making processes.[31] Information Sharing practices may entail discussions about test results, disease prognosis, treatment options, health-related advice, guidance and support in making decisions, providing educational materials, and the use of technologies to facilitate communication.[30] For the Participation domain, patients and families are encouraged and empowered to actively participate and partner in care and decision-making at their preferred level of engagement.[31] Actual practices entail shared decision-making through understanding the patient and family's values, exploring options, and considering alternatives that align with patient and family decisions and priorities.[30] To foster partnership with patients and their families, the healthcare team may offer guidance and mentoring, recognizing the patient and family's roles and responsibilities in care decisions.[30] The fourth and final domain, Collaboration, involves patients, families, and healthcare providers working together in various aspects of care delivery and improvement, whether that be through patient and family experience surveys or participating in focus groups.[30]

Current practices of family engagement encompass a spectrum of activities that extend beyond mere presence. Olding et al. characterized family engagement in critical care along a spectrum, spanning from passive presence to active involvement.[32,33] The categories identified to classify domains of family engagement in the ICU setting are: (1) Family presence, (2) Family needs, (3) Communication and receiving information, (4) Decision-making, and (5) Contribution to care.[33] The most passive component, 'Family presence', involves the presence of family

members at the bedside or as witnesses to invasive procedures.[34] The 'Family needs' domain, a slightly more active domain than 'family presence', addresses the psychological, social, and physical needs of families, with actual practices including the provision of emotional support through counselling services or arranging accommodations for family members.[35] Actual practices of 'Communication and receiving information' may entail maintaining regular contact between care providers and family, educating families on the patient's condition, and keeping them informed about treatment plans and any changes in the patient's health status.[33,34] 'Decision-making' is a more active form of family engagement that may involve surrogate decision-making, where the family may assume the responsibility of making care decisions for the patient when the patient is unable to do so themselves.[36] Another form is shared decision-making, where the family collaborates with the patient and care providers to make decisions that align with patient and family preferences and values.[8] 'Contribution to care' is the most active form of family engagement and entails family members participating in essential patient care tasks.[33] These tasks may involve families assisting the patient with bathing, massaging, cleaning, emotional support, mobility assistance and delirium detection.[33,34]

While Olding et al.'s model offers a structured framework for categorizing family engagement strategies, the categories are not mutually exclusive and there is significant overlap between them. This spectrum of engagement underscores the complexity and fluidity of family roles in critical care environments. Recognizing and understanding the fluidity and overlaps between these categories is essential for developing effective strategies to engage families. Healthcare providers must be flexible and responsive, adapting their approaches to meet the dynamic needs of both patients and their families.[24] By fostering a collaborative environment and

promoting active family involvement, care teams can enhance the quality of care and improve outcomes for critically ill patients.[33]

Another important framework for understanding patient and family engagement in health and healthcare delivery was proposed by Carman et al.[12] The multidimensional framework proposed occurs along a continuum of engagement from consultation to involvement to partnership and shared leadership.[12] Consultation involves patients participating but possessing restricted power or decision-making authority.[12] Involvement includes patients and families possessing a more active role in discussions and decision-making processes, contributing their perspectives and experiences to inform healthcare practices and policies.[12] Partnership and shared leadership entail patients and families being fully integrated into decision-making processes and sharing authority alongside care providers and leaders.[12] At each stage of the continuum, three different levels of engagement can occur: direct care interactions, organizational design and governance, and policy making.[12] Direct care engagement involves incorporating patients' values, experiences, and perspectives in relation to preventing, diagnosing, and treating conditions.[12] At the level of organization design and governance, engagement integrates patients' and families' values, experiences, and perspectives into the structure and management of healthcare institutions.[12,37] Healthcare institutions may consult patients and families by seeking their feedback through surveys and involving them in hospital advisory councils.[12] At the partnership end of the continuum, patients and families may act as integral decision-makers on hospital safety and quality improvement committees.[12,38] Policy making includes patients and families as equal and active partners in setting priorities and making decisions on health policy, program development, and implementation.[12]

Patient, organizational, and societal factors can influence patient or family readiness and their ability to engage at each level. Patient factors encompass individual attributes such as their beliefs, knowledge and attitudes; organizational factors include policies, practices and resources; and societal factors include social, economic and political influences.[12]

This framework highlights the multifaceted nature of patient and family engagement in healthcare. Carman et al.'s framework complements existing models of PFCC while also providing a comprehensive guide for healthcare providers and administrators to assess, strategize, and implement patient and family engagement initiatives.

By prioritizing the needs of the patient and the family, encouraging collaboration in decision-making, and incorporating patient and family preferences into care practices, the models and frameworks discussed offer important insights on how to improve the delivery of healthcare. With this information, healthcare providers can better address patient and family needs and foster meaningful partnerships with them while enhancing the overall quality of healthcare delivery.

### 1.3 Impact on Patient and Family Outcomes

Engaging families in patient care within critical care settings has been linked to numerous beneficial outcomes. A systematic review of family engagement strategies found that engaging families in critical care delivery leads to improved patient, family, and health care provider outcomes.[39] The engagement interventions that most often led to improvements in family-centred outcomes mainly involved communication and information dissemination.[39] Specific strategies used were giving families educational resources such as pamphlets and videos, including families in patient rounds, providing access to technology (e.g., phone calls, texts, web platform) to facilitate updates from the healthcare team about the patient's condition, and scheduling

regular meetings with specially trained family navigators.[39,40] Providing families with clear and consistent information improves their understanding of the patient's condition and care plan, which also facilitates decision-making.[24,40,41] This increased involvement may reduce the sense of powerlessness and alleviate mental health symptoms experienced by the family, leading to improved family satisfaction with care.[24,39,40,42] Wang et al. identified three studies that reported negative family-centred outcomes. Each of these interventions utilized somewhat depersonalized approaches, such as avatars or letters, and involved following up with family members whose loved ones died in the ICU.[39] These findings underscore the importance of personalized and timely support strategies in family engagement interventions to mitigate negative mental health outcomes.

Another systematic review of family engagement interventions in the ICU illustrated that increased family involvement in critical care benefits not only the family but also patients.[15] Improvements in mental health symptoms, care satisfaction, and health-related quality of life were consistently observed across various studies.[15,39] Furthermore, the literature consistently shows that family engagement interventions, at the very least, are not harmful; there were no interventional studies that lead to worsened patient outcomes.[4,15,39,43]

The benefits of family engagement extend beyond the patient and family to better healthcare system outcomes. Implementing PFCC approaches at the institutional or unit level has led to improvements in employee recruitment and retention, reduced operating costs and costs per case, a decrease in resource utilization, and an increase in the efficiency of care through shorter lengths of stay and reduced diagnostic tests and referrals.[4,13,24,37,44-47] Thus, family engagement in critical care enhances the care experience for patients and families while contributing to the overall effectiveness and sustainability of healthcare systems.

### 1.4 Barriers and Facilitators

Understanding the barriers and facilitators to family engagement in critical care settings is essential for optimizing PFCC and enhancing outcomes for patients, families, and healthcare systems. Barriers and facilitators to family engagement can be studied at the level of the patient and family, provider, and healthcare system.

At the patient and family level, barriers to family involvement in care typically revolve around emotional distress, patient acuity, unrealistic expectations, communication challenges and other personal characteristics, such as personal and cultural beliefs, health literacy, prior experiences with healthcare, and a lack of access to resources.[14,16,34,40,48-54] Facilitators at this level include family presence in the ICU and emotional support, coaching, encouragement, and practical guidance from hospital staff.[16,40,48,51,53,55]

At the provider level, barriers often stem from unsupportive care provider attitudes, inadequate training and support for involving families in care, time constraints due to increased workloads, and resource availability.[16,34,40,51,52,56] Facilitators at this level include comprehensive training programs, support for healthcare providers, characteristics of communication, skills and knowledge, empathy, respect, compassion, and mutual goal setting between patients, families, and providers.[16,34,40,51,56,57]

At the healthcare system level, barriers frequently originate from organization policies or practices that do not prioritize or adequately support family engagement in care, such as visitation restrictions and insufficient training for clinicians, the lack of leadership support, and resource limitations, such as insufficient staffing, environment and budgetary constraints.[16,34,50,51,58] Facilitators at this level include policies and practices promoting family involvement, clinician orientation programs, staff morale and positive staff relations, adequate

personnel and support from individuals in leadership positions, and unit characteristics and resources, such as private rooms, unrestricted visitation policies, educational materials for patients, families, and staff.[48,49,51,54,55] Healthcare teams and organizations can address the challenges at the different levels and implement strategies to support family engagement in intensive care, improving care quality and outcomes.

This review has described the theoretical frameworks, current knowledge base, and challenges and strategies for family engagement in intensive care. Yet there are significant gaps in our understanding of the role of family engagement in the intensive care setting. There is a lack of empirical data on how family members actually engage in care in the intensive care setting. There is also a lack of data on the impact of family presence in the ICU on patient outcomes. Addressing these gaps may provide crucial insights into how involving families more actively in care can potentially enhance patient outcomes, improve overall care satisfaction, and contribute to the development of evidence-based guidelines for family engagement in intensive care settings.

Due to these gaps identified in the literature regarding actual family engagement practices in intensive care and their impacts on patient outcomes, the "Direct Observation of Family Engagement Practice in a Cardiovascular Intensive Care Unit" study was designed to empirically examine how families participate in care and investigate their influence on patient health and recovery.

## Chapter 2: Direct Observation of Family Engagement Practice in a Cardiovascular Intensive Care Unit

The study was presented as an abstract at the Canadian Cardiovascular Congress – Vascular 2023 on October 27th, 2023.

The manuscript has not yet been submitted for publication.

**Direct Observation of Family Engagement Practice in a Cardiovascular Intensive Care Unit**

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**ABSTRACT**

**Background:** Engaging families in care delivery is recommended by cardiovascular and critical care professional societies. However, there is limited data on how family members actually engage in care in the intensive care unit setting and the relationship to patient outcomes.

**Methods:** Family members in a cardiovascular intensive care unit (CVICU) were observed between October and December 2022. Data was collected on family presence, number of family members present, type and amount of engagement activity, and observation time per patient. The type of family engagement observed was categorized as active family presence, communication, direct contribution to care, decision-making, or family needs. The relationship between family presence and patient clinical data was explored.

**Results:** There were 104 patients with 151 observation periods (AM, n=47; PM, n=50; evening, n=55). 74 patients had one observation period and 30 had multiple observation periods. The mean observation time per period per patient was 161.0±47.7 minutes. Most patients (n=61; 58%) had family members visit. The mean number of family members present per period per patient was 1.3±0.6. Family members were present, on average, for 69% of the observation period. The most common types of family engagement domains were communication (n=61; 100%), active family presence (n=36; 59%), and direct contribution to care (n=35; 57%). The most common active family presence activity was presence for physician rounds (n=20; 56%). The most common direct contribution to care activity was assisting with feeding behaviors (n=23; 66%). Patients who had family present were three times less likely to be re-admitted to the hospital at 30 days compared to those without family present (5% vs 16%; P=0.05).

**Conclusion:** This study reported direct observations of family engagement practice in an intensive care setting and explored the association between family presence and patient

outcomes. The data generated will inform efforts to design interventions to increase family engagement in intensive care.

## INTRODUCTION

Family engagement is a collaborative approach to care wherein family members are actively involved in patient care as partners alongside the healthcare team.[1] Engaging families in care is recommended by cardiovascular and critical care professional societies and is recognized as a fundamental goal of healthcare delivery.[2] In critical care settings, where acute illness, sedation, and analgesia may limit the patient's ability to be involved in their own care, family involvement is particularly important.[3] Beyond the family role in providing physical and emotional support to patients, family members may also be involved in communication with the healthcare team, surrogate and shared decision-making, and providing care directly to their loved ones. Family involvement in Intensive Care Unit (ICU) care has been shown to improve the care quality and lead to improved patient- and family-centred outcomes.[4]

Prior studies exploring patient- and family-centred care strategies in the ICU have reported on overall unit practices and policies in critical care settings.[5,6] However, there is limited data on how family members actually engage in care in the ICU. There is also a need to explore the relationship between family engagement practices and patient outcomes. Insufficient knowledge of the actual engagement practices of family members within the ICU environment is a gap in our understanding of the impact of family engagement in patient care.[7,8]

The purpose of this study is to describe the actual engagement practices in a cardiovascular intensive care unit (CVICU) and to explore the relationship between family engagement and patient outcomes. Understanding how family members engage in care is crucial for developing targeted strategies and interventions and, ultimately, improving patient- and family-centred outcomes in the ICU.

## METHODS

### Study Design and Setting

This was a prospective naturalistic observational study in the CVICU of the Jewish General Hospital (JGH), an academic tertiary care center in Montreal, Canada, between October to December 2022. The study was performed as a quality improvement (QI) project and was approved by the institutional quality improvement department. Institutional research ethics approval was subsequently obtained for retrospective patient-level data for this study. The reporting of this study was done in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines.[9,10]

The JGH is situated in an urban setting and has a catchment area of considerable ethnic, cultural, and linguistic diversity. The JGH's CVICU has 16 beds equipped for advanced hemodynamic and ventilator support and admits adult patients with medical and surgical cardiovascular conditions. The CVICU has an open visitation policy and allows family presence at all times. Family visitors receive information regarding the ways in which they can assist with the care of their loved one (i.e., assistance with mobility, oral care, or nutrition). Other family engagement strategies such as family presence during daily team rounds, resuscitation, or invasive procedures and routine structured family care conferences to establish goals of care in high-risk patients are not within the usual standard of practice.

### Participants

All patients who were admitted to the CVICU during the observational periods were included in the study. Family members of these patients were included in the observation. Family members were defined broadly as individuals with a biological, legal, or emotional relationship with the patient, and included anyone whom the patient wished to be involved in their care.[11]

Patients who were in the CVICU but not admitted to the CVICU, such as for a short period of monitoring post-procedure, were excluded from the current study. No formal sample size calculation was performed due to the nature of this observational study.

**Data Sources and Measurement**

Observation sessions took place on weekday mornings (7:30am-11:30am), afternoons (11:30am-3:30pm), and evenings (3:30pm-7:45pm). The dates of observation sessions were discontinuous and were based on study personnel availability. On dates of observation, study personnel systematically walked through the CVICU at 15-minute intervals. Each observation period was carried out in time blocks lasting approximately 2 to 4 hours. Study personnel recorded whether family was present in the patient's room. If family was present in the room, study personnel recorded the number of family members present as well as the specific engagement activities and behaviors observed. Family members were not approached by study personnel in order to conduct observations as unobtrusively as possible.

Family engagement domains in the ICU were categorized based on the classification system developed by Olding and colleagues: family presence, family needs, communication and education, decision-making, and direct care contribution.[12] Within each domain, specific engagement behaviors were identified based on our prior research.[13] Family presence included behaviors such as active family presence during rounds, procedures, and resuscitation, personalization of the patient's room, and passive in-room presence. Communication behaviors encompassed interactions with the patient, nurses, physicians, and other healthcare providers, as well as family members facilitating patient communication with other family members (phone and video calls). Direct contributions to care included mobilizing the patient, grooming and hygiene, feeding, and assisting with medication administration. Decision-making behaviors

involved participation in surrogate or shared decision-making processes. Family needs included the presence of other family members, involvement with social workers, and engagement in educational or informational activities like reading leaflets or watching videos. A checklist was developed for study personnel to record the specific engagement behaviors observed.

**Data Collection**

The following data was collected prospectively by study personnel: observation duration, time of day of observation (AM, PM, EVE), family visitor presence, number of family members present per patient, type of family engagement category, and specific family engagement behaviors or activities. During the data collection process, any behaviors that were not explicitly described or categorized in the checklist were documented under the 'other' category. This ensured that all relevant behaviors observed during the study could be included.

The following patient data was collected from the electronic health record: age, sex, admission for a medical or surgical condition, length of CVICU and overall hospital stay, discharge location, death in hospital, emergency room visit within 30 days or 1 year, and re-hospitalization within 30 days or 1 year.

**Bias**

Bias was minimized by including all admitted patients and their family members who were present.

**Statistical Analysis**

Continuous data are presented as mean with standard deviation and categorical data are presented as frequencies and percentages. Subgroup analyses were performed by categorizing patients into groups based on those with family present versus those without family present. For categorical data, chi-squared tests were used, and Fisher's exact test was employed when two or

more cells had expected counts less than five to ensure robust statistical analysis. For continuous data, between-group differences were tested with the independent samples t-test. All p values are two-sided with values ≤ 0.05 indicating statistical significance. Statistical tests were done using the SPSS 29.0.1.1 statistical software (IBM Corp, Armonk, New York).

**RESULTS**

There were 104 patients observed within 151 observation periods (AM, n=47; PM, n=50; EVE, n=54). 74 patients were observed only for one session and 30 patients were observed over multiple sessions (range 2 to 6 observation periods). The mean observation time per period per patient was 161.2±47.9 minutes. Most patients (n=61; 59%) had family members visit. Family was present for 49% of patients in the morning, 62% of patients in the afternoon, and 54% of patients in the evening. The mean number of family members present per period per patient was 1.3±0.6. Family members were present, on average, for 69% of the observation period.

The most common types of family engagement domains were communication (n=61; 100%; mean time=74.5±39.1 minutes), active family presence (n=36; 59%; mean time=24.7±14.1 minutes), and direct contribution to care (n=35; 57%; mean time=27.8±16.1 minutes; **Figure 1**). The most common communication activity was communication with the patient (n=61; 100%; mean time=70.8±39.6 minutes; **Table 1**). The most common active family presence activity was presence for physician rounds (n=20; 33%; mean time=23.3±10.6 minutes). The most common direct contribution to care activity was assisting with feeding behaviors (n=23; 38%; mean time=25.8±15.1 minutes).

There were no differences in patient age, CVICU length of stay, or hospital length of stay for patients who had family present compared to those who did not have family present during the observation period (all P>0.05; **Table 2**). Patients who had family present were more likely

to die in the hospital as compared to those without family present (10% vs 0%, P=0.04) but, when discharged, were three times less likely to be re-admitted to the hospital at 30-days (5% vs 16%; P=0.05). No significant differences were found in 1-year re-admission rates or 1-year emergency room visits between the groups.

For patients with family present, males were less likely to die and more likely to be discharged home than females (P<0.05 for both; **Supplemental Table S1**). For patients without family present, there were no sex-specific differences in demographic and clinical characteristics.

## DISCUSSION

The purpose of this study was to observe family engagement practices in a CVICU and explore the relationship between family presence and patient outcomes. We found that family presence was common, with 59% of patients observed having family present during an observation period. Family members were primarily engaged in communication, active family presence, and direct contribution to care. Family presence was not associated with CVICU or hospital length of stay but was associated with a reduced likelihood of hospital re-admission.

Prior studies on family engagement in the critical care setting have reported the landscape of family engagement policies and practices but have not described the actual performance of family engagement practices. A survey from the World Federation of Societies of Intensive and Critical Care Medicine of 345 ICUs from 40 countries reported the frequency of how often family engagement strategies were fully, somewhat or not in place.[14] Another survey of 39 cardiac ICUs in the United States and Canada similarly reported on the frequency of family engagement strategies in their institutions.[15] However, neither of these studies reported on how

family members were actually involved in care. There was one observational study of 7 ICUs in Canada that found that a family member was present in only 23% of rounds.[16]

To our knowledge, there has been only one prior study reported in the literature of naturalistic observations of family engagement practices in a critical care environment. Papautsky and colleagues observed family activities in a single medical ICU.[17] The focus of this study was to characterize the interactions of visitors with the clinical care team, as well as the location of these interactions, and to categorize the engagement activities performed. Visitor activities were considered as either information exchanges with the healthcare team or as nonclinical patient care, and then further divided into subcategories. Similar to our study, a trained observer visualized the presence and activities of family members unobtrusively from outside the patient room. They also did not include overnight observations or observations during holiday periods. However, there were several key differences as compared to our study. Our study quantified the time spent performing each engagement activity in a cardiac ICU using established engagement categories, whereas the study by Papautsky and colleagues qualitatively described the type of engagement activities performed and developed a new categorization scheme of engagement activities based on their observations. Our study also explored the relationship between family engagement and patient outcomes. Thus, our study complements and adds to the only prior reported naturalistic observational study in this population and setting.

The most prevalent engagement activities observed were communication with the patient and healthcare team members, active presence during rounds, and direct contribution to patient care. Evidence-based strategies can be implemented into standard critical care practice to support the performance of these activities. ICU communication facilitators have been shown to reduce family depression.[18] Family participation in ICU rounds is another engagement strategy that has

shown promise but has not been widely implemented.[14,15,19] Novel strategies can also be developed to target areas where engagement may be lacking, such as shared decision-making. In addition, many family members may wish to be more involved in care but do not have the knowledge or opportunity on how to increase their level of participation.[20] Digital tools may be a useful approach to instruct family members on how to be more involved in care. There is evidence that the use of digital tools to improve family engagement is feasible and may improve family comprehension and satisfaction.[21]. Further research is needed to understand which engagement strategies family members wish to be more involved in.

Our study advances the understanding of family engagement in ICUs by linking family presence with patient factors and outcomes. We identified an association between family being present during an observation period and reduced likelihood of re-admission following hospital discharge. It is possible that family members who were present were more likely to act as caregivers for ICU survivors, and that ICU survivors who have caregivers were less likely to require hospital re-admission. Family-centred interventions have been shown to improve both patient-centred and clinical outcomes.[22] Our study provides additional evidence of this relationship between family engagement and patient outcomes. Generating evidence that supports the role of family engagement in ICU care is crucial, as a lack of evidence that family engagement improves patient outcomes may be a limiting factor for family engagement uptake in routine critical care delivery.

Another interesting finding is that patients who had family present were more likely to die in the CVICU than those without family present. Family may be more likely to be present when their loved ones are critically ill or in a palliative state, either to spend more time with them or to participate in shared decision-making. The relationship between family presence and

mortality, and the potential linkage between them, needs to be explored in future research studies.

There were several limitations to this study. First, this was an observational study performed in a single CVICU, which limits the generalizability of the findings to other critical care settings or geographic regions. Studies in other ICU settings and locations are warranted to improve the characterization of family involvement in care. Second, detailed family member demographic data was not collected since approaching the family member to collect this data could influence their behavior and skew the naturalistic observations. Family characteristics such as age, gender, race and ethnicity, socioeconomic status, and relationship to the patient may influence family engagement practice. Third, observations were only conducted on weekdays, potentially overlooking variations in family engagement practices on weekends or holidays. Future studies could consider longitudinal data collection spanning multiple days or weeks to provide a more comprehensive understanding of family engagement patterns. Fourth, certain aspects of family engagement, such as private conversations or interactions behind closed curtains, may not have been fully captured during observations. Finally, as an observational study, no determination can be made regarding causality between engagement practices and patient outcomes.

## CONCLUSIONS

Our study represents an initial effort to characterize actual family engagement behaviors in a critical care setting. This information can be used to plan engagement strategies with ICUs. Further studies are needed to better characterize family engagement across a broad range of ICU types and settings.

**REFERENCES**


1. Medicine CotLHCSiAIo. Engaging Patients, Families, and Communities. In: Smith M, Saunders R, Stuckhardt L, McGinnis JM, eds. *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America.* National Academies Press (US); 2013.
2. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, Cox CE, Wunsch H, Wickline MA, Nunnally ME, et al. Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU. *Critical Care Medicine*. 2017;45:103. doi: 10.1097/CCM.0000000000002169
3. Devlin JW, Skrobik Y, Gélinas C, Needham DM, Slooter AJC, Pandharipande PP, Watson PL, Weinhouse GL, Nunnally ME, Rochwerg B, et al. Clinical Practice Guidelines for the Prevention and Management of Pain, Agitation/Sedation, Delirium, Immobility, and Sleep Disruption in Adult Patients in the ICU. *Critical Care Medicine*. 2018;46:e825-e873. doi: 10.1097/ccm.0000000000003299
4. Goldfarb MJ, Bibas L, Bartlett V, Jones H, Khan N. Outcomes of Patient- and Family-Centered Care Interventions in the ICU: A Systematic Review and Meta-Analysis. *Critical Care Medicine*. 2017;45:1751. doi: 10.1097/CCM.0000000000002624
5. Kleinpell R, Heyland DK, Lipman J, Sprung CL, Levy M, Mer M, Koh Y, Davidson J, Taha A, Curtis JR. Patient and family engagement in the ICU: Report from the task force of the World Federation of Societies of Intensive and Critical Care Medicine. *Journal of Critical Care*. 2018;48:251-256. doi: 10.1016/j.jcrc.2018.09.006
6. Burns KEA, McDonald E, Debigaré S, Zamir N, Vasquez M, Piche-Ayotte M, Oczkowski S, Group ftCCCT. Patient and family engagement in patient care and research in Canadian intensive care units: a national survey. *Canadian Journal of*

*Anesthesia/Journal canadien d'anesthésie*. 2022;69:1527-1536. doi: 10.1007/s12630-022-02342-w

7. Goldfarb M, Alviar C, Berg D, Katz J, Lee R, Liu S, Maitz T, Padkins M, Prasad R, Roswell R, et al. Family Engagement in the Adult Cardiac Intensive Care Unit: A Survey of Family Engagement Practices in the Cardiac Critical Care Trials Network. *Circulation: Cardiovascular Quality and Outcomes*. 2023;16:e010084. doi: 10.1161/CIRCOUTCOMES.123.010084
8. McAndrew NS, Jerofke-Owen T, Fortney CA, Costa DK, Hetland B, Guttormson J, Harding E. Systematic review of family engagement interventions in neonatal, paediatric, and adult ICUs. *Nursing in Critical Care*. 2022;27:296-325. doi: 10.1111/nicc.12564
9. Elm Ev, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *Journal of Clinical Epidemiology*. 2008;61:344-349. doi: 10.1016/j.jclinepi.2007.11.008
10. Cuschieri S. The STROBE guidelines. *Saudi Journal of Anaesthesia*. 2019;13:S31. doi: 10.4103/sja.SJA_543_18
11. Brown SM, Rozenblum R, Aboumatar H, Fagan MB, Milic M, Lee BS, Turner K, Frosch DL. Defining Patient and Family Engagement in the Intensive Care Unit. *American Journal of Respiratory and Critical Care Medicine*. 2015;191:358-360. doi: 10.1164/rccm.201410-1936LE
12. Olding M, McMillan SE, Reeves S, Schmitt MH, Puntillo K, Kitto S. Patient and family involvement in adult critical and intensive care settings: a scoping review. *Health Expectations*. 2016;19:1183-1202. doi: 10.1111/hex.12402

13. Goldfarb M, Bibas L, Burns K. Patient and Family Engagement in Care in the Cardiac Intensive Care Unit. *Canadian Journal of Cardiology*. 2020;36:1032-1040. doi: 10.1016/j.cjca.2020.03.037

14. Kleinpell R, Heyland DK, Lipman J, Sprung CL, Levy M, Mer M, Koh Y, Davidson J, Taha A, Curtis JR. Patient and family engagement in the ICU: Report from the task force of the World Federation of Societies of Intensive and Critical Care Medicine. *Journal of critical care*. 2018;48:251-256. doi: 10.1016/j.jcrc.2018.09.006

15. Goldfarb M, Alviar C, Berg D, Katz J, Lee R, Liu S, Maitz T, Padkins M, Prasad R, Roswell R, et al. Family Engagement in the Adult Cardiac Intensive Care Unit: A Survey of Family Engagement Practices in the Cardiac Critical Care Trials Network. *Circ Cardiovasc Qual Outcomes*. 2023:e010084. doi: 10.1161/circoutcomes.123.010084

16. Au SS, Roze des Ordons AL, Parsons Leigh J, Soo A, Guienguere S, Bagshaw SM, Stelfox HT. A Multicenter Observational Study of Family Participation in ICU Rounds. *Crit Care Med*. 2018;46:1255-1262. doi: 10.1097/ccm.0000000000003193

17. Papautsky EL, Abdulbaseer U. Capturing the Work of Patients' Family Members in the Medical Intensive Care Unit Using Naturalistic Observations. *HERD: Health Environments Research & Design Journal*. 2024;17:84-91. doi: 10.1177/19375867231190620

18. Curtis JR, Treece PD, Nielsen EL, Gold J, Ciechanowski PS, Shannon SE, Khandelwal N, Young JP, Engelberg RA. Randomized Trial of Communication Facilitators to Reduce Family Distress and Intensity of End-of-Life Care. *American journal of respiratory and critical care medicine*. 2016;193:154-162. doi: 10.1164/rccm.201505-0900OC

19. Calderone A, Debay V, Goldfarb MJ. Family Presence on Rounds in Adult Critical Care: A Scoping Review. *Crit Care Explor*. 2022;4:e0787. doi: 10.1097/cce.0000000000000787

20. Hetland BD, McAndrew NS, Kupzyk KA, Krutsinger DC, Pozehl BJ, Heusinkvelt JM, Camenzind CE. Family Caregiver Preferences and Contributions Related to Patient Care in the ICU. *West J Nurs Res*. 2021:1939459211062954. doi: 10.1177/01939459211062954

21. Shin JW, Choi J, Tate J. Interventions using digital technology to promote family engagement in the adult intensive care unit: An integrative review. *Heart Lung*. 2022;58:166-178. doi: 10.1016/j.hrtlng.2022.12.004

22. Goldfarb MJ, Bibas L, Bartlett V, Jones H, Khan N. Outcomes of Patient- and Family-Centered Care Interventions in the ICU: A Systematic Review and Meta-Analysis. *Crit Care Med*. 2017;45:1751-1761. doi: 10.1097/ccm.0000000000002624

**Table 1. Percentage of Patients by Family Engagement Domain**

| Family Engagement Domain and Activities | N (%) | Mean duration (mins) ± SD |
|---|---|---|
| **ACTIVE FAMILY PRESENCE** | 36 (59%) | 24.7 ± 14.1 |
| During physician rounds | 20 (33%) | 23.3 ± 10.6 |
| During procedures | 14 (23%) | 20.9 ± 9.4 |
| During resuscitation | 0 (0%) | 0 |
| Personalization of room | 9 (15%) | 20.8 ± 9.0 |
| **COMMUNICATION** | 61 (100%) | 74.5 ± 39.1 |
| With patient | 61 (100%) | 70.8 ± 39.6 |
| With nurses | 45 (74%) | 29.7 ± 16.7 |
| With physicians | 22 (36%) | 18.4 ± 7.6 |
| With other health care professionals | 19 (31%) | 19.7 ± 6.7 |
| Facilitates with others (phone, video, etc.,) | 10 (16%) | 24.0 ± 14.5 |
| **DECISION-MAKING** | 8 (13%) | 16.9 ± 5.3 |
| Surrogate decision-making | 1 (2%) | 30.0 |
| Shared decision-making | 7 (11%) | 15.0 ± 0 |
| **DIRECT CARE** | 35 (57%) | 27.8 ± 16.1 |
| Mobilization | 21 (34%) | 20.0 ± 11.0 |
| Personal hygiene | 11 (18%) | 15.0 ± 0 |
| Feeding | 23 (38%) | 25.8 ± 15.1 |
| Assisting with medication | 2 (3%) | 15.0 ± 0 |
| **FAMILY NEEDS** | 14 (23%) | 15.0 ± 0 |

| | | |
|---|---|---|
| Accompanied by another family member | 9 (15%) | 15.0 ± 0 |
| Involvement with social worker | 1 (2%) | 15.0 |
| Informational intent (reading leaflet, etc.) | 5 (8%) | 15.0 ± 0 |

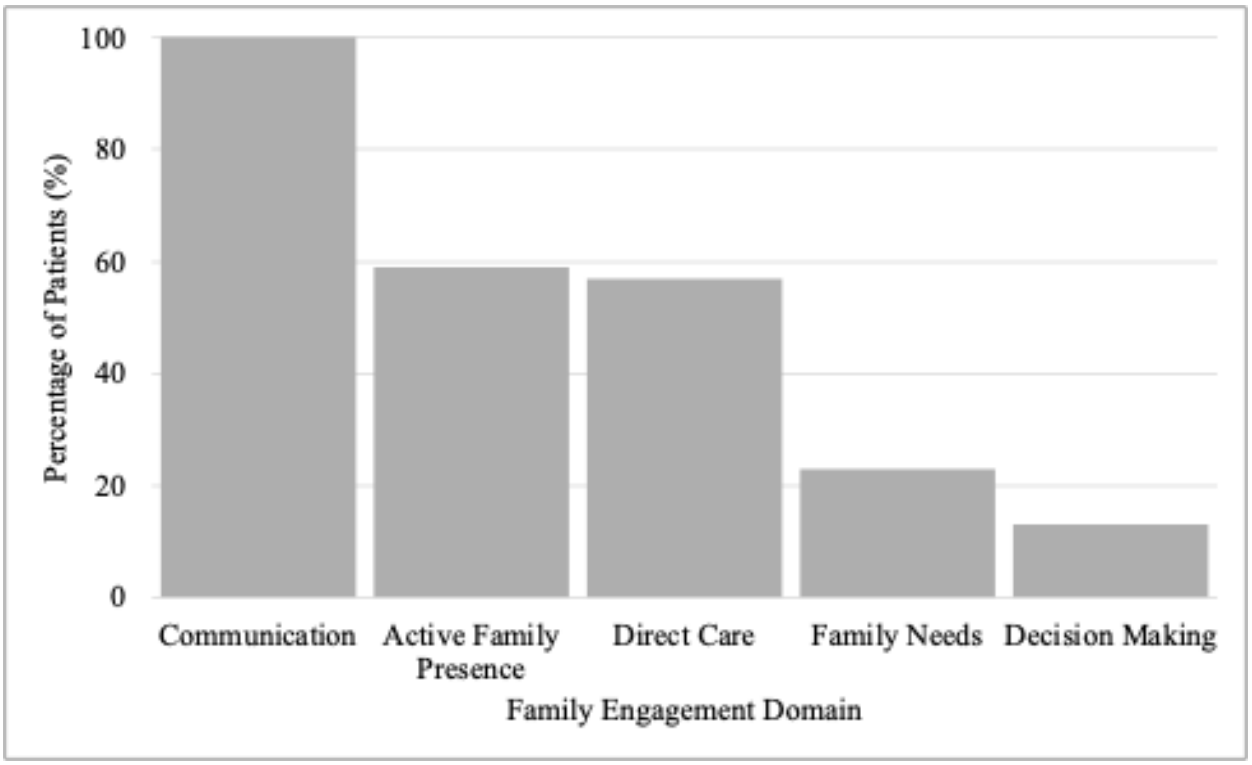
**Legend.** The percentages within each Family Engagement Domain may total more or less than 100% since the activities listed are not mutually exclusive. Families could engage in multiple activities simultaneously within each domain and across different domains; thus, the percentages may overlap within and between domains. For example, within the "Active Family Presence" domain, a family member might be present during physician rounds or procedures and also personalize the room. Concurrently, they could be involved in activities from other domains, such as "Communication", "Decision-Making", "Family Needs", or "Direct Care."

**Table 2. Comparison of Patient Outcomes with and without Family Present in the CVICU**

| | **With family present (N=61)** | **Without family present (N=43)** | ***P*-values** |
|---|---|---|---|
| Age (years) | 72.9 ± 11.4 | 72.2 ± 10.7 | 0.74 |
| CVICU Length of stay (days) | 2.1 ± 2.5 | 2.0 ± 1.9 | 0.96 |
| Hospital length of stay (days) | 14.0 ± 14.4 | 13.4 ± 15.6 | 0.83 |
| **Discharge Destination** | | | |
| Home | 47 (77%) | 36 (84%) | 0.40 |
| Rehab or acute care hospital | 5 (8%) | 6 (14%) | 0.35 |
| Long-term care facility | 3 (5%) | 1 (2%) | 0.64 |
| Death | 6 (10%) | 0 (0%) | 0.04 |
| **Post-Discharge Outcomes** | | | |
| Hospital re-admission at 30-days | 3 (5%) | 7 (16%) | 0.05 |
| Hospital re-admission at 1 year | 17 (28%) | 15 (35%) | 0.45 |
| ER-Visit 30-days | 6 (10%) | 8 (19%) | 0.20 |
| ER-Visit 1 year | 22 (36%) | 17 (40%) | 0.72 |

Abbreviations: CVICU, cardiovascular intensive care unit; ER, emergency room

**Figure 1. Percentage of Patients by Family Engagement Domain**



**Supplemental Table S1. Sex-Specific Comparison of Patient Outcomes With and Without Family Present in the CVICU**

| | **With family present (N=61)** | | ***P*-values** | **Without family present (N=43)** | | ***P*-values** |
|---|---|---|---|---|---|---|
| | **Male (N=38)** | **Female (N=23)** | | **Male (N=26)** | **Female (N=17)** | |
| Age (years) | 70.5 ± 11.6 | 77.0 ± 9.6 | 0.03 | 70.6 ± 11.2 | 74.7 ± 9.6 | 0.23 |
| CVICU length of stay (days) | 2.2 ± 2.2 | 1.9 ± 2.9 | 0.66 | 1.6 ± 0.9 | 2.7 ± 2.8 | 0.16 |
| Hospital length of stay (days) | 12.0 ± 10.6 | 17.4 ± 18.9 | 0.21 | 11.4 ± 17.2 | 16.4 ± 12.6 | 0.32 |
| **Discharge Destination** | | | | | | |
| Home | 33 (87%) | 14 (61%) | 0.02 | 23 (88%) | 13 (76%) | 0.41 |
| Rehab or acute care hospital | 2 (5%) | 3 (13%) | 0.36 | 2 (8%) | 4 (24%) | 0.19 |
| Long-term care facility | 2 (5%) | 1 (4%) | 1.0 | 1 (4%) | 0 (0%) | 1.0 |
| Death | 1 (3%) | 5 (22%) | 0.03 | 0 (0%) | 0 (0%) | N/A |
| **Post-Discharge Outcomes** | | | | | | |
| Re-admission 30-days | 3 (8%) | 0 (0%) | 0.28 | 4 (15%) | 3 (18%) | 1.0 |
| Re-admission 1 year | 11 (29%) | 6 (26%) | 0.81 | 10 (38%) | 5 (29%) | 0.54 |
| ER-Visit 30-days | 5 (13%) | 1 (4%) | 0.40 | 4 (15%) | 4 (24%) | 0.69 |
| ER-Visit 1 year | 13 (34%) | 9 (39%) | 0.70 | 11 (42%) | 6 (35%) | 0.65 |

Abbreviations: CVICU, cardiovascular intensive care unit; ER, emergency room

## Chapter 3: Discussion

Direct observation of family engagement practices in a CVICU yielded a number of important insights. We found that family involvement in the CVICU is common with about 6 in 10 patients observed having family present at some point during the study period. Family also participated in care in multiple ways, including communication, decision-making, hands-on care activities, maintaining an active presence at the patient's bedside, and addressing their own needs through support and educational resources.

Communication emerged as the most prevalent form of engagement, with families consistently interacting with both patients and members of the healthcare team. All family members observed communicated with the patient even though many patients did not appear to be responsive. Nevertheless, families still talked to their loved ones as if they could hear them or used gestures to communicate when the patient was unable to respond verbally due to intubation, oxygen masks, severe respiratory distress, heavy sedation, neurological conditions or postoperative complications. This shows how many families adapt their communication methods – whether through spoken words, gestures, or touch – to maintain a close bond and offer comfort despite the challenging circumstances. Family communication with healthcare team members was also routinely observed, with most interactions occurring between families and nurses more frequently than with any other healthcare team members such as physicians, social workers, patient care assistants, etc. This observation is likely due to nurses' more frequent presence at the patient's bedside due to their role in providing direct care and care coordination, making them the primary point of contact for families seeking information and support.[59] While we observed that families frequently communicated with a healthcare team member, it is the quality of these interactions that plays a key role in ensuring that families feel informed, supported, and involved

in the care of their loved one.[60-62] Existing literature highlights that when communication is clear and effective, families generally feel more comfortable and are more engaged, leading to a more supportive and collaborative environment and better patient- and family-centred outcomes.[62,63] Several factors can influence the effectiveness of the communication between families and the healthcare team, with challenges including health literacy, social and cultural factors, family emotional state, and the healthcare team's competence and willingness to communicate clearly and effectively.[60,63] Differences in health literacy can influence how well families grasp medical terms and instructions, while social and cultural factors like language differences, beliefs and traditions, race, and socioeconomic background can affect how clearly and sensitively information is conveyed.[60,63] Moreover, family members' emotional state, often influenced by stress and anxiety given their circumstances, can impact how well they are able to participate in care conversations.[63,64] In addition, the healthcare team's willingness and competence for communicating clearly and effectively can significantly impact the quality of these interactions, as their ability and readiness to convey information accurately and empathetically directly influences how well families understand and engage in the care process.[63,65,66]

Our findings are consistent with literature emphasizing the importance of communication in improving patient outcomes. A recent review found that effective communication, whether through verbal exchanges, nonverbal gestures, or a mix of both, was essential for improving patient-centred outcomes, such as patient satisfaction, quality of life, and physical and mental health.[67] Improvement in these patient-centred factors was associated with better recovery from illness.[67,68] Our study found an association between family presence and reduced short-term hospital readmissions, but not long-term or emergency room visits, suggesting that family presence and participation in care during admission may be important factors in aiding recovery.

Improvements in communication and understanding of the acute illness through increased family presence enhance patient care and may contribute to lower short-term readmission rates. However, long-term readmission rates and emergency room visits may not be directly affected by family engagement in care, as they are often influenced by factors unrelated to the initial admission.[69-71] Our study did not include family-centred outcomes, which could be explored in future studies.

We also found that family presence varied throughout the day with more frequent visits in the afternoon and evening. ICU team rounds, however, typically occur in the morning.[72] In our study, only one-third of patients with family present at some time during the observation period had family members present during morning rounds. This may result in reduced communication opportunities between the family and the healthcare team. Family participation in ICU team rounds is associated with better patient and family-centred outcomes.[50] Family members who participate in rounds report improved communication and this may be the mechanism that improves patient and family-centred outcomes.[73-76] Thus, it is possible that the absence of family members during these morning rounds could contribute to less favorable outcomes. Families who missed rounds might have had fewer opportunities to engage in care decisions, communicate effectively with the care team, and contribute to the overall patient experience. Consequently, this lack of engagement could potentially affect care satisfaction, quality of care, length of stay, and hospital re-admission rates.[15,77]

Family involvement in decision-making was the least common category of engagement observed. Families often play an integral role as surrogate decision-makers or as part of a shared decision-making approach with the healthcare team. There are several potential explanations for the low frequency of decision-making observed in our study. First, it is possible that family

involvement in decision-making was not part of the culture of the unit observed (i.e., family members may not be invited to participate in decision-making). Second, patients may have been able to participate themselves in the decision-making process. Since we did not collect information on patient acuity, it is possible that patients may have had the capacity to participate in decision-making instead of their family members. Third, much of the decision-making process, particularly about the daily care plan, occurs during morning team rounds. As most patients did not have family present during team rounds, it is possible that this was a missed opportunity to participate in shared decision-making along with the healthcare team. Several ways to increase family participation in decision-making in the ICU setting have been described including appointing family liaisons to facilitate interactions, organizing regular structured family meetings with the healthcare team, incorporating digital tools, and providing family members with validated decision aids.[40,78-81] Decision aids, in particular, have been shown to increase the knowledge level of family surrogate decision-makers and reduce decisional conflict.[80,82]

Family members attending to their own needs were not commonly observed in our study. Families rarely interacted with social workers and had minimal use of informational resources. Yet taking care of family needs is primordial to ensuring that family members are capable of participating in their loved one's care. The ICU experience has been characterized by family members as that of shock and disorientation and more than half of family members report the need for physical, emotional and/or mental support.[2,3] Fostering a family-friendly environment can provide the needed family support and promote greater engagement in care.[40,83,84] Developing policies to ensure families receive adequate support, increasing the availability of educational resources and access to counselling services, and creating a more welcoming

atmosphere can help meet family needs more effectively.[40,49,84] Digital tools may also provide families with access to needed resources in a timely manner.[81]

There may also be racial/ethnic and gender differences in the family engagement in care.[85] An observational study of 226 family members in three ICUs reported that families who self-identify as Black are more likely than White family members to participate in support methods that include touch, personal care, and spiritual care, as well as incorporate audio/sound in their interactions.[85] Gender has also been shown to influence the caregiver role and may influence engagement in ICU care.[86] Due to the naturalistic nature of our study, we did not capture family member demographics. Future studies could explore the ways that different ecological groups engage in care, as this would provide insights into designing interventions for diverse groups.

To encourage effective family engagement and ensure providers can identify and meet family needs, there is a need to educate healthcare professionals on PFCC principles and opportunities. These programs could also focus on cultivating key traits such as respect and empathy and could incorporate training in cultural competence and sensitivity to ensure effective and meaningful engagement with families from diverse backgrounds.[16,30,51] Although this training can lead to improved communication and better relationships with patients and families, efforts to collect data on the impact of PFCC education on professional-family interactions remain scarce.[16,32,87] More research may be required for a better understanding of the effectiveness of these educational programs.

Hospital administrators could also promote family engagement by integrating feedback mechanisms like family satisfaction surveys into their routine care policies. By regularly collecting and analyzing these insights, institutions could identify areas for improvement and

devise strategies accordingly to be responsive to the needs of patients and their families. This approach may help in refining strategies to enhance family engagement and support, potentially leading to better patient- and family-centred outcomes in intensive care settings.

While the observation of actual family engagement practice has provided us with important insights into the family role in intensive care, there is a need to develop other methods that could potentially capture and characterize actual family engagement practice on a wider scale. Recently, the FAMily Engagement (FAME) tool was developed and validated in a single-center study to measure the degree of family engagement in intensive care.[88,89] The FAME tool is a 12-item self-reported questionnaire filled out by family members to report how they are engaged in care. FAME quantifies the 5 engagement domains explored in our study: family presence, family needs, communication, decision-making, and direct care contribution. FAME can be reported as an overall score and as engagement domain scores.[88] Further research is needed to validate FAME in a multicenter cohort and with diverse patient/family populations, as well as to see if the tool can be used in real-time during hospitalization to evaluate the impact of family-centred interventions on family engagement. The FAME tool has the potential to benchmark and compare performance internally and across institutions.

## Conclusions

This was the first study to directly observe and quantitatively report on actual family engagement practices in a critical care setting, as well as to find a relationship between family presence and patient outcomes. The insights gained offer a valuable foundation for developing targeted interventions to increase family engagement in acute cardiovascular and intensive care. These findings suggest a compelling need to integrate structured family engagement practices

into routine ICU care to optimize patient outcomes and enhance overall healthcare delivery. Additional studies investigating PFCC interventions are needed to define evidence-based care strategies, which will inform cardiac and critical care professional society guidelines and change practice. Family engagement improves collaboration between healthcare providers and families and improves the quality of care while also reducing healthcare costs. Building strong partnerships between the medical team, patient, and family is the essence of PFCC and ensures that critically ill patients and their families receive care that meets their specific needs.

**References**


1. Chivukula U, Hariharan M, Rana S, Thomas M, Andrew A. Enhancing Hospital Well-being and Minimizing Intensive Care Unit Trauma: Cushioning Effects of Psychosocial Care. *Indian Journal of Critical Care Medicine : Peer-reviewed, Official Publication of Indian Society of Critical Care Medicine*. 2017;21:640-645. doi: 10.4103/ijccm.IJCCM_468_14
2. Gill M, Bagshaw SM, McKenzie E, Oxland P, Oswell D, Boulton D, Niven DJ, Potestio ML, Shklarov S, Marlett N, et al. Patient and Family Member-Led Research in the Intensive Care Unit: A Novel Approach to Patient-Centered Research. *PLOS ONE*. 2016;11:e0160947. doi: 10.1371/journal.pone.0160947
3. Anderson WG, Arnold RM, Angus DC, Bryce CL. Posttraumatic Stress and Complicated Grief in Family Members of Patients in the Intensive Care Unit. *Journal of General Internal Medicine*. 2008;23:1871-1876. doi: 10.1007/s11606-008-0770-2
4. Goldfarb MJ, Bibas L, Bartlett V, Jones H, Khan N. Outcomes of Patient- and Family-Centered Care Interventions in the ICU: A Systematic Review and Meta-Analysis. *Critical Care Medicine*. 2017;45:1751. doi: 10.1097/CCM.0000000000002624
5. Brown SM, Rozenblum R, Aboumatar H, Fagan MB, Milic M, Lee BS, Turner K, Frosch DL. Defining Patient and Family Engagement in the Intensive Care Unit. *American Journal of Respiratory and Critical Care Medicine*. 2015;191:358-360. doi: 10.1164/rccm.201410-1936LE
6. Canada A. People powered health. 2021.
7. Devlin JW, Skrobik Y, Gelinas C, Needham DM, Slooter AJC, Pandharipande PP, Watson PL, Weinhouse GL, Nunnally ME, Rochwerg B, et al. Clinical Practice

Guidelines for the Prevention and Management of Pain, Agitation/Sedation, Delirium, Immobility, and Sleep Disruption in Adult Patients in the ICU. *Crit Care Med*. 2018;46:e825-e873. doi: 10.1097/ccm.0000000000003299

8. Goldfarb MJ, Bechtel C, Capers Q, de Velasco A, Dodson JA, Jackson JL, Kitko L, Piña IL, Rayner-Hartley E, Wenger NK, et al. Engaging Families in Adult Cardiovascular Care: A Scientific Statement From the American Heart Association. *Journal of the American Heart Association*. 2022;11:e025859. doi: 10.1161/JAHA.122.025859
9. Nickel WK, Weinberger SE, Guze PA, Physicians ftPPiHCotACo. Principles for Patient and Family Partnership in Care: An American College of Physicians Position Paper. *Annals of Internal Medicine*. 2018;169:796-799. doi: 10.7326/M18-0018
10. Quality AfHRa. Guide to Patient and Family Engagement in Hospital Quality and Safety. 2023.
11. Burns KEA, Misak C, Herridge M, Meade MO, Oczkowski S. Patient and Family Engagement in the ICU. Untapped Opportunities and Underrecognized Challenges. *American Journal of Respiratory and Critical Care Medicine*. 2018;198:310-319. doi: 10.1164/rccm.201710-2032CI
12. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, Sweeney J. Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies. *Health Affairs*. 2013;32:223-231. doi: 10.1377/hlthaff.2012.1133
13. Prior SJ, Campbell S. Patient and Family Involvement: A Discussion of Co-Led Redesign of Healthcare Services. *Journal of Participatory Medicine*. 2018;10:e5. doi: 10.2196/jopm.8957

14. Kleinpell R, Heyland DK, Lipman J, Sprung CL, Levy M, Mer M, Koh Y, Davidson J, Taha A, Curtis JR. Patient and family engagement in the ICU: Report from the task force of the World Federation of Societies of Intensive and Critical Care Medicine. *Journal of Critical Care*. 2018;48:251-256. doi: 10.1016/j.jcrc.2018.09.006

15. Duong J, Wang G, Lean G, Slobod D, Goldfarb M. Family-centered interventions and patient outcomes in the adult intensive care unit: A systematic review of randomized controlled trials. *Journal of Critical Care*. 2024;83:154829. doi: 10.1016/j.jcrc.2024.154829

16. Grover S, Fitzpatrick A, Azim FT, Ariza-Vega P, Bellwood P, Burns J, Burton E, Fleig L, Clemson L, Hoppmann CA, et al. Defining and implementing patient-centered care: An umbrella review. *Patient Education and Counseling*. 2022;105:1679-1688. doi: 10.1016/j.pec.2021.11.004

17. Edgman-Levitan S, Schoenbaum SC. Patient-centered care: achieving higher quality by designing care through the patient's eyes. *Israel Journal of Health Policy Research*. 2021;10:1-5. doi: 10.1186/s13584-021-00459-9

18. Kogan AC, Wilber K, Mosqueda L. Person-Centered Care for Older Adults with Chronic Conditions and Functional Impairment: A Systematic Literature Review. *Journal of the American Geriatrics Society*. 2016;64:e1-e7. doi: 10.1111/jgs.13873

19. Santana MJ, Manalili K, Jolley RJ, Zelinsky S, Quan H, Lu M. How to practice person-centred care: A conceptual framework. *Health Expectations*. 2018;21:429-440. doi: 10.1111/hex.12640

20. Mehta A, Cohen SR, Chan LS. Palliative care: A need for a family systems approach. *Palliative & Supportive Care*. 2009;7:235-243. doi: 10.1017/S1478951509000303

21. Wright LM, Leahey M. *Nurses and families: a guide to family assessment and intervention*. F. A. Davis; 2005.

22. Johnson BE, Ray WA. Family Systems Theory. In: *Encyclopedia of Family Studies*. John Wiley & Sons, Ltd; 2016:1-5.

23. Wright LM, Leahey M. Trends in nursing of families. *Journal of Advanced Nursing*. 1990;15:148-154. doi: 10.1111/j.1365-2648.1990.tb01795.x

24. Leon AM, Knapp S. Involving Family Systems in Critical Care Nursing: Challenges and Opportunities. *Dimensions of Critical Care Nursing*. 2008;27:255. doi: 10.1097/01.DCC.0000338866.47164.6d

25. Kokorelias KM, Gignac MAM, Naglie G, Cameron JI. Towards a universal model of family centered care: a scoping review. *BMC Health Services Research*. 2019;19:564. doi: 10.1186/s12913-019-4394-5

26. Johnson BH. Family-centered care: Four decades of progress. *Families, Systems, & Health*. 2000;18:137-156. doi: 10.1037/h0091843

27. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, Cox CE, Wunsch H, Wickline MA, Nunnally ME, et al. Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU. *Critical Care Medicine*. 2017;45:103. doi: 10.1097/CCM.0000000000002169

28. Kuo DZ, Houtrow AJ, Arango P, Kuhlthau KA, Simmons JM, Neff JM. Family-Centered Care: Current Applications and Future Directions in Pediatric Health Care. *Maternal and Child Health Journal*. 2012;16:297-305. doi: 10.1007/s10995-011-0751-7

29. Johnson B, Abraham M, Conway J, Simmons L, Edgman-Levitan S, Sodomka P, Schlucter J, Ford D. *Partnering with Patients and Families to Design a Patient- and*

*Family-Centered Health Care System*. Bethesda, MD: Institute for Patient- and Family-Centered Care.; 2012.

30. Hsu C, Gray MF, Murray L, Abraham M, Nickel W, Sweeney JM, Frosch DL, Mroz TM, Ehrlich K, Johnson B, et al. Actions and processes that patients, family members, and physicians associate with patient- and family-centered care. *BMC Family Practice*. 2019;20:1-11. doi: 10.1186/s12875-019-0918-7

31. Hill C, Knafl KA, Santacroce SJ. Family-Centered Care from the Perspective of Parents of Children Cared for in a Pediatric Intensive Care Unit: An Integrative Review. *Journal of pediatric nursing*. 2017:S0882-5963(0817)30531-30536. doi: 10.1016/j.pedn.2017.11.007

32. Dijkstra BM, Felten-Barentsz KM, van der Valk MJM, Pelgrim T, van der Hoeven HG, Schoonhoven L, Ebben RHA, Vloet LCM. Family participation in essential care activities: Needs, perceptions, preferences, and capacities of intensive care unit patients, relatives, and healthcare providers—An integrative review. *Australian Critical Care*. 2023;36:401-419. doi: 10.1016/j.aucc.2022.02.003

33. Olding M, McMillan SE, Reeves S, Schmitt MH, Puntillo K, Kitto S. Patient and family involvement in adult critical and intensive care settings: a scoping review. *Health Expectations : An International Journal of Public Participation in Health Care and Health Policy*. 2016;19:1183-1202. doi: 10.1111/hex.12402

34. Goldfarb M, Alviar C, Berg D, Katz J, Lee R, Liu S, Maitz T, Padkins M, Prasad R, Roswell R, et al. Family Engagement in the Adult Cardiac Intensive Care Unit: A Survey of Family Engagement Practices in the Cardiac Critical Care Trials Network.

*Circulation: Cardiovascular Quality and Outcomes*. 2023;16:e010084. doi: 10.1161/CIRCOUTCOMES.123.010084

35. Al-Mutair AS, Plummer V, O'Brien A, Clerehan R. Family needs and involvement in the intensive care unit: a literature review. *Journal of Clinical Nursing*. 2013;22:1805-1817. doi: 10.1111/jocn.12065

36. Boyd EA, Lo B, Evans LR, Malvar G, Apatira L, Luce JM, White DB. "It's not just what the doctor tells me:" factors that influence surrogate decision-makers' perceptions of prognosis. *Critical Care Medicine*. 2010;38:1270-1275. doi: 10.1097/CCM.0b013e3181d8a217

37. America CotLHCSi, Medicine Io. Engaging Patients, Families, and Communities. In: Smith M, Saunders R, Stuckhardt L, McGinnis JM, eds. *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America.* National Academies Press (US); 2013.

38. Ponte PR, Conlin G, Conway JB, Grant S, Medeiros C, Nies J, Shulman L, Branowicki P, Conley K. Making patient-centered care come alive: achieving full integration of the patient's perspective. *The Journal of Nursing Administration*. 2003;33:82-90. doi: 10.1097/00005110-200302000-00004

39. Wang G, Antel R, Goldfarb M. The Impact of Randomized Family-Centered Interventions on Family-Centered Outcomes in the Adult Intensive Care Unit: A Systematic Review. *Journal of Intensive Care Medicine*. 2023;38:690-701. doi: 10.1177/08850666231173868

40. Bélanger L, Desmartis M, Coulombe M. Barriers and facilitators to family participation in the care of their hospitalized loved ones. *Patient Experience Journal*. 2018;5:56-65. doi: 10.35680/2372-0247.1250

41. Torbey M. La réponse aux besoins de la famille dans un contexte de soins intensifs : une question d'intégration. 2013;10.

42. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: Postintensive care syndrome–family. *Critical Care Medicine*. 2012;40:618. doi: 10.1097/CCM.0b013e318236ebf9

43. Williams CM. The identification of family members' contribution to patients' care in the intensive care unit: a naturalistic inquiry. *Nursing in Critical Care*. 2005;10:6-14. doi: 10.1111/j.1362-1017.2005.00092.x

44. Charmel PA, Frampton SB. Building the business case for patient-centered care. *Healthcare Financial Management: Journal of the Healthcare Financial Management Association*. 2008;62:80-85.

45. DiGioia AI, Lorenz H, Greenhouse PK, Bertoty DA, Rocks SD. A Patient-Centered Model to Improve Metrics Without Cost Increase: Viewing All Care Through the Eyes of Patients and Families. *JONA: The Journal of Nursing Administration*. 2010;40:540. doi: 10.1097/NNA.0b013e3181fc1

46. Epstein RM, Franks P, Shields CG, Meldrum SC, Miller KN, Campbell TL, Fiscella K. Patient-Centered Communication and Diagnostic Testing. *Annals of Family Medicine*. 2005;3:415-421. doi: 10.1370/afm.348

47. Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, Jordan J. The impact of patient-centered care on outcomes. *The Journal of Family Practice*. 2000;49:796-804.

48. Burns KEA, McDonald E, Debigaré S, Zamir N, Vasquez M, Piche-Ayotte M, Oczkowski S. Patient and family engagement in patient care and research in Canadian intensive care units: a national survey. *Canadian Journal of Anaesthesia*. 2022;69:1527-1536. doi: 10.1007/s12630-022-02342-w

49. Cypress B, Gharzeddine R, Rosemary Fu M, Ransom M, Villarente F, Pitman C. Healthcare professionals perspective of the facilitators and barriers to family engagement during patient-and-family-centered-care interdisciplinary rounds in intensive care unit: A qualitative exploratory study. *Intensive and Critical Care Nursing*. 2024;82:103636. doi: 10.1016/j.iccn.2024.103636

50. Goldfarb M, Bibas L, Burns K. Patient and Family Engagement in Care in the Cardiac Intensive Care Unit. *The Canadian Journal of Cardiology*. 2020;36:1032-1040. doi: 10.1016/j.cjca.2020.03.037

51. Hetland B, McAndrew N, Perazzo J, Hickman R. A qualitative study of factors that influence active family involvement with patient care in the ICU: Survey of critical care nurses. *Intensive and Critical Care Nursing*. 2018;44:67-75. doi: 10.1016/j.iccn.2017.08.008

52. Kiwanuka F, Shayan SJ, Tolulope AA. Barriers to patient and family-centred care in adult intensive care units: A systematic review. *Nursing Open*. 2019;6:676-684. doi: 10.1002/nop2.253

53. Laitinen P, Isola A. Promoting participation of informal caregivers in the hospital care of the elderly patient: informal caregivers' perceptions. *Journal of Advanced Nursing*. 1996;23:942-947. doi: 10.1046/j.1365-2648.1996.09012.x

54. Roze des Ordons AL, Au S, Blades K, Stelfox HT. Family participation in ICU rounds—Working toward improvement. *Journal of Evaluation in Clinical Practice*. 2020;26:1620-1628. doi: 10.1111/jep.13345

55. Lloyd B, Elkins M, Innes L. Barriers and enablers of patient and family centred care in an Australian acute care hospital: Perspectives of health managers. *Patient Experience Journal*. 2018;5:55-64. doi: 10.35680/2372-0247.1270

56. Baerg K, Anderson T, Thiessen H. Six ways to get a grip on patient and family centered care during the undergraduate medical years. *Canadian Medical Education Journal*. 2024;15:78-82. doi: 10.36834/cmej.71342

57. Hamilton R, Kleinpell R, Lipman J, Davidson JE. International facilitators and barriers to family engagement in the ICU: Results of a qualitative analysis. *Journal of Critical Care*. 2020;58:72-77. doi: 10.1016/j.jcrc.2020.04.011

58. Mohammadi N, Seyedfatemi N, Hashemi S. Hindrances to the implementation of family-centered care approach: a grounded theory study. *Revista Latinoamericana de Hipertensión*. 2020;15.

59. Nygaard AM, Haugdahl HS, Laholt H, Brinchmann BS, Lind R. Professionals' narratives of interactions with patients' families in intensive care. *Nursing Ethics*. 2022;29:885-898. doi: 10.1177/09697330211050995

60. Cicekci F, Duran N, Ayhan B, Arican S, Ilban O, Kara I, Turkoglu M, Yildirim F, Hasirci I, Karaibrahimoglu A, et al. The communication between patient relatives and physicians

in intensive care units. *BMC Anesthesiology*. 2017;17:97. doi: 10.1186/s12871-017-0388-1

61. Fernández-Martínez E, Mapango EA, Martínez-Fernández MC, Valle-Barrio V. Family-centred care of patients admitted to the intensive care unit in times of COVID-19: A systematic review. *Intensive & Critical Care Nursing*. 2022;70:103223. doi: 10.1016/j.iccn.2022.103223

62. Reifarth E, Garcia Borrega J, Kochanek M. How to communicate with family members of the critically ill in the intensive care unit: A scoping review. *Intensive and Critical Care Nursing*. 2023;74:103328. doi: 10.1016/j.iccn.2022.103328

63. Jones M. Improving family communication in critical care. *Canadian Journal of Critical Care Nursing*. 2023;34:15-24. doi: 10.5737/23688653-34115

64. Choi J, Hoffman LA, Schulz R, Ren D, Donahoe MP, Given B, Sherwood PR. Health Risk Behaviors in Family Caregivers During Patients' Stay in Intensive Care Units: A Pilot Analysis. *American journal of critical care : an official publication, American Association of Critical-Care Nurses*. 2013;22:41-45. doi: 10.4037/ajcc2013830

65. Kwame A, Petrucka PM. A literature-based study of patient-centered care and communication in nurse-patient interactions: barriers, facilitators, and the way forward. *BMC Nursing*. 2021;20:158. doi: 10.1186/s12912-021-00684-2

66. Kwame A, Petrucka PM. Communication in nurse-patient interaction in healthcare settings in sub-Saharan Africa: A scoping review. *International Journal of Africa Nursing Sciences*. 2020;12:100198. doi: 10.1016/j.ijans.2020.100198

67. Sharkiya SH. Quality communication can improve patient-centred health outcomes among older patients: a rapid review. *BMC Health Services Research*. 2023;23:886. doi: 10.1186/s12913-023-09869-8

68. Lamers SMA, Bolier L, Westerhof GJ, Smit F, Bohlmeijer ET. The impact of emotional well-being on long-term recovery and survival in physical illness: a meta-analysis. *Journal of Behavioral Medicine*. 2012;35:538-547. doi: 10.1007/s10865-011-9379-8

69. Fischer C, Lingsma HF, Marang-van de Mheen PJ, Kringos DS, Klazinga NS, Steyerberg EW. Is the Readmission Rate a Valid Quality Indicator? A Review of the Evidence. *PLoS ONE*. 2014;9:e112282. doi: 10.1371/journal.pone.0112282

70. Ruppert MM, Loftus TJ, Small C, Li H, Ozrazgat-Baslanti T, Balch J, Holmes R, Tighe PJ, Upchurch GRJ, Efron PA, et al. Predictive Modeling for Readmission to Intensive Care: A Systematic Review. *Critical Care Explorations*. 2023;5:e0848. doi: 10.1097/CCE.0000000000000848

71. Kreca SM, Albers IS, Musters SCW, van Dijkum EJMN, Tuinman PR, Eskes AM, Besselink MGH, Bakker CA, van Langen R, Heidsma C, et al. The effect of family-centered care on unplanned emergency room visits, hospital readmissions and intensive care admissions after surgery: a root cause analysis from a prospective multicenter study in the Netherlands. *Patient Safety in Surgery*. 2024;18:14. doi: 10.1186/s13037-024-00399-8

72. Hillmann B, Schwarzkopf D, Manser T, Waydhas C, Riessen R. Structure and concept of ICU rounds: the VIS-ITS survey. *Medizinische Klinik - Intensivmedizin und Notfallmedizin*. 2022;117:276-282. doi: 10.1007/s00063-021-00830-3

73. Jacobowski NL, Girard TD, Mulder JA, Ely EW. Communication in critical care: family rounds in the intensive care unit. *American Journal of Critical Care: An Official Publication, American Association of Critical-Care Nurses*. 2010;19:421-430. doi: 10.4037/ajcc2010656

74. Mangram AJ, McCauley T, Villarreal D, Berne J, Howard D, Dolly A, Norwood S. Families' Perception of the Value of Timed Daily "Family Rounds" in a Trauma ICU. *The American Surgeon™*. 2005;71:886-891. doi: 10.1177/000313480507101021

75. Schiller WR, Anderson BF. Family as a member of the trauma rounds: a strategy for maximized communication. *Journal of Trauma Nursing: The Official Journal of the Society of Trauma Nurses*. 2003;10:93-101. doi: 10.1097/00043860-200310040-00001

76. Simon K, Sankara IR, Gioe C, Newcomb P. Including Family Members in Rounds to Improve Communication in Intensive Care. *Journal of Nursing Care Quality*. 2021;36:25-31. doi: 10.1097/NCQ.0000000000000483

77. Dukhanin V, Dy SM, Sharma R, Vass M, Zhang A, Bass EB, Rosen M. Patient and Family Engagement: Rapid Response. In: *Making Healthcare Safer IV: A Continuous Updating of Patient Safety Harms and Practices*. Rockville (MD): Agency for Healthcare Research and Quality (US); 2023.

78. Goldfarb M. Family Engagement in Critical Care Cardiology: A Guide for Clinicians. *Canadian Journal of Cardiology*. 2023;39:562-565. doi: 10.1016/j.cjca.2022.10.001

79. Mork M, Laxdal G, Wilkinson G. Patient and family engagement in Alberta's Strategic Clinical Networks. *CMAJ*. 2019;191:S4-S6. doi: 10.1503/cmaj.190596

80. Xing Y, Cai W, Wang A, Yuan Y, Zhang R. Effectiveness of decision aids on critically ill patients' outcomes and family members' knowledge, anxiety, depression and decisional

conflict: A systematic review and meta-analysis. *Nursing in Critical Care*. 2024. doi: 10.1111/nicc.13115

81. Shin JW, Choi J, Tate J. Interventions using digital technology to promote family engagement in the adult intensive care unit: An integrative review. *Heart & Lung: The Journal of Critical Care*. 2023;58:166-178. doi: 10.1016/j.hrtlng.2022.12.004

82. Lei Y, Zhou Q, Tao Y. Decision Aids in the ICU: a scoping review. *BMJ Open*. 2023;13:e075239. doi: 10.1136/bmjopen-2023-075239

83. Maxwell KE, Stuenkel D, Saylor C. Needs of family members of critically ill patients: A comparison of nurse and family perceptions. *Heart & Lung: The Journal of Cardiopulmonary and Acute Care*. 2007;36:367-376. doi: 10.1016/j.hrtlng.2007.02.005

84. Tham SS, Solomon P. Family Involvement in Routine Services for Individuals With Severe Mental Illness: Scoping Review of Barriers and Strategies. *Psychiatric Services (Washington, DC)*. 2024:appips20230452. doi: 10.1176/appi.ps.20230452

85. Nunez ER, Villa G, McFadden R, Palmisciano A, Lanini I, O'Mahony S, Curtis JR, Levy MM, Amass T. Differences in Family Involvement in the Bedside Care of Patients in the ICU Based on Self-Identified Race. *Critical Care Explorations*. 2021;3:e0365. doi: 10.1097/CCE.0000000000000365

86. Swinkels J, Tilburg Tv, Verbakel E, Broese van Groenou M. Explaining the Gender Gap in the Caregiving Burden of Partner Caregivers. *The Journals of Gerontology Series B, Psychological Sciences and Social Sciences*. 2019;74:309-317. doi: 10.1093/geronb/gbx036

87. Rossignol L. Relationship between Participation in Patient- and Family-Centered Care Training and Communication Adaptability among Medical Students: Changing Hearts, Changing Minds. *The Permanente Journal*. 2015;19:54-58. doi: 10.7812/TPP/14-110

88. Goldfarb M, Debigaré S, Foster N, Soboleva N, Desrochers F, Craigie L, Burns KEA. Development of a Family Engagement Measure for the Intensive Care Unit. *CJC open*. 2022;4:1006-1011. doi: 10.1016/j.cjco.2022.07.015

89. Hallot S, Debay V, Debigaré S, Foster N, Soboleva N, Burns KEA, Goldfarb M. Validation of an Instrument to Measure Family Engagement in Acute Cardiac Care. *CJC Open*. 2023;5:208-214. doi: 10.1016/j.cjco.2022.11.021