

Université de Montréal

Nurses' perceptions of family involvement in delirium assessment, prevention and management in postoperative cardiac surgery patients

By

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This dissertation is titled:

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Résumé

Introduction: Le délirium est fréquent chez les adultes qui récupèrent d'une chirurgie cardiaque à l'unité de soins intensifs (USI), et les familles sont de plus en plus sollicitées à participer aux soins entourant cette complication. Cette étude avait pour but de décrire la perception qu'ont les infirmières et les infirmiers de la participation des familles dans les soins entourant l'évaluation, la prévention et la gestion du délirium en période postopératoire de chirurgie cardiaque à l'USI.

Méthode: Un échantillon de convenance composé de 6 infirmières et infirmiers (âge moyen 38 ans) a été recruté dans deux USI de Montréal. Après avoir obtenu leur consentement éclairé par écrit, les participantes et participants ont pris part à une entrevue individuelle semi-structurée. Les analyses descriptives ont été réalisées selon la méthode de Braun et Clarke (2006).

Résultats: Cinq thèmes ont été identifiés : 1) les familles peuvent être impliquées dans les soins entourant le délirium quand les patients ont atteint une certaine stabilité, 2) la participation des familles peut être facilitée par l'entremise du transfert d'informations, 3) la contribution des familles est utile pour la détection du délirium, 4) les familles peuvent prendre des mesures concrètes lorsque le délirium survient, et 5) la participation des familles est influencée par certaines caractéristiques.

Conclusions: Cette étude suggère que les infirmières et les infirmiers perçoivent assez favorablement la participation de la famille dans les soins entourant le délirium en période postopératoire de chirurgie cardiaque à l'USI, selon le niveau de préparation et les caractéristiques de celle-ci.

Mots clés: Chirurgie cardiaque, délirium, perception des infirmières, participation de la famille, unité de soins intensifs.

Abstract

Introduction: Delirium is common in adults recovering from cardiac surgery in the intensive care unit (ICU), and families are increasingly solicited to participate in the care surrounding this complication. The aim of this study was to describe nurses' perceptions of family involvement in care surrounding the assessment, prevention and management of delirium in the postoperative period of cardiac surgery in the ICU.

Methods: A convenience sample of 6 nurses (mean age 38 years) was recruited from two Montreal ICUs. After obtaining written informed consent, participants took part in a semi-structured individual interview. Descriptive analyses were performed using the method of Braun and Clarke (2006).

Results: The analysis revealed five themes directly related to nurses' perceptions of family involvement in care of the patient in delirium, namely: 1) families can be involved in delirium care once patients have achieved hemodynamic stability and neurocognitive orientation, 2) family involvement can be facilitated through information transfer, 3) family input is helpful for delirium detection, 4) families can take concrete action when delirium occurs, and 5) family involvement is influenced by certain characteristics.

Conclusions: This study suggests that nurses perceive family involvement in delirium care quite favorably in the postoperative period of cardiac surgery in the ICU, depending on the level of preparation and characteristics of the family.

Keywords: Cardiac surgery, delirium, nurse's perception, family involvement, Intensive Care Unit

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List of acronyms and abbreviations

ABCDEF: A bundle comprising (Assess, prevent, and manage pain; Both Spontaneous Awakening/Breathing Trials; Choice of analgesia and sedation; Delirium: assess, prevent, manage; Early mobility; and Family engagement)

APA: American Psychiatric Association

CAD: Coronary Artery Disease

CABG: Coronary Artery Bypass Graft

CAM-ICU: Confusion Assessment Method–Intensive Care Unit

CCDSS: Canadian Chronic Disease Surveillance System

CEC: Circulation Extra-Corporelle

CFSNT: Calgary Family Systems Nursing Theory

CIUSSS: Centre Intégré Universitaire de Santé et de Services Sociaux

CPB: Cardiopulmonary Bypass

CVA: Cerebrovascular Accidents

DSM-5-TR: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

DPCS: Delirium Post-Cardiac Surgery

EF: Ejection Fraction

FAM-CAM: Family Confusion Assessment Method

Family-HELP: Family Hospital Elder Life Program

FFVM: Flexible Family Visitation Model

FSN: Family Systems Nursing

HbA1C: Hemoglobin A1C

HBP : High Blood Pressure

HELP: Hospital Elder Life Program

HSCM : Hôpital du Sacré-Cœur de Montréal

ICDSC: Intensive Care Delirium Screening Checklist

ICM : Institut de Cardiologie de Montréal

ICU : Intensive Care Unit

LOS: Length of Stay

MI: Myocardial Infarction

MIs : Multi-component Interventions

MMSE: Mini-Mental State Examination

MSICU: Medical Surgical Intensive Care Unit

NCD: Neurocognitive Disorders

NRS: Numeric Rating Scale

P: Participant

PAD: Pain, Agitation, and Delirium

PADIS: Pain, Agitation, Delirium, Immobility and Sleep disruption

POD: Postoperative Delirium

RASS: Richmond Agitation-Sedation Scale

RFVM: Restrictive Family Visitation Model

RN: Registered Nurse

SCCM: Society of Critical Care Medicine

SIGN: The Scottish Intercollegiate Guidelines Network

SIRS: Systemic Inflammatory Response Syndrome

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respects to all the victims who have tragically lost their lives in the pursuit of freedom. We shall never forget those who courageously fought for women's rights, life, and freedom.

Foreword

I recall the initial encounter with a post-cardiac surgery patient in the ICU vividly. It left me profoundly shaken to witness someone in such a critical state despite being a nurse at the time. The predominant emotion I felt was fear. Observing an unconscious patient surrounded by a complex system of wires and tubes, with a dedicated medical team escorting him to the ICU, left me feeling hesitant to approach. This experience helped me empathize with the emotional reactions family members may experience when they encounter their loved ones in a similar post-operative state of cardiac surgery.

The inspiration for my current research project emerged at the beginning of my master's studies when I recognized an opportunity to utilize my extensive nursing experience, particularly in the field of cardiac surgery, where I have over 15 years of practice. In the cardiac surgery ICU in Iran, we regularly involved family members when postoperative delirium occurred. This approach had multiple benefits on my practice: it helped patients reconnect with reality through conversations with their families, reduced aggression towards the healthcare team, and facilitated the challenging care tasks for these vulnerable patients. In my exploration of diverse healthcare environments in Quebec, it became apparent that adopting certain practices was inconsistent across the board. Specifically, in the ICU, I observed a notable variation in the involvement of nurses in deciding whether to adopt or reject specific measures. Moreover, the extent of family involvement in the care of various ICU patients varied significantly. Notably, for cardiac surgery patients who experienced delirium post-surgery, the implementation of this practice varied based on individual ICU system policies or the nurses' familiarity with the approach. This inconsistency led me to realize that the universality of this practice was not evident across different healthcare settings. Based on this valuable experience and my project supervisor's support, I decided to investigate ICU nurses' perceptions of family involvement in the context of post-cardiac surgery delirium. With the guidance of my research co-director, who specializes in delirium post-cardiac surgery, we were able to refine and enhance my research project.

For my patriots who advocate for freedom.

Chapter 1: The research problem

1.1 Problem statement

As per the most recent data from the Canadian Chronic Disease Surveillance System (CCDSS), approximately 1 in 12 Canadian adults aged 20 and over, which equates to 2.6 million individuals, have been diagnosed with heart disease (CCDSS, 2018). Heart disease manifests differently in men and women. Men are twice as likely to experience a heart attack compared to women. Additionally, men tend to be diagnosed with heart disease approximately ten years earlier than women (55–64 vs 65–74 years of age) (CCDSS, 2018). While not all heart disease will necessitate cardiac surgery, coronary artery bypass graft (CABG), as well as heart valve repair and replacement, are among the most common surgical procedures performed in North America (McDermott, Freeman et Elixhauser, 2018). The number of coronary artery angioplasty procedures performed in Canada in 2020-2021 ranked sixth among inpatient surgeries (Michas, 2022). In addition, as the population ages and care become more sophisticated, cardiac surgery is also being performed on older, sicker, and more complicated patients (Kilic et al., 2014).

Post-operative care for the cardiac surgery patient is an essential subspecialty of critical care medicine. Evidence shows that successful outcomes after cardiac surgery depend highly on the quality of interdisciplinary care provided (Williams et al., 2019). In particular, the immediate post-operative period after cardiac surgery in the intensive care unit (ICU) is a dynamic time characterized by hemodynamic lability and significant fluctuations in vascular tone, fluid shifts, and coagulopathy. To achieve the goal of hemodynamic stability, all organ systems must be appropriately managed by specially trained clinicians using various support devices (e.g., mechanical ventilators, intra-aortic balloon pumps, etc.) (Engelman et al., 2019). ICU nurses are crucial in monitoring critically ill post-operative cardiac surgery patients (Vardanjani et al., 2018). Common aspects of nursing care in this patient group include maintaining airway patency, monitoring vital signs, and recording intake and output hourly. Considering cardiac surgery patients are at high risk for developing post-operative complications involving the cardiovascular and respiratory systems, kidneys, and central nervous systems, nurses play a huge role in screening, preventing, and managing these conditions (Vardanjani et al., 2018).

Of all complications, delirium is one of the most common following cardiac surgeries, with an estimated incidence between 17% and 50% (Arenson et al., 2013; Barr et al., 2013; Benkreira et

al., 2019; European Delirium et American Delirium, 2014; Mailhot et al., 2019; McPherson et al., 2013). Delirium is a severe disturbance in mental abilities that results in confused thinking and reduced awareness of the environment (American Psychiatric Association, 2022). There are three main types of delirium: 1) hyperactive, characterized by agitation or aggressive behavior; 2) hypoactive, characterized by withdrawal and decreased consciousness, and 3) mixed, involving a combination of hyperactive and hypoactive symptoms. Following cardiac surgery, the occurrence of delirium gradually increased over time after ICU admission, demonstrating a significant time effect between the first and third day of ICU admission (Mailhot et al., 2019), and it can last anywhere between a few hours to several days (APA, 2022). Evidence suggests that delirium can often be traced to one or more predisposing factors precluding the patient, including smoking, hypertension, cardiac disease, sepsis, and premorbid dementia. Precipitating factors relating to the clinical context include the surgery itself, the presence of a severe medical condition (e.g., unalleviated pain, hypoxemia, low cardiac output, sepsis, etc.), substance intoxication/withdrawal, or multiple causes (APA, 2022).

Independent of its duration and underlying cause, delirium is often disturbing for cardiac surgery patients and their relatives and is associated with worse outcomes than patients with no delirium (Sanson et al., 2018), including increased mortality, morbidity, and long-term cognitive dysfunction (Moskowitz et al., 2017). Delirium has been associated with prolonged psychological distress in both patients and their families, persisting for many years after discharge from the ICU (Boehm et al., 2021). Postoperative delirium extends beyond distressing patients and families, contributing to a significant economic burden on the healthcare system. Research indicates cumulative costs of \$44,291 per patient over a year, while severe delirium results in cumulative costs of \$56,474 during the same period (Gou et al., 2021).

Given the common occurrence of delirium and the adverse outcomes associated with its presence, ICU nurses are typically encouraged to perform routine delirium assessment at least once per shift using a validated screening tool (Engelman et al., 2019). Aside from routine assessment, actively preventing delirium through diverse non-pharmacologic orientation strategies is increasingly recognized as a key piece in enhancing the quality of care in the ICU in general (Devlin et al., 2018). The lack of consensus on the management of delirium in ICU patients further justifies the

importance of preventing delirium. Based on available evidence and position statements, pharmacologic management of delirium begins with assessing the patient's existing medications to determine if anything may be exacerbating or causing the condition (Devlin et al., 2018). Antipsychotic medications have traditionally been the primary approach for treating delirium in critically ill patients (Devlin et al., 2018). However, the latest literature and guidelines from the Society of Critical Care Medicine (SCCM) discourage the routine use of antipsychotics for delirium in critically ill adults (Devlin et al., 2018). Therefore, nonpharmacologic approaches continue to serve as the foundation of delirium management (Devlin et al., 2018; Mart et al., 2021; SIGN-guidelines, 2019).

The adoption of non-pharmacological strategies for delirium management is encapsulated within the ABCDEF bundle (comprising Assess, Prevent, and Manage Pain; Both Spontaneous Awakening/Breathing Trials; Choice of analgesia and sedation; Delirium: Assess, Prevent, Manage; Early Mobility; and Family engagement) in critical care (Marra et al., 2017). These non-pharmacological strategies are primarily derived from the 2013 clinical practice management guidelines titled "Management of Pain, Agitation, and Delirium in Adult Patients in the Intensive Care Unit (ICU PAD)" (Barr et al., 2013a). Simple orientation measures such as the use of clocks, minimizing light/noise, early mobilization, and correcting hearing or visual impairments (through hearing aids or glasses) can be used by nurses to improve patient's cognition and reduce the risk of delirium (Devlin et al., 2018; Soiza et Myint, 2019). Likewise, Siddiqi and colleagues (2016) proposed a multi-component delirium preventive bundle of interventions to promote orientation focusing on early mobilization, cognitive stimulation, display of familiar objects, bowel/bladder care, nutrition/hydration, sleep hygiene, oxygenation, pain management, and many more (Siddiqi et al., 2016). The incidence of delirium could be reduced by up to 19% when ICU nurses use these intervention strategies (Contreras et al., 2021).

The ABCDEF bundle has expanded to encompass family engagement (represented as the 'F') as a crucial component of any ICU treatment plan (Marra et al., 2017). In a broader sense, family engagement includes their active role in caregiving, decision-making, attendance during rounds, presence during procedures like cardiopulmonary resuscitation, and contributing to enhanced patient safety. Active involvement of family members leads to a higher implementation rate of

interventions aimed at reducing and treating delirium. Active family participation increases the implementation of delirium prevention interventions. While open ICU visitation policies are gradually changing worldwide, there is a rising demand to enhance engagement with family members in order to improve patient care and delirium prevention techniques (Morandi et al., 2017). The SCCM has recently released revised guidelines for family-centered care in neonatal, pediatric, and adult ICUs. These guidelines delineate 23 evidence-based strategies to enhance family presence, support, communication, and engagement in the care of ICU patients (Devlin et al., 2018). The recommendations cover a broad spectrum of practices, from common ones like 24-hour ICU visitation policies to more intricate approaches involving the active participation of patients and families in discussions regarding care goals and various ICU activities, such as rounds, early mobility, delirium prevention, and the development of patient- and family-centered policies, as well as the use of ICU diaries. These diverse options offer ICU facilities numerous avenues to enhance patient and family engagement in their units (Devlin et al., 2018).

Although clinicians, patients, and their families generally perceive family presence as facilitating delirium management (Bannon et al., 2018), family involvement in adult ICU is not standardized (Davidson et al., 2017). This may be explained by the fact that the involvement of families in the ICU is a complex and vast phenomenon that includes active actions, such as participation in direct care and the transfer of information (Slettmyr et al., 2022). Also worth mentioning is that family involvement in patient care marks a departure from the disease-centric practice of solely focusing on the physiological care of an individual patient while considering the loved ones and their expertise (Olding et al., 2016). In practice, these changes in the family's role and involvement may lead to mixed feelings for ICU clinicians, particularly nurses (Burns et al., 2018). According to recent studies about delirium, nursing staff reported challenges like increased workload (Agar et al., 2012), stress (Brooke et Manneh, 2018), and frustration (Zamoscik et al., 2017). In another study, nurses managed to provide individualized, person-centered care despite the many challenges faced caring for patients with delirium (LeBlanc et al., 2018). In Canada, Smithburger and colleagues (2017) explored the perceptions of nurses, physicians, and patients' families about current delirium prevention practices. While most physicians (93%) and all nurses believed families could assist with delirium prevention, only 50% reported speaking with family members

about delirium and delirium prevention (Smithburger et al., 2017). Although interesting, the survey format and the focus on delirium-prevention practices did not capture the full scope and depth of nurses' perceptions about family involvement in delirium care in critically ill postoperative cardiac surgery patients.

In summary, delirium is one of the most common complications in post-operative cardiac surgery patients in the ICU. While pharmacological treatments have not proved effective in the prevention and treatment of delirium, several pieces of research show the importance of family involvement as a non-pharmacological strategy for the prevention and management of this condition in critically ill patients who have undergone cardiac surgery (Eghbali-Babadi et al., 2017; Mailhot et al., 2017). Of all healthcare professionals, nurses have the potential to play a leading role in facilitating patient and family involvement surrounding delirium care in the ICU. However, ICU nurses' perceptions of family involvement in this context have not been investigated.

Family Systems Nursing (FSN) is the conceptual systemic lens used to support this study on family participation in critical care. Indeed, the FNS makes it possible to perceive the family as a whole by conceptualizing the links between the evolution of the health problem and family dynamics (Duhamel, 2015; Wright et al., 2014). In addition, this approach promotes collaboration between nurses, patients, and families by avoiding a hierarchical relationship between them (Wright et al., 2014) and recognizing families' expertise and skills in their health experiences (Duhamel, 2015; Wright et al., 2014). As suggested by the FSN theory, involving families in patient care offers vital information and reduces their sense of helplessness. Nurses, concentrating on health promotion and treatment and addressing biopsychosocial issues, can greatly enhance the overall well-being of both patients and their families during difficult circumstances (Wright et Leahey, 1987).

1.2 Goal and research questions

The present study aimed to describe the perceptions of ICU nurses regarding what facilitates or complicates family involvement in the care surrounding the assessment, prevention, and management of delirium in critically ill cardiac surgery patients. Two questions were formulated to meet the study's aim:

1. According to the nurses' perceptions, what are the barriers and facilitators to family involvement in delirium care in the early postoperative days of cardiac surgery in the ICU?
2. How do ICU nurses perceive the benefits of family involvement in terms of delirium care?

Chapter 2: Literature review

2.1 Synthesis of the state of knowledge

This section reviews the theoretical and empirical literature regarding the three main themes under study: delirium after cardiac surgery, the nursing care surrounding this condition in the ICU, and family involvement in post-surgical cardiac surgery care. The FSN conceptual framework and contribution to the present work are also discussed.

2.2 Delirium after cardiac surgery

2.2.1 Definition, classification, and risk factors

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5-TR) defines delirium as "a disturbance in attention and awareness" which can develop in a short period of time (hours to a few days) (APA, 2022). Delirium symptoms (e.g., reduced ability to direct, focus, sustain, and shift attention) and related mental status disruption can vary greatly throughout the day. Conceptually, delirium must be distinguished from confusion and agitation (APA, 2022). According to the DSM-5-TR agitation occurs in several Neurocognitive Disorders (NCD) when a person is confused or frustrated. The main signs of agitation are disruptive motor or vocal activity associated with cognitive impairment at an advanced stage. In particular, it could manifest as combative behavior when resisting caregiving duties, such as bathing and dressing (APA, 2022).

Conversely, delirium, as mentioned previously, can be classified into hyperactive, hypoactive, and mixed subtypes (APA, 2022). In hyperactive delirium, there is excessive psychomotor activity, presenting as agitation, but also hypervigilance and restlessness. Hypoactive delirium, on the other hand manifests as a slow level of activity in which drowsiness and somnolence coexist (in practice, this type remains unrecognized due to its difficulty in detection). A patient with mixed delirium shows both hyperactive and hypoactive delirium; these symptoms appear and fluctuate rapidly over the day or from one day to the other (APA, 2022). The overall incidence of delirium in the ICUs is 45-50% (Contreras et al., 2021; Krewulak et al., 2018), 11% of cases are hypoactive delirium (Krewulak et al., 2018). After cardiac surgery specifically, 17-50% of patients experience delirium (Arenson et al., 2013; Barr et al., 2013; Benkreira et al., 2019; European Delirium et American Delirium, 2014; Mailhot et al., 2019; McPherson et al., 2013).

Various risk factors in the ICU influence the onset of delirium in postoperative cardiac surgery patients. The following tables summarize risk factors related to cardiac surgery patients (Table 1) and precipitating factors associated with cardiac surgery itself (Table 2).

Table 1: Patient-related Risk Factors for Delirium in Cardiac Surgery

Category	Risk Factor	Justification
Sociodemographic characteristics	Age (e.g., > 65 years)	Advanced age (mean age of 70 years) can impact the occurrence of delirium post-cardiac surgery (DPCS).
	Low education level	Low educational level was found to be associated with DPCS.
Pre-operative medical history	Sensory impairment (e.g., vision/hearing)	The likelihood of experiencing DPCS is 16 times higher in the presence of sensory impairment.
	History of hypertension (HBP)	When HBP history is present in over 44% of patients, the occurrence of DPCS exceeds 4.4%.
	Carotid artery disease in the form of stroke or hemorrhage	A history of carotid artery disease may make the occurrence of DPCS 6 times more likely.
	Sleep disorders	Sleep disorders may increase the incidence of DPCS by more than half, reaching 63%.
	History of atrial fibrillation (AF) and arrhythmia	A preoperative history of AF or other arrhythmias may increase the risk of DPCS by approximately 11%.
	Gastritis/ulcer problems	Approximately 4 times more likely to experience DPCS.
	Alcohol use	DPCS is 2.6 times more likely to occur in patients with a history of consuming more than three glasses of alcohol per day.

	Heart failure with a low ejection fraction (EF <30%)	Patients with this risk factor may experience a 4-6% higher incidence of DPCS.
	History of renal disease	A history of renal disease is associated with an 8% higher likelihood of experiencing DPCS.
Pre-operative laboratory values	Diabetes and Elevated preoperative HbA1c level	There is a potential link between diabetes and elevated preoperative HbA1c levels with an increased risk of DPCS in these patients ($\geq 6\%$).
	Low preoperative serum albumin	A decrease of 1 g/L in preoperative serum albumin is associated with a higher risk of DPCS.
Pre-operative mental health status	Preoperative depression	Patients with preoperative depression are at an elevated risk of DPCS. This association may be attributed to factors such as decreased serotonergic activity in the brain, elevated cortisol concentration, and/or poor physical condition.
	Low Mini-Mental State Examination (MMSE) scores	MMSE scores, with a comparison of 27 points versus 28 points, are associated with an increased risk of DPCS.

(Andrási et al., 2022; Cereghetti et al., 2017; H. Chen et al., 2021; Eshmaey et al., 2020; Fatehi Hassanabad et al., 2021; Guenther et al., 2013; Järvelä et al., 2018; Kirfel et al., 2021; Koster et al., 2013; Kotfis et al., 2019; Kotfis et al., 2018; Kumar et al., 2017; Mangusan et al., 2015; Ordóñez-Velasco et Hernández-Leiva, 2021; Sanson et al., 2018; Simeone et al., 2018; Smulter et al., 2013; Sugimura et al., 2020; Tafelmeier et al., 2019; ten Broeke et al., 2018)

Table 2. Procedure-related Risk Factors for Delirium in Cardiac Surgery

Category	Risk Factor	Justification
Intra-operative characteristics	Longer cardiopulmonary bypass (CPB) durations and	Both longer CPB durations (15 to 60 minutes more than average) and extended surgical durations are associated with an increased risk of DPCS.

	longer surgical durations	
	Volume load during operation	High volume given during operation may increase the risk of DPCS 3 times more likely.
	Type of surgery	DPCS is 5.4 times more likely in combined procedures (two or more procedures in the same intervention) than single procedures such as CABG or valve surgery.
Post-operative characteristics	Low cardiac output syndrome	Low cardiac output syndrome is associated with a 30% higher risk of developing DPCS.
	The presence of systemic inflammatory response syndrome (SIRS) in the ICU	SIRS is associated with a high chance of the DPCS (27% more).
	Receiving blood product transfusions	Transfusions during or after cardiac surgery, particularly in relation to intraoperative loss of blood cells, are 1-2 times more likely to be associated with the occurrence of DPCS.
	Longer period of ventilation	The longer the ventilation period, the higher the risk of developing DPCS.
	Post-operative AF	Patients who develop AF after surgery are 1.5 to 4.8 times more likely to experience DPCS.
	Highest temperature recorded and sodium concentration in ICU	The highest temperature recorded in the ICU is associated with a high risk of developing DPCS (2 times more likely). Patients with high sodium concentration in ICU are 1.2 times more likely at risk to develop DPCS.
	Longer ICU stay	Patients with an ICU stay exceeding 4 hours to 10 days are at risk of 1.3 to 3 times more likely to develop DPCS.

Elevated postoperative creatinine	Elevated creatinine after surgery is associated with a high chance of developing DPCS (2.4 times more likely).
Longer hospital stays	Patients with a stay of 3 to 9 days more are at risk of developing DPCS.
Cumulative benzodiazepine/opioids dosages	Post operative high cumulative benzodiazepine/opioids dosages is associated with developing DPCS.
Poor postoperative pain control	Higher pain score on numeric rating scale (NRS) is associated with DPCS.
Chemical/physical restraint use	DPCS is significantly associated with the use of chemical (23%) and physical restraint (34.5%) post surgery.

(Andrási et al., 2022; Cereghetti et al., 2017; H. Chen et al., 2021; Guenther et al., 2013; Habeeb-Allah et Alshraideh, 2021; Järvelä et al., 2018; Kotfis et al., 2018; Kumar et al., 2017; Norkienė et al., 2013; O’Neal et Shaw, 2016; Ordóñez-Velasco et Hernández-Leiva, 2021; Sanson et al., 2018; Smulter et al., 2013; Sugimura et al., 2020; Tafelmeier et al., 2019)

2.2.2 Impact of delirium on recovery after cardiac surgery.

Aside from risk factors, several studies have highlighted the impact of delirium on postoperative cardiac surgery patient recovery in the ICU and beyond. Accordingly, a recent Australian retrospective observational study by Jones and colleagues (2019) illuminates delirium's extensive impact on healthcare resources after cardiac surgery. Patients who developed delirium experienced significantly longer stays in both ICU and hospital (up to 21 days). One of the key takeaways from the research on ICU cardiac surgery patients is the significant independent association between delirium and post-surgical complications, particularly the need for re-intubation and tracheostomy in the ICU (Jones et al., 2019). Other similar studies, including cardiac surgery ICU patients, have also underscored the common occurrence of postoperative delirium following cardiac surgery, noting that affected patients often require more prolonged mechanical ventilation (Andrási et al., 2022; Habeeb-Allah et Alshraideh, 2021; Järvelä et al., 2018; Norkienė et al., 2013; Salluh et al., 2015), longer ICU stay (3-9 days more) (Habeeb-Allah et Alshraideh, 2021; Järvelä et al., 2018; Kumar et al., 2017; Norkienė et al., 2013), chemical/physical restraint use (Sanson et al., 2018),

experience extended hospitalization periods (Habeeb-Allah et Alshraideh, 2021; Kotfis et al., 2018; Sanson et al., 2018; Tafelmeier et al., 2019) impaired recovery/rehabilitation, and a higher in-hospital mortality rate (Salluh et al., 2015). A scoping review by la Cour and colleagues including studies conducted in general ICU settings, as well as those carried out in post-anesthesia care units, indicated that among the different delirium motor subtypes, patients with mixed delirium had the most prolonged delirium duration, the highest lengths of ICU and hospital stay, and the highest mortality rates (la Cour et al., 2022).

Even after hospital discharge, patients who developed delirium after cardiac surgery experienced significantly more cognitive issues compared to those who did not. The study identified post-operative delirium as an independent risk factor for long-term problems such as memory issues, concentration difficulties, confusion/disorientation, sleep disturbances, nightmares, emotional challenges, and decreased mobility after hospital discharge. Furthermore, patients who developed delirium had a notably higher rate of hospital readmissions (de la Varga-Martínez et al., 2023). In older ICU patients, delirium is mainly associated with accelerated cognitive decline and long-term functional and neuropsychological deficits (Ely et al., 2001), therefore, it is crucial to explore the experiences of patients and their families while encountering this phenomenon. Understanding their perspectives can provide valuable insights for developing effective interventions and support systems to address the psychological challenges arising from delirium. The latter part of this section focuses on the distinct impacts of delirium as perceived by patients who have experienced it, their families, and nurses.

2.2.3 Experience of patients, families, and clinicians with delirium in the ICU.

This section explores the literature related to perspectives of patients, families, and clinicians on delirium experiences. Given the limited studies on this matter, specifically within the context of the cardiac surgery ICU, insights from the general ICU and other care departments were also searched for. This approach was considered to be essential to establishing a minimal foundation on the topic of interest.

Patients. Patients experiencing delirium in the general ICU typically feel disruptions in contact and communication due to their impaired ability to express themselves effectively. Their

perception of time becomes greatly distorted, causing irregular sleep patterns. Predominant emotions during this time include anger, fear, guilt, and shame (Van Rompaey et al., 2016). Patients have difficulty recalling the beginning of the period of delirium, but they gradually recover and express relief once the delirium has subsided (Van Rompaey et al., 2016). Feelings of vivid, distressing, disturbing memories resembling flashbacks of their traumatic experiences in the general ICU are often perceived as persecutory, with many memories being hallucinatory or delusional. Some patients recall factual memories of staff interactions and medical procedures, while others have uncertain memories, making them unsure if the horrifying events were real or not (Wade et al., 2015).

Families. In medical and gerontological contexts, delirium profoundly affects family caregivers of older adults. They often face the overwhelming responsibility of providing full-time care, resulting in fear, fatigue, frustration, depression, illness, financial strain, and overall stress (Carbone et Gugliucci, 2015). The delirious loved one becomes highly dependent on the caregiver for daily needs, making the caregiver the decision-maker, provider, and protector. This level of care can take a toll on the caregiver's psychological well-being, isolating them from social support and causing feelings of missing out on life and emotional exhaustion (Carbone et Gugliucci, 2015). Family members often struggle to handle agitated behaviors during delirium episodes and may misinterpret the causes, leading to self-doubt about their caregiving abilities. For caregivers, this situation is more distressing than for patients or their nurses (Carbone et Gugliucci, 2015). In addition to compassion and worry, family members experienced anxiety, fear, uncertainty, and apprehension as their loved ones experienced delirium. Moreover, they valued communicating with the healthcare team, actively contributing to the patient's care, and observing positive signs of improvement (Boehm et al., 2021).

Nurses. Medical-surgical ICU nurses often describe delirium as an unpleasant event in which patients become disoriented, distressed, and unpredictable, often attempting to remove medical tubes and get out of bed (Zamoscik et al., 2017). Caring for these patients is generally emotionally and physically exhausting, with time management challenges causing additional stress (Zamoscik et al., 2017). Additionally, the unpredictable nature of delirious patients raises safety concerns for nurses, leading to increased time and resource allocation to ensure everyone's well-being (Thomas

et al., 2021). In acute care wards, nurses often have limited knowledge to detect delirium, leading to under-recognition of the condition and underestimation of the importance of delirium prevention (Lim et al., 2022). Nurses report employing care strategies like closely monitoring and listening to delirious patients, which may cause stress, anxiety, and inner conflicts (Lim et al., 2022). These findings emphasize the urgency of implementing strategies to prevent and manage delirium in the ICU, including in recovering cardiac surgery patients (Sugimura et al., 2020).

2.3 Detection, prevention, and management of delirium after cardiac surgery in the ICU

This section elucidates the latest methods for detecting delirium, followed by exploring recent discoveries in delirium prevention and management in cardiac surgical and general critical care settings. It will encompass both pharmacological and non-pharmacological approaches.

2.3.1 Current recommendations for detection of delirium and challenges.

Screening tools are valuable in detecting delirium (Cortés-Beringola et al., 2021). It can support the timely and accurate detection of delirium symptoms in postoperative cardiac surgery patients and, is highly recommended by best practice guidelines (Dubiel et al., 2022; SIGN-guidelines, 2019). In critical care settings, the Confusion Assessment Method for the ICU (CAM-ICU) and Intensive Care Delirium Screening Checklist (ICDSC) have been designed and validated with high sensitivity and specificity (T.-J. Chen et al., 2021; Frenette et al., 2016). The ICDSC demonstrated higher sensitivity compared to the CAM-ICU in the cardiac surgery ICU (Nishimura et al., 2016), but both instruments have been demonstrated to be more suitable than other assessment tools for use in the ICU (T.-J. Chen et al., 2021; Frenette et al., 2016; Nishimura et al., 2016). PAD's guidelines recommend both instruments for delirium screening (Barr et al., 2013b). In terms of structure, the CAM-ICU has four items (Table 3) and the ICDSC has eight items (Table 3), allowing them to be completed quickly and with minimal training, even for patients unable to speak, including those on mechanical ventilation (T.-J. Chen et al., 2021; Miranda et al., 2023).

Table 3. Comparative Overview of Delirium Assessment Tools in ICU

Assessment Tool	Principal Evaluated Items	Scoring Instructions
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I.C.D.S.C. (Bergeron et al., 2001)	1. Altered Level of Consciousness	<ul style="list-style-type: none"> • Score “0” if (calm, cooperative, interacts with environment without prompting) • Score “1” if (patient only interacts or responds when stimulated by light touch or voice: no spontaneous interaction or movement)
	2. Inattention	<p>“1” for any of the following:</p> <ul style="list-style-type: none"> • Difficulty following conversation or instructions • Easily distracted by external stimuli • Difficulty in shifting focuses
	3. Disorientation	<p>“1” for any obvious mistake in person, place or time</p>
	4. Hallucination/ delusions/ psychosis	<p>“1” for any one of the following:</p> <ul style="list-style-type: none"> • Manifestation of hallucinations or of behaviour probably due to hallucinations (e.g., catching non-existent object) • Delusions • Gross impairment in reality testing
	5. Psychomotor agitation or retardation	<p>“1” for any of the following:</p> <ul style="list-style-type: none"> • Hyperactivity requiring additional sedatives or restraints to control potential dangerousness (e.g., pulling out IV lines, hitting staff). • Hypoactivity or clinically noticeable psychomotor slowing. Differs from depression by fluctuation in consciousness and inattention.

	6. Inappropriate speech or mood	<p>“1” for any of the following (score 0 if unable to assess):</p> <ul style="list-style-type: none"> • Inappropriate, disorganized, or incoherent speech • Inappropriate display of emotion related to events or situations
	7. Sleep-wake/cycle disturbance	<p>“1” for any of the following:</p> <ul style="list-style-type: none"> • Sleeping less than 4 hours or waking frequently at night (do not consider wakefulness initiated by medical staff or loud environment). • Sleeping during most of day
	8. Symptom fluctuation	<p>“1” for fluctuation of the manifestation of any item or symptom over 24 hours (e.g., from one shift to another).</p>
	TOTAL SCORE (0-8/8):	<p>A score > 4 suggests delirium. A score > 4 is not indicative of the severity of the delirium.</p>
CAM-ICU (Ely et al., 2001)	1. Acute change or fluctuating course of mental status	<p>Evaluation of baseline mental status and whether it’s been fluctuating in the last 24 hrs.</p>
	2. Inattention	<p>Asking patient to squeeze the examiner’s hand when they hear the letter “A”. Suppose the patient is unable to try picture recall.</p>
	3. Altered level of consciousness (current RASS level)	<p>The current level of consciousness/RASS score</p>

	4. Disorganized thinking	Yes/no questions and command following.
	TOTAL SCORE (0-4/4):	A patient is considered positive for delirium if items 1 and 2 are present along with either items 3 or 4.
FAM-CAM (Inouye et al., 2012)	1. Acute onset or fluctuating course (Questions 1, 10) and 9 (for fluctuation)	1. During the past few days, have you noticed any changes in your friend or relative's thinking or concentration, such as being less attentive, appearing confused or disoriented (not knowing where he/she was), behaving inappropriately, or extremely sleepy all day? (<i>Any Change</i>) 10. When did these changes first begin? (<i>Acute Onset</i>)
	2. Inattention (Question 2)	2. Did he/she have difficulty focusing attention, for example, being easily distracted or having trouble keeping track of what you were saying at any time? (<i>Inattention</i>)
	3. Disorganized thinking (Question 3,5,6 and 7 is supportive)	3. Was his/her speech disorganized, incoherent, rambling, unclear, or illogical at any time? (<i>Disorganized Speech</i>) 5. Was he/she disoriented, for example, thinking he/she was somewhere other than where he/she was, or misjudging the time of day at any time? (<i>Disorientation</i>) 6. Did he/she seem to see or hear things which weren't actually present, or seem to mistake what he/she saw or heard for something else at any time? (<i>Perceptual Disturbance</i>) 7. Did he/she behave inappropriately, such as wandering, yelling out, or being combative or agitated at any time? 8. Please tell me more about the changes you noticed in Questions 1-7.

		<p>9. Were these changes (from Questions 1-7) present all the time, or did they come and go from day to day? (<i>Fluctuation</i>)</p> <p>11. Overall, have these changes been getting better, worse, or staying about the same?</p>
	<p>4. Altered level of consciousness (Question 4)</p>	<p>4. Did he/she seem excessively drowsy or sleepy during the daytime at any time? (<i>Excess Drowsiness</i>)</p>
	<p>TOTAL SCORE (0-4/4):</p>	<p>According to the CAM diagnostic algorithm, the FAM-CAM is considered positive: <i>the presence of acute onset or fluctuating course AND inattention AND EITHER disorganized thinking or altered level of consciousness.</i></p>

* The scale is collected from the entire 8- h shift or the previous 24 h

Another important screening tool related to delirium detection, relevant to current study, is the Family Confusion Assessment method (FAM-CAM). Similar to the CAM, the FAM-CAM (Table 3) is available to the public and can be accessed freely on the Hospital Elder Life Program (HELP) website. It is a concise, comprehensive tool to aid family members and caregivers in identifying delirium (Inouye et al., 2012). The validation study of FAM-CAM in the cardiac surgical ICU was limited, but studies conducted in the general adult ICU demonstrated high sensitivity and specificity of this tool (Greindl et al., 2022; Rosgen et al., 2018). Additionally, the application of this tool by family members in the ICU is considered acceptable feasible and includes strategies for integrating family-administered delirium detection into routine patient care (Parsons Leigh et al., 2021).

Unlike hyperactive delirium, which is likely to capture the attention of healthcare professionals, hypoactive delirium may be neglected by clinicians, leading to delays in diagnosis and treatment. Hence, it is crucial to conduct routine delirium assessments, ideally at 8 to 12 hours intervals, to detect this subtype of delirium, specifically in the cardiac surgery ICUs (Nishimura et al., 2016;

Zhang et al., 2016). Even with the assistance of a tool, it's crucial to recognize that delirium can still manifest without a positive test result due to its fluctuating nature. Healthcare professionals should not depend solely on a single assessment result upon a patient's hospital admission (SIGN-guidelines, 2019). In clinical practice, although various tools for delirium screening and diagnosis are accessible, healthcare professionals still encounter difficulties in detecting delirium, which can significantly impact long-term outcomes, often leading to undetected patient cases (Barron et Holmes, 2013; Lange et al., 2019). Contributing to the problem, multiple qualitative studies indicated that nurses identified the primary obstacles to delirium detection as the absence or insufficiency of appropriate screening tools and comprehensive delirium protocols and lack of education (regarding the signs and symptoms, risk factors, and adverse consequences of delirium) within the care setting (Oosterhouse et al., 2016; Palacios-Ceña et al., 2016; Rowley-Conwy, 2017; Xing et al., 2017; Zamoscik, Godbold et Freeman, 2017).

2.3.2 Current recommendations for prevention and management of delirium.

Use of medication. Due to the complex nature of delirium pathogenesis (Page et al., 2013; Van Den Boogaard et al., 2018), recent guidelines do not recommend the use of any antipsychotic drugs and haloperidol for the prevention of delirium (Devlin et al., 2018; Oh et al., 2019; SIGN-guidelines, 2019).

There is insufficient evidence to assess the impact of antipsychotics on cognitive function, delirium severity, or caregiver burden (Neufeld et al., 2019). There is limited evidence suggesting that second-generation antipsychotics may reduce delirium incidence in postoperative patients, but further research is needed. No neurological harms were observed with haloperidol or second-generation antipsychotics for delirium prevention or treatment, but there was a tendency for increased cardiac effects in individuals receiving antipsychotics (Neufeld et al., 2019). Conflicting results were also found on the utility of melatonin for preventing delirium in hospitalized and postoperative geriatric patients (Asleson et Chiu, 2020). Therefore, non-pharmacological approaches should be prioritized in this context.

Similar to delirium prevention, best practice guidelines do not recommend the use of any drugs as a first line of management of delirium (SIGN-guidelines, 2019). Still, some medications, such as

Haloperidol are recommended to address symptoms of agitation and aggressiveness when a patient has become a threat to his security or the security of others (SIGN-guidelines, 2019). Aside from these circumstances, guidelines support non-pharmacological approaches in this context (SIGN-guidelines, 2019). The SIGN guidelines are recognized as the foremost reference document and the standard of practice when addressing delirium in clinical settings. By adhering to the SIGN guidelines, our research aligns with the most current, evidence-based best practices in preventing, assessing, and managing delirium.

Non-pharmacological interventions and bundle of care. Delirium prevention focuses on reducing brain damage and physical stress. Nurses can help by providing simple orientation aids (clocks, quiet environments), promoting early movement, and ensuring patients have glasses or hearing aids if needed. These measures enhance cognition and lower delirium risk (Devlin et al., 2018; Soiza et Myint, 2019). Likewise, Siddiqi and colleagues proposed a multi-component delirium preventive bundle of interventions to promote orientation (Siddiqi et al., 2016).

Below are a few of these preventive measures (Heydari Gorji et al., 2017; Siddiqi et al., 2016):

- Placing the clocks and calendars in front of the patients
- Evaluating patient's orientation in all spheres: time, place, and person
- Offering flexible visiting hours for families and friends
- Listening to music and favorite radio programs
- Preventing dehydration
- Encouraging the patients to do activities and mobilization
- Providing a comfortable sleep
- Pain and discomfort management
- Constipation prevention
- Maintaining a stable environment for patients

- Communicating with patients according to their cultures and native languages
- Minimizing the use of catheters or covering them

Implementing non-pharmacological interventions in patients across three Brazilian ICUs, such as periodic reorientation, cognitive stimulation, correction of sensory deficits, environmental management, and sleep promotion, has been linked to a significant decrease in the incidence of delirium. This observation stems from a single-center randomized controlled trial conducted in these ICUs from February to September 2019 (Faustino et al., 2022).

Evidence-based guidelines were published by the SCCM in 2013, aiming to reduce the long-term impairments associated with intensive care survivors' physical, mental, and cognitive functioning, focusing on Pain, Agitation, and Delirium (PAD) (Barr et al., 2013). It was revised in 2018 to become the PADIS: P: Pain (Pain), A: Agitation/Sedation (Agitation/Sedation), D: Delirium (Delirium), I: Immobility (Rehabilitation/Mobilization), and S: Sleep disruption (Devlin et al., 2018). This document includes 37 recommendations based on the latest evidence aimed at preventing delirium in ICU patients (Devlin et al., 2018). These recommendations include nonpharmacological pain management interventions such as massage, music therapy, cold therapy, and relaxation. Also, guidelines recommend improving cognition, sleep, mobility, hearing, and vision in critically ill adults to reduce modifiable risk factors for delirium. Additionally, the letter "F" in the ABCDEF bundle, focusing on family engagement, helps family caregivers to participate in the assessment of delirium using the CAM-ICU (Devlin et al., 2018).

Considering that delirium is a situation where great attention is needed and that short staff and timing can be problematic, these recommendations include family involvement. Indeed, the family can be viewed as a valuable resource to help nurses and clinical teams in the context of delirium at different levels: communication, information transfer, and direct involvement in care (Devlin et al., 2018). Echoing these recommendations, a bundle of interventions under the acronym ABCDEF (**A**ssess, prevent, and manage pain; **B**oth spontaneous awakening and breathing trials; **C**hoice of Analgesia and Sedation; **D**elirium assess, prevent, and manage; **E**arly Mobility and Exercise; **F**amily engagement/empowerment) was developed as a clinical guide for clinicians in the interdisciplinary management of patients with delirium (Devlin et al., 2018; Marra et al., 2017;

Marra et al., 2016). In the bundle, the family is encouraged to participate in the care and guide the orientation of the treatments; they act as substitute decision-makers by expressing the wishes and preferences of the hospitalized person who cannot do so (Marra et al., 2017).

2.4 Family involvement in delirium care activities in the ICU

2.4.1 What do we know about family involvement in delirium care activities in the ICU?

The involvement of family members in the critical care experience and decision-making practice is regarded as a factor of affiliation, a basic human need (Davidson et al., 2019). Taking action during a crisis defines our identities and enables us to navigate the crisis. Being involved in the care decreases feelings of helplessness, fear, and horror (Davidson et al., 2019). According to SIGN guidelines, family caregivers are valuable in preventing, detecting, and managing delirium. Family members can detect delirium using assessment tools such as FAM-CAM (Inouye et al., 2012). Furthermore, defining the delirium signs and symptoms and asking the family caregivers to notify any changes in the patient's normal behavior are recommended. The family caregivers can prevent delirium by delivering nonpharmacological multicomponent interventions, such as reorientation. The guidelines recommend offering flexible visiting hours to manage delirium symptoms while family members provide support and reassurance (SIGN-guidelines, 2019).

2.4.1.1 Families' involvement in the prevention of delirium.

It has been shown that family participation can reduce the occurrence of delirium. Extended family visitation and the availability of psychological support could be particularly advantageous for promoting positive outcomes in this regard (Liang et al., 2021; Lin et al., 2022). Two studies have been conducted in recent years supporting families' involvement in preventing delirium in the general ICU (Rosa et al., 2019) and one additional study in cardiac surgery patients specifically (Lin et al., 2023).

A study conducted in Brazilian adult mixed medical-surgical ICUs examined the impact of a flexible family visitation model (FFVM) compared to a restrictive family visitation model (RFVM) on preventing delirium in adult ICU patients (Rosa et al., 2017). The RFVM allowed for less than 4.5 hours of family visitation per day, while the FFVM permitted up to 12 consecutive hours of visitation by two or fewer close family members. CAM-ICU was applied at least once

every 12-hour shift for patients with a RASS score of ≥ -3 . The study found that the FFVM was associated with a reduced incidence of delirium (10% vs 21%), shorter duration of delirium/coma (1.5 days vs 3 days), and a shorter ICU stay (3.0 days vs 4.0 days) when compared to the RFVM (Rosa et al., 2017). In a follow-up randomized clinical trial involving 1295 family members, the study titled "Effect of Flexible Family Visitation (with 4.8 hours compared to 1.4 hours in the restricted visitation group) on Delirium Among Patients in the Intensive Care Unit" reported reduced median anxiety scores (6.0 vs. 7.0) and depression scores (4.0 vs. 5.0) when compared to the restricted visitation group (Rosa et al., 2019).

In the context of cardiac surgery patients specifically, a randomized controlled study by Lin and colleagues (Lin et al., 2023) involving 80 patients undergoing cardiac valve surgery investigated the impact of family intervention on postoperative delirium (POD) incidence and ICU outcomes. The experimental group received family intervention involving family caregivers in delirium management during ICU visits, while the control group received routine ICU visits. The intervention involved psychological support, orientation training, cognitive stimulation, prevention of sensory deprivation, and participation in ICU life care and lasted up to 7 days post-surgery. The results indicated that the experimental group had significantly lower POD incidence (7.5% vs. 27.5%) and shorter ICU stays (46 hours vs. 66 hours). Additionally, family caregivers in the experimental group experienced reduced anxiety (2.5% vs. 17.5%) and depression (2.5% vs. 25.0%) and higher satisfaction. These findings suggest that incorporating family intervention into routine nursing practice can be beneficial in reducing POD, improving ICU outcomes, and enhancing family caregivers' well-being (Lin et al., 2023). Supporting this assumption, two recent systematic reviews and meta-analysis showed that in ICU, families who participate in non-pharmacological delirium-prevention interventions are significantly more satisfied with the care, with potential reduction in anxiety and depression for family members (Liang et al., 2021; Lin et al., 2022).

2.4.1.2 Families' involvement in the detection of delirium.

In addition to participating in prevention and management efforts, families could help detect delirium sooner (Fiest et al., 2020). Indeed, families often represent the most valuable source of

information to identify an acute change in the patient's cognitive functioning, which could indicate delirium (Mailhot et al., 2020; Parsons Leigh et al., 2021b).

In a study by Flanagan and Spencer (2016) the FAM-CAM (described previously) administered by family members demonstrated a strong correlation (91%) with the clinician-derived CAM-ICU and DSM-5 criteria for delirium. The FAM-CAM showed high specificity (100%) and sensitivity (78%) when compared to the DSM-5 criteria. These results highlighted the benefits of utilizing the FAM-CAM alongside the CAM-ICU and DSM-5 to achieve a definitive diagnosis of delirium (Flanagan et Spencer, 2016).

Krewulak and colleagues (2019) conducted a study to validate two family-caregiver-administered delirium detection tools, FAM-CAM and Sour Seven questionnaire, for use during the patient's ICU stay. The findings showed that family caregivers identified delirium in 5 patients (38%) using the FAM-CAM and delirium or possible delirium in 8 patients (62%) using the Sour Seven questionnaire. This study demonstrated that family administration of delirium detection tools is both feasible and well-received in the ICU setting (Krewulak et al., 2019).

Parsons Leigh and colleagues (2021) conducted a mixed-methods study in a Medical Centre ICU to validate family-administered delirium detection tools in Canada. These tools included the FAM-CAM and Sour Seven questionnaires and were used once daily for up to five days. The study involved focus groups with critical care physicians, registered nurses, patients, and family members. The research explored perceptions regarding family members' delirium knowledge upon ICU admission, the acceptability of family-administered detection, and its feasibility. The findings indicated strong agreement among ICU providers and family members that these tools can positively impact patient care by allowing family members familiar with the patients to contribute insights into their well-being. The study supported the involvement of family members in delirium detection, highlighting its potential to enhance patient outcomes and the experiences of both patients and families (Parsons Leigh et al., 2021).

2.4.1.3 Families' involvement in the management of delirium.

Aside from delirium prevention, family involvement can also be used to manage delirium. A recent integrative review by Sahawneh et Boss (2021), including 12 studies, revealed that family

members generally expressed a strong desire to participate in non-pharmacologic interventions when delirium occurs. The family-delivered interventions include reorienting and providing familiar objects to aid the patients' comfort (Sahawneh et Boss, 2021). In another review by McKenzie et Joy (2019), the involvement of family caregivers in providing interventions to patients with delirium was found to lead to a reduction in the length of hospital stay and is likely to decrease the duration of delirium. Additionally, the findings suggest that such interventions may alleviate family anxiety, are easily implementable, and are well-received by both caregivers and staff (McKenzie et Joy, 2019).

Concerning cardiac surgery, the randomized pilot study of Mailhot and colleagues (2017) in Quebec, Canada, showed that implementing an intervention involving family caregivers to manage delirium in this context is acceptable and feasible. Based on the preliminary results of the pilot study, delirium occurred 28% less frequently. It lasted two days less on average in the intervention group than in the standard-of-care group (Mailhot et al., 2017). The intervention was also found promising to reduce the length of hospital stays following cardiac surgery, improve patient recovery and self-confidence, and decrease family caregivers' anxiety while involved in their role (Mailhot et al., 2017). In another study conducted in cardiac surgery ICU, MENTOR_D, a nursing educational intervention developed by Mailhot and colleagues (2022), was found to promote family involvement in delirium management in postcardiac surgery care. Nurses can use MENTOR_D strategies to engage families in nonpharmacological delirium management, such as orientation. In addition, it reduces anxiety by increasing family self-efficacy and improving the patient's recovery by reducing the severity of delirium (Mailhot et al., 2022).

2.4.2 Attitudes and perceptions of healthcare providers and caregivers towards family involvement in the care of patients experiencing delirium.

In this section, we will explore healthcare providers' and caregivers' attitudes and perceptions regarding family involvement in the care of patients experiencing delirium. Although studies on this topic are not explicitly conducted in the cardiac surgery ICU field, we have identified two recent relevant studies conducted with clinicians in the general ICU with similar themes.

The study by Smithburger and colleagues (2017) in Canada examined nurses' perceptions of family involvement in preventing delirium in Medical Surgical Intensive Care Unit (MSICU). The nurses believed that involving the families would be beneficial in delirium prevention. Families can encourage the patient's cognition by asking questions as part of the intervention or talking to them. However, nurses cited a few barriers to family involvement in delirium prevention activities, including time limitations to educate families and insufficient knowledge of family members about delirium and its prevention. Thus, nurses believe families may accidentally harm patients due to stress and anxiety. In order to reduce family fears during delirium-prevention activities, the nurses recommended using one-on-one education strategies. The authors investigated that even though nurses routinely assess bedside delirium, delirium management remains ineffective and suboptimal (Smithburger et al., 2017).

In a more recent qualitative study, also conducted in Canada, critical care providers (including five physicians and six registered nurses) and participants from the Family ICU Delirium Detection Study (comprising seven former patients and their family members) engaged in four focus groups (Parsons Leigh et al., 2021). The study revealed that patients, family members, and healthcare providers perceived family involvement in delirium detection and using family-administered delirium detection tools at the bedside as feasible and valuable for patient care and family members' coping. The findings indicated strong support for the active engagement of family members at the bedside, driven by the belief that such participation could lead to earlier delirium detection and non-pharmacological management, ultimately improving patient health outcomes and enriching the experiences of family members by involving them in the clinical process and granting them a sense of purpose (Parsons Leigh et al., 2021).

In conclusion, this literature review on delirium in the cardiac surgery ICU emphasizes its significant impact on patients, families, and healthcare providers. Family involvement has the potential to improve delirium prevention, detection, and management. Current recommendations encourage the integration of family members as vital members of the cardiac ICU team. Evidence suggests that this integration is not only feasible and acceptable but can also improve patient well-being and proactively address delirium. By promoting collaboration and an interdisciplinary approach, healthcare teams can improve outcomes, support families, and tackle the challenges of

delirium in the cardiac surgery ICU. However, clinicians' perceptions of this subject remain an understudied area, warranting further research to enhance understanding and practice.

2.5 Conceptual framework

This project applied the Family System Nursing (FSN) Theory. Concerned with the relationship between family dynamics and health, Wright and Leahey (1987) developed the Calgary FSN Theory (CFSNT) to support families with health problems. The FSN theory reconnects with the human nature of illness and the process of creating therapeutic change (Wright et Leahey, 1987).

FSN theory highlights the importance of nurses adapting their assumptions about families facing life-threatening illnesses. Regardless of the assessment models, nurses should personalize their approach, forming hypotheses to guide interactions. Families, especially those with members in the ICU, strongly seek regular updates on the patient's condition. Engaging families in patient care, as per FSN theory, not only provides crucial information but also reduces their sense of helplessness. By focusing on health promotion and addressing biopsychosocial issues, nurses significantly enhance the well-being of both patients and families during difficult times (Wright et Leahey, 1987).

The FSN theory emphasizes the importance of establishing a relationship between families and nurses as a key component of these interventions. It also highlights how family-nurse and family-patient dynamics can affect patients' health, which makes familiarity and individualized care crucial in delirium care (Wright et Leahey, 1987). FSN focuses on sustaining health, promoting healing, and addressing both health promotion and illness suffering. It recognizes the reciprocal influence of relationships on health/illness and operates through a conceptual lens that considers interactions between multiple systems levels. The nurse, utilizing FSN, assesses and intervenes at the appropriate systems level, whether individual, family, nurse-family relationship, healthcare system, or broader societal and cultural contexts (Bell, 2009). FSN operates within a therapeutic relationship between nurses and patients/families, emphasizing the acquisition of skills to inquire about and intervene in relationships. The approach values collaborative, non-hierarchical relationships and adopts a strengths-based orientation, focusing on competencies and strengths rather than deficits.

By understanding these dynamics, nurses can better understand the consequences of life-threatening illnesses on families and the role families play in the care process. There are six assumptions defined in this model based on the experiences of families with life-threatening illnesses. In our project, we have adapted the six assumptions of FSN to involve the family in the care surrounding assessing, preventing, and managing delirium in critically ill cardiac surgery patients. The six assumptions of FSN likely offer a comprehensive framework that aligns with the nature of our project, which focuses on nurses' perceptions of family involvement in delirium assessment, prevention, and management in critically ill postoperative cardiac surgery patients.

Assumption #1: The Diagnosis of Life-Threatening Illness Is a Social Contract

In the first assumption, an illness is diagnosed, and a social contract begins between the patient, family, and healthcare providers. A diagnosis of delirium by health care providers involves all these parties. The parties begin negotiating the diagnosis, whether the patient/family accepts it. Families and patients do not expect delirium to occur when admitted to the cardiac surgery ICU. The ICU nurses can recognize the effects of delirium diagnosis on family members (like anger, denial, etc.) and help them participate in the management process.

Assumption #2: A Life-Threatening Diagnosis Changes the Family's Life Trajectory

Families undergo a new event after the diagnosis of delirium, and nurses can assist them in adapting to and passing this crisis phase.

Assumption #3: Families Need to Review a Life-Threatening Event

The nurse must give the family time to accept and review the new situation and answer all their questions.

Assumption #4: Family Members' Reactions Influence the Course of a Life-Threatening Illness

In a critical situation like a life-threatening disease, people react differently. Diseases and family involvement are interrelated. Therefore, the presence of family members at the bedside can rapidly detect delirium, especially close family members like spouses who know their loved ones well.

Assumption #5: Family Function is Often Altered by Life-Threatening Illness

Through new events and critical situations, the role and functions of the family can be changed. For example, as nurses manage their delirious patients, they can use the family model to involve them in their loved one's care rather than leaving them unresponsive.

Assumption #6: Family Members' Beliefs about a Life-Threatening Illness Influence How They and the Patient Cope with the Situation

Families' different beliefs are valuable and vital resources that may impact how the disease is diagnosed and coped with and its physical and behavioral reactions. Therefore, nurses need to be aware of family values and beliefs, especially in critical situations where it may be challenging to respect them.

In recent years, nurses continue to feel compelled to learn more about how to best include families in their care. Therefore, FSN in this project will help us understand how ICU nurses perceive family involvement in assessing and managing delirium in critically ill cardiac surgery patients.

2.6 Relevance and added value for the nursing discipline

In most clinical care contexts, family involvement is integral to providing patient- and family-focused care and ensuring optimal patient outcomes (Mackie et al., 2018; Park et Schumacher, 2014). As mentioned earlier, nurses play a central role in advocating and facilitating patient- and family-focused care practices (Mackie et al., 2018), including social support for high family function and health (Shamali et al., 2019). However, despite its importance, family involvement in care can be a challenging and complex process for both healthcare providers and families (Petriwskyj et al., 2014). For example, a lack of education about therapeutic conversations with families and a lack of time can hinder nurses from actively involving families in care (Hoplock et al., 2019).

Family involvement has been found effective in assessing, preventing, and managing ICU delirium in the ICU, specifically through non-pharmacological interventions. Still, family involvement at the direct care level requires a shift from the traditional approach of working for patients toward working with patients and families. A better understanding of ICU nurses' perceptions of family

involvement in the delirium prevention and management care processes is essential. Their attitudes may help or hinder a family's involvement in care (Mackie et al., 2018). Promoting family participation in the ICU care process can significantly reduce the risk of delirium in patients sustaining cardiac surgery, with the added benefit of alleviating the workload of ICU nurses.

Chapter 3: Research methodology

3.1 Study design

We employed a descriptive qualitative research design for this study, utilizing semi-structured interviews to gather in-depth data. This methodological approach was chosen to provide a straightforward portrait of the participants' experiences and perspectives comprehensively (Doyle et al., 2020).

3.2 Study sites

Our study was conducted in two francophone ICUs, each located in a university-affiliated hospital in Montréal, Quebec, Canada: 1. Hôpital du Sacré-Cœur de Montréal (HSCM) from the CIUSSS du Nord-de-l'Île-de-Montréal, and 2. Institut de Cardiologie de Montréal (ICM). The first site has 36 ICU beds and approximately 120 nurses and performs 1-2 cardiac surgeries daily on average. The second site has 30 beds and 80 nurses and performs eight cardiac surgeries per day.

These sites were chosen to enhance diversity in nurses' clinical experiences and perspectives on cardiac surgery by leveraging their unique specialties, encompassing various surgical methods, patient demographics, family visiting policies, and healthcare settings. One ICU (HSCM) is a mixed unit, providing care across various diagnoses, including cardiac surgery. The other (ICM) is specialized only in cardiac surgery critical care. While both ICUs have recently moved to new spaces, allowing each patient to have an individual room and facilitating family presence at the bedside, this leads to the abolition of family visiting hours in one site (HSCM) and not in the other (ICM) (visiting hours are not defined, and families can visit patients with the coordination of the nursing staff).

3.3 Sampling strategy

A convenience sampling approach was used for this study (Elfil et Negida, 2017). The recruitment process (described more thoroughly in section 3.4) involved disseminating written and verbal announcements by the research team during various shifts, including day, night, and evening, to ensure a broad outreach to potential nurse participants. The selection of nurses for participation was based primarily on their availability and interest in contributing to the research project. The specific eligibility criteria are described below.

3.3.1 Inclusion Criteria

- We primarily targeted Registered Nurses (RNs) who are actively working in an ICU where cardiac surgery is routinely performed, ensuring that the study is directly relevant to this specific clinical setting.
- To understand the broader implications of nursing practices on patient care, nursing managers and clinical nurse specialists, who might influence ICU nursing, practices at the bedside, were also encouraged to participate.
- In order to capture a diverse range of insights and experiences, participants from various socio-demographic characteristics such as age, gender, and level of education, as well as professional backgrounds including years of experience in the cardiac surgery ICU were encouraged to participate. We also put special emphasis on recruitment during the evening and night shifts, as delirium is known to be more prevalent during these periods and interactions during family visiting hours are common.

3.3.2 Exclusion Criteria

- Nurses whose involvement in the ICU did not constitute the majority of their working hours were excluded to maintain the study's focus.
- Any nurse who declined audio recording of the interviews was also excluded from the study, as these recordings were essential for ensuring the accuracy of data collection and analysis.

3.4 Recruitment

After obtaining ethical research approval (Appendix I), from both the study sites and the University of Montreal, recruitment was initiated in collaboration with the ICU head nurses at each study site. Before commencing recruitment, the research supervisors presented the project to the head nurses at each site. Two key strategies were used to prepare the study sites to the recruitment process: First, a formal announcement (Appendix II) was posted in the employee lounge room and on the private ICU nurses' Facebook page in collaboration with the head nurses of each unit. Secondly, the student researcher visited each ICU site in person during March and April 2023 and explained the research project and confirmed the dates and time the research team was planning to be on the

unit to attending nurses during planned staff meetings. Following the deployment of these preparatory strategies, nurses interested in participating were encouraged to contact the student researcher directly (either by telephone, email, or even in person during the planned recruitment periods on the unit). After expressing interest, nurses' eligibility was verified. Eligible nurses were then briefed on the study procedures, and the student researcher provided the consent form (Appendix III) and explained it thoroughly, after which the participants voluntarily signed it. Each participant also received a second copy of the consent form for their records. Following the signing of the consent form, the interview was carried out at the time and place convenient for the nurses. Prior to the interviews, participants were provided with information about the research project's title, the expected interview duration, the use of audio recording devices, and the assurance of anonymity. Additionally, participants were recalled of their right to withdraw from the study at any time without the need for justification or facing any questions. Recruitment of nurses stopped when data saturation was reached. We considered saturation to be achieved when the coding phase reaches the point where no new codes emerge from the data and there are only repeated instances of existing codes (Saunders et al., 2018).

3.5 Data collection

Interviews were scheduled at various times throughout the day, including between 6:00 and 8:00 AM to accommodate night shift nurses and from 9:00 to 18:30 to accommodate those on day and evening shifts. With the assistance of the unit assistants, one of the unoccupied patient rooms in the ICU was selected as the interview location for participants who wanted to perform the interview during their work hours. When this was the case, the interview room's door was closed during the sessions to ensure confidentiality. Both participants and the student researcher adhered to hospital protocols by wearing surgical masks to prevent the spread of COVID-19 virus. Additionally, they maintained a two-meter distance as per these guidelines.

Nurses' participation in data collection included completing a self-reported socio-demographic questionnaire (~5 minutes) and a semi-directed individual interview (~45-60 minutes). The socio-demographic questionnaire (Appendix IV) was used to collect descriptive information relating to age, gender, ethnicity, level of education, number of years of experience in cardiac surgery ICU, as well as other elements informing about the professional background and the characteristics of

the participants. The documentation of these characteristics eventually helped appreciate the level of heterogeneity of the participants constituting our sample.

Five out of six interviews were conducted in person, while one was conducted online via a video conference meeting using the Teams software. Interviews conducted during participants' work hours were arranged in a quiet room within the ICU in accordance with their preferences and in coordination with the ICU head nurses. One of the six interviews was conducted online and outside of working hours in a quiet room within the research laboratory, separate from the ICU.

During the interviews, a logbook (Appendix V) was completed. This tool aided in taking notes throughout the research, to keep track of the participants' reactions, the ICU environment and etc. This approach also ensured that collected informations were documented in a structured manner, facilitating ease of review and analysis at a later stage. An example of this organization includes naming participants in the logbook according to the numbers used in the recording device, and subsequently, in the transcript files within the Word documents. Following the conclusion of the interviews, the research director provided each participant with a CAD 100-dollar e-transfer as compensation, and receipts were obtained as proof. To prevent any loss of data, audio recordings were made using two types of voice recorders.

3.6 Precipitated themes and semi-structured interview

Our interview questions covered three major themes: assessment, prevention and management of delirium by family involvement. For the interviews, a semi-structured interview guide (Appendix VI) was designed following the recently published survey addressing Health care providers' perception of family involvement (Smithburger et al., 2017) and based on the FSN theory (Wright et Leahey, 1987). The guide comprised six primary questions and several prompt questions designed to assist in exploring nurses' perceptions regarding the involvement of families in assessing and managing delirium in cardiac surgical ICU patients.

To obtain a more accurate description of nurses' perception of family involvement in delirium care, open-ended questions were used to allow participants to express themselves. Recording and transcription processes were used during the interviews. This approach can be made so that records can be retrieved and reviewed at any time (Cooper et Endacott, 2007).

3.6.1 Interview guide based on FSN theory and Smithburger study survey

To design our interview guide, we drew upon the foundational principles of the FSN Theory and the empirical findings from Smithburger et al.'s work to create a holistic and multifaceted approach to understanding nurses' perceptions of family involvement in delirium care for patients recovering from cardiac surgery. Here's how each element informed the interview guide:

3.6.1.1 FSN Theory Application

- Assumption #1 (Social Contract): We incorporated questions to explore how nurses negotiate the diagnosis of delirium with families, aiming to understand the social dynamics between healthcare providers, patients, and families. This assumption guided us to inquire about nurses' practices in involving families in the care surrounding delirium, mirroring the negotiation of a "social contract."
- Assumption #2 (Life Trajectory): Our questions sought to capture how occurrence of delirium might alter a family's participation in the care trajectory and how nurses assist families in navigating this complication, aligning with the second assumption of FSN.
- Assumption #3 (Reviewing the Event): We included questions to assess how nurses may or may not prepare families to the occurrence of delirium, and how they provided information and tried to include the family in patient's care once the delirium had occurred.
- Assumption #4 (Family Reactions): By asking about the differences in care routines between patients with and without family presence, we aimed to understand the influence of family members' reactions on the management of delirium, consistent with the fourth assumption.
- Assumption #5 (Altered Family Function): Our interview guide explored how nurses facilitate family involvement in care depending on family characteristics (which involves family roles and functions), aligning with the fifth assumption.
- Assumption #6 (Family Beliefs): We included questions to understand family beliefs about delirium and how these beliefs influence their involvement in care, resonating with the sixth assumption of FSN.

3.6.1.2 Integration of Smithburger et al.'s Findings

- **Survey Questions on Family Visits and Participation:** Inspired by Smithburger et al (Smithburger et al., 2017), we asked nurses about their routine interactions with families, starting on cardiac surgery patient admission, and the extent to which they involve families in care, aiming to capture the frequency and nature of family participation in the ICU.
- **Barriers to Family Involvement:** Reflecting on Smithburger et al.'s findings on barriers to discussing delirium with families, we incorporated questions to identify challenges nurses face in engaging families in delirium care and prevention.
- **Delirium Prevention Strategies:** Drawing from Smithburger et al.'s survey on delirium prevention strategies families could conduct, we inquired about nurses' perspectives on what could be done in general to prevent delirium in the ICU.

By integrating the comprehensive framework of FSN theory with empirical insights from Smithburger and colleagues' work, our questionnaire aims to explore the dynamics of family involvement in delirium care from the perspective of ICU nurses. This approach ensures that we capture the practical challenges and opportunities of family involvement in enhancing delirium care in the cardiac surgery ICU setting.

3.6.2 Pre-testing of the interview guide

Four nurse volunteers, with relevant experience with delirium care and not working at the study sites, took part to the pre-testing of the interview guide. This exercise led us to think that some questions were too vague and allowed us to adjust the content to be more specific about family involvement, while still respecting FSN theory. Therefore, insights gathered from these pre-interviews were used to slightly refine the interview guide to ensure the collection of comprehensive and valuable data. Additionally, it helped train the student researcher to develop a sense of how to conduct interviews.

3.7 Data management

Participants were identified by a code in order to maintain the anonymity of the socio-demographic data questionnaire responses and interview verbatims.

This key linking the name of the participants to the codes was compiled in a password-protected computer file and archived on the principal investigator's secure server at CIUSSS NÎM.

All consent forms and socio-demographic questionnaires are kept under lock and key in a stream (with a key) in the principal investigator's office in paper version and in a confidential computer file protected by a secure server in digital version.

All interviews were recorded, transcribed, and denominalized to facilitate observation and note-taking during the interviews. The audio file and the verbatim will be kept over seven years on the same server. They can be used for other secondary projects (2-3) in connection with the involvement of families in the care of ICU patients.

The last recordings and transcripts were securely stored on a password-protected USB drive for efficient data management. To prevent data loss, immediately after collecting data, the student researcher shared the data with the research director's team using Teams software. Furthermore, the research director and co-director generated backup copies on each research department computer. Data management, organization, and analysis were facilitated through the use of Microsoft Word Transcribing Office 365 software. Microsoft Word and Microsoft Excel were also employed to manage data and record reflections from the logbook.

3.7.1 Data analysis

Descriptive statistics were used to summarize the demographic data collected. The majority of descriptive qualitative studies use codes generated from the data (Sandelowski, 2000), including in vivo codes (the use of language that has been directly taken from the data) (Kahlke, 2014).

Thematic analysis was conducted using Braun and Clarke's approach (Braun et Clarke, 2006). This approach comprises six phases. The steps of this method are described as follows:

1. **Familiarization:** It can help the researcher move beyond identifying apparent implications of the records by reading and re-reading the transcripts, listening to the audio recordings, and making notes of any initial analytic observations (Braun et Clarke, 2006).

Microsoft Word was used to convert the audio-recorded interviews into transcriptions. In this step, the student researcher read all transcriptions several times. In addition, notes made in the logbook during interviews were transferred and stored electronically. The research director team revised all collected data, transcriptions, and notes for accuracy and representativity.

2. **Coding:** a systematic process of identifying and labeling relevant data features (concerning the research question). Coding is the first step in identifying data patterns because it groups similar data segments (Braun et Clarke, 2006).

During this step, the student researcher read and coded transcripts line by line independently. This process was done manually by using a coding structure (using different colors for labeling the codes) according to the research questions and six assumptions of the FSN theory. All data was fragmented into segments, phrases, and sentences in this stage. After employing this approach, eight distinct codes were recognized: 1) strategies used by the nurse, 2) characteristics of the patient, 3) characteristics of the nurse, 4) characteristics of the family, 5) family as an information source, 6) impact on the care routine, 7) work conditions, 8) suggestions for additional measures/strategies. All works were validated with the research director's team.

3. **Searching for themes:** The 'search' for themes is not simply one of 'discovery'; the themes are not in the data waiting to be uncovered by an intrepid researcher. Instead, the researcher clusters codes to create a plausible mapping of critical patterns in the data (Braun et Clarke, 2006).

The codes were analyzed during this step to identify basic themes. Codes were grouped together based on their relationships and similarities. This stage involved connecting codes to identify sub-themes. To optimize the process, the student researcher created a table containing all labeled codes along with their corresponding verbatims. For example, the code category "Characteristics of the patient" was thoroughly examined to identify similar ideas. In the initial phase, three basic themes emerged, namely, "A critical aspect of postoperative care is hemodynamic stability," "Diagnosing delirium can be challenging," and "Interaction between patients and their families". The student researcher met regularly with the research director team to discuss thematic definitions and assignments.

4. **Reviewing themes:** The researcher pauses the process of theme generation to check whether the candidate themes exhibit a good “fit” with the coded data and the entire data set and whether each has a clear, distinct ‘essence’ or central organizing concept. Reviewing may lead to fewer changes or discarding candidate themes and restarting the previous phase (Braun et Clarke, 2006).

As part of this critical phase, the student researcher carefully reviewed the codes and basic themes. Modifications were made based on recommendations from the research director team from the previous step. Confirmed coded phrases and sentences were then organized into categories that were used to identify significant themes for the next step. All changes were validated again by the research director team.

5. **Defining and naming themes:** Writing theme definitions (effectively a summary of each theme) and selecting a theme name to ensure the conceptual clarity of each theme and provide a road map for the final write-up (Braun et Clarke, 2006).

The student researcher searched for meaningful names for each extracted major theme based on their understanding of the concept. In this stage, initially, six themes were identified. Subsequently, following a review by the research director team, five definitive themes were established and named for the results section.

6. **Writing the report:** The researcher weaves their analytic narrative and vivid, compelling data extracts. Themes provide the organizing framework for the analysis, but analytic conclusions are drawn across themes (Braun et Clarke, 2006).

The prepared themes were analyzed as research results to provide a deeper understanding. This step requires close coordination with the research director team. Each theme was presented individually, and the essence of each theme was defined and described. A summarized conclusion of the report was then provided based on the verbatims regrouped for each sub-theme. More pertinent verbatims were selected to support the explanation of each sub-theme.

3.8 Scientific criteria

The scientific rigor criteria for qualitative data proposed by Lincoln and Guba were used to optimize the credibility, reliability, transferability, and confirmability of the results of this study (Fortin et Gagnon, 2016; Lincoln et Guba, 1985).

3.8.1 Credibility

Credibility refers to the accuracy of data (Fortin et Gagnon, 2016). The interviews were transcribed by student researcher and revised by director team to accurately and objectively reflect the data (Fortin et Gagnon, 2016). Data analysis was done iteratively throughout the data collection and analysis process and validated by consultation between director team (Fortin et Gagnon, 2016; Lincoln et Guba, 1985). The student researcher used a logbook to develop her reflectivity (e.g. recording the steps taken in data cleaning, preprocessing and etc.) and ensure the accuracy of the results (by creating a transparent and traceable trail of data). She discussed these possible biases with the research director team (Fortin et Gagnon, 2016).

3.8.2 Transferability

Transferability corresponds to applying conclusions to similar contexts (Fortin et Gagnon, 2016). To do this, the student researcher provided a detailed description of the context (environment and participants) and the method used in this study (recruitment, data collection, and analysis) (Fortin et Gagnon, 2016; Lincoln et Guba, 1985).

3.8.3 Reliability

The reliability criterion refers to the integrity of the data collected (Fortin et Gagnon, 2016). It is about obtaining similar responses when the study is repeated with the same participants in a similar context (Fortin et Gagnon, 2016; Lincoln et Guba, 1985). To ensure this criterion, the student researcher consulted with the research director team to validate the data collection methods, the data analysis, and the conclusions obtained (Fortin et Gagnon, 2016).

3.9 Ethical considerations

The ethical aspects of the research protocol were submitted to the ethics and research committees of the CIUSSS du Nord-de-l'Île-de-Montréal and the ICM. In addition, these ethical aspects are consistent with the procedures of the Tri-Council of Canada (Canadian Institutes of Health Research, 2018).

Ethical approval was obtained from the affiliated universities and the participating institutions' research ethics boards, approval number # MP-32-2023-2575, on December 2nd, 2022.

Before data collection began, participants were provided with free and informed consent. Participants had access to a detailed description of the context of the study, its purpose, its conduct, the data analysis, and the method of presenting the results. This consent allowed them to accept or refuse to answer questions during the semi-structured interviews. Similarly, participants had the right to leave the study at any time, with no justification or questions being asked.

During the interviews, confidentiality is maintained as part of the student researcher's responsibility. In addition to a digital voice recorder with memory, the student researcher used a personal cellphone with a safe password as a secondary device during the interviews. Interviews were recorded anonymously. All information is kept in the research director's office to protect confidentiality. For safety reasons, a backup copy of the recorded interviews was kept in the director and co-director's office in case of data loss. To avoid disruptions during the interview, it was essential to verify all internet and telephone connections in advance and ensure all electronic devices were fully charged and functional. In the event of technical difficulties, participants were informed that the interview could be rescheduled. During the interviews, the student researcher ensured that the interview process was respectful to the participants, allowing them to express themselves freely (Sandelowski, 2000).

Interested individuals physically met with a student researcher to ensure participant confidentiality in the workplace study. Different time schedules were provided to accommodate participants' availability, ensuring coverage for their patients during the interviews. Additionally, all recorded materials, transcriptions, and verbatim files were anonymized. Participants signed an explicit and voluntary consent form, emphasizing the commitment to protecting their privacy. In addition,

digital audio recordings during interviews have been kept in a confidential file with a password on a server at the research director team's offices. Access to these recordings was granted only to the research director's team. In addition, during the transcription and analysis of the data, the documents obtained were handled with caution and security (Microsoft Outlook was used for exchanging data through emails: the secured university platform) so that only our director and co-director of research could access them, ensuring the smooth running of the process. Finally, when the study is completed, all files, recordings, and documents will be kept in the office of the research director team for seven years in order to protect all the information and data obtained.

To conclude, there are a few risks and benefits for the participants in the research project. The potential risks and disadvantages of the research project stemming from the required interview time. To reduce these risks, participants will choose the timing of the interview. Besides the time factor, the interviews may be distressing for nurses who have dealt with ICU delirium in the past. The student researcher explained all interview processes, so the participants felt less stressed. In addition, they were informed that they could leave the interview at any time if they felt uncomfortable. The risk associated with COVID-19 Pandemic: There are risks associated with entering the research center during the current COVID-19 pandemic. We aimed to minimize the risks and protect participants as much as possible. A rigorous infection prevention and control procedure was in place, including wearing personal protective equipment, hand hygiene, disinfecting surfaces and equipment, and respecting safety distance.

The potential benefits of their participation are the advancement of knowledge in nursing sciences. Nurse participants could also feel a sense of accomplishment by participating in research to optimize the care experience for the clientele of their unit. A third possible advantage is also to positively anticipate the change in future procedures, position oneself in their professional roles, and participate in the co-construction of possible solutions, optimizing the involvement of relatives in care.

Among the potential disadvantages for nurse participation is the work overload resulting from the current lack of personnel in the environment, which can accentuate the lack of availability of the

latter. Different time slots were offered to participants at their convenience to overcome this inconvenience.

Chapter 4: Results

This chapter describes the research sample based on the collected socio-demographic information. Afterwards, the results analysis will be presented along with corresponding verbatims to answer the research questions. The verbatims are presented in French (the language used by the participants during the interviews) and will be translated into English later for dissemination activities. We presented verbatims in their original language to limit the interpretation bias.

4.1 Description of the research sample

Three of the six participants were currently working at the ICM, and three were working at the HSCM. Five of them identified as female, and one as male. The participants' age ranged from 27 to 49 years old, with a mean age of 38. Among the six participants, the majority (n=5) held a bachelor's degree, while one held a master's degree (n=1). The participants had 2 to 15 years of experience in cardiac surgery ICU. Five (83%) participants were bedside nurses, while one (17%) was a nursing manager. All participants identified as Caucasian (Table 4).

Table 4. Socio-demographic characteristics of participants (N=6)

Variable	n (%)
Gender, Female	5 (83)
Age	
20-29	1 (17)
30-39	3 (50)
40-49	2 (33)
Job title	
Nurse	5 (83)
Nurse Manager	1 (17)
Education level	
Bachelor's degree	5 (83)
Master's degree	1 (17)

Years of experience *	
0-5 years	1 (17)
6-10 years	1 (17)
11-15 years	4 (67)
Ethnic origin, Caucasian	6 (100)

**Note.* In cardiac surgery intensive care unit (ICU)

4.2 Themes

Data analysis revealed five themes describing ICU nurses' perceptions of family involvement in the care surrounding delirium in patients recovering from cardiac surgery. We further divided the themes into subthemes to achieve a more detailed and nuanced understanding of the data. Subthemes offer a way to structure large and complex themes, illustrating the hierarchical arrangement of meaning within the data (Braun et Clarke, 2006). The identified themes and their corresponding sub-themes are provided in Table 5.

Table 5. The five themes and their corresponding sub-themes defined in this project

Theme 1	Families can be involved in delirium care once patients have reached hemodynamic stability, and neurocognitive orientation preferably
	1.1. Immediate post-operative care is mainly focused on hemodynamic stability
	1.2. Choosing the right time to involve the family
	1.3. Patients' neurological conditions complicate interactions with families and their participation in care.
Theme 2	Family involvement can be facilitated by nurses focusing on sharing information
	2.1. Sharing information to the family before delirium occurs
	2.2. Sharing information to the family when delirium has occurred
	2.3. Educational materials may be used to facilitate nurses' work
Theme 3	Family input is helpful to nurses for the detection of delirium

	3.1. Nurses have no prior knowledge of patients
	3.2. Delirium can manifest in various forms
	3.3. Nurses refer to families to confirm the presence of delirium
Theme 4	Families can take concrete actions when delirium occurs
	4.1. Nurses may rely on families to perform multiple tasks, particularly those they encounter difficulties performing
	4.2. Facilitators that enable family members to be present and involved at the bedside.
	4.3. Nurses attempt to balance the involvement of the family with the patient's needs.
Theme 5	Family characteristics influence family involvement in delirium care.
	5.1. Families are typically concerned and stressed out in the early post-operative phase of cardiac surgery.
	5.2. Family's anxiety is at its highest when delirium occurs.
	5.3. Some families show obvious signs of willingness to participate in delirium care.
	5.4. Some families tend to refrain from participating in the care of a patient with delirium.

4.2.1 Theme 1. Families can be involved in delirium care once patients have reached hemodynamic stability, and neurocognitive orientation, preferably.

This theme explores how families become integral to delirium care after patients achieve medical stability, emphasizing the conditions under which nurses deem family involvement beneficial. It addresses sub-themes related to the timing, readiness, and appropriateness of family participation in patient care.

4.2.1.1 Sub-theme 1.1 Immediate post-operative care is mainly focused on hemodynamic stability.

Cardiac surgery patients' care, particularly immediately post-operation, necessitates a focus on hemodynamic stability, demanding significant attention from nursing staff and, at times, collaborative interdisciplinary efforts to promptly address any issues. This involves careful consideration of ventilatory status, acid-base balance, electrolyte levels, as well as proper administration of sedation and pain control (Stephens et Whitman, 2015). According to most ICU nurses (n=5), providing care in cardiac surgery ICU is complicated because these patients are intubated from the operating room and have several devices (e.g., cardiac monitor, chest drain, etc.). Vital signs may vary significantly from one patient to another or change quickly in the same patient, leading nurses to be particularly attentive to patients' conditions during that critical period. Therefore, immediate post-operative care mainly focuses on monitoring the patients for hemodynamic stability. Unstable patients, either at admission or later on during hospitalization, take a lot of attention to the nursing staff and sometimes even interdisciplinary team efforts to address the issues promptly.

« C'est compliqué de gérer un patient de soins intensif [...]. Ils arrivent dans le service, intubés ou non [...] ils sont souvent instables... » (P. 3)

4.2.1.2 Sub-theme 1.2. Choosing the right time to involve the family.

The dual responsibility of providing emotional support to families and intensive care to cardiac surgery patients can complicate nursing tasks, underscoring the need for balancing empathy with clinical care in these sensitive situations. According to most nurses (n=5), the family's first visit after cardiac surgery should occur once routine procedures have been completed and the patient's condition has stabilized, even if the patient is unconscious and intubated.

« [...] dès qu'on a terminé tous les examens avant même de commencer à réveiller le patient on fait venir la famille au chevet. » (P. 2).

This should occur within the first hour of the patient's admission to the ICU.

« [...] quand on a stabilisé le patient [...] on les fait rentrer. C'est souvent une demi-heure, 1h après l'admission du patient » (P. 3).

Also, some nurses (n=2) highlighted that they find it difficult to be present for both family members and cardiac surgery patients when the family is emotionally distressed. The dual

responsibility involves reassuring and supporting the family while managing the complex care requirements of the patient recovering from cardiac surgery.

« Si j'ai quelqu'un qui est beaucoup dans l'émotion, c'est plus difficile parce qu'il faut que je traite les 2, c'est-à-dire faut que je rassure la famille, puis il faut que je m'occupe du patient. » (P. 4)

4.2.1.3 Sub-theme 1.3. Patients' neurological conditions complicate interactions with families and their participation in care.

The challenges posed by patients' post-operative conditions, such as somnolence, memory loss, and confusion, can diminish their motivation to engage with nurses and participate in their care. During the first 24 hours post cardiac surgery, patients may experience somnolence, loss of memory or confusion after surgery, and difficulty following instructions. They feel exhausted and cannot follow the care. Nurses (n=3) pointed out that patients' pain and cognitive state may lessen their motivation to interact with nurses and participate in nursing care, particularly during the first 24 hours after cardiac surgery.

« Les premiers 24, 48 h, les patients sont très fatigués, [...] je veux pas qu'on épuise le patient non plus. » (P. 6).

The administration of analgesia can lead to drowsiness in patients, which may result in confusion regarding their surroundings and difficulty recognizing nurses and comprehending the purpose of their care. Patients with this lack of understanding and drowsy state might struggle to follow multiple instructions consecutively.

« Quand les patients sont éveillés, extubés, parfois l'analgésie, ça fait qu'ils sont très endormis. Parfois ils collaborent pas nécessairement aux soins [...]. La personne comprend pas nécessairement ce qui s'est passé, comprend pas nécessairement qui on est, pourquoi on veut faire ça. C'est un enjeu supplémentaire. [...] Puis de respecter toutes les consignes, ils sont incapables de suivre plusieurs consignes, une à la suite de l'autre. » P. 2

Most participants (n=4) stated that family involvement may be limited in the first few days after surgery. According to their statements, the presence of family members at the bedside depends on the patient's condition and ability to recognize their family members. Some patients may want to

see their families, while others may prefer not to have visitors. When patients cannot recognize their family members, it can stress the family.

« [...] il y en a qui (la famille) sont comme très perturbés par le fait que le patient les reconnaisse pas. » (P. 4).

A patient can feel the stress of family members, which may also negatively impact the patient's well-being, exacerbating the overall situation.

« Le patient ressent le stress de la famille. Et puis forcément, ça fait qu'empirer les choses. » (P. 3)

4.2.2 Theme 2. Family involvement can be facilitated by nurses focusing on sharing information.

The process of sharing information about a patient's condition in the cardiac surgery ICU involves two key steps. Initially, ICU nurses prefer to communicate with the family before they visit the patient at the bedside. During this phase, nurses aim to establish trust with the family members by briefly explaining how the cardiac surgery went and updating them on the patient's current condition in the ICU. The second step occurs at the patient's bedside, where nurses maintain respect for patient privacy and the specific medical procedures performed. Generally, information sharing includes verbal explanations and distributing educational materials, such as brochures in the ICU. In routine ICU interactions, nurses regularly update family members on the patient's cardiac surgery condition but only address delirium complications if they arise.

4.2.2.1 Sub-theme 2.1 Sharing information to the family before delirium occurs.

Nurses advocate meeting families at the ICU entrance to build trust, share patient status, and guide on comforting gestures. They also stress the importance of privacy during certain procedures, limiting family presence to ensure patient dignity. This approach aims to balance informative support with respect for patient care and privacy.

Some nurses (n=4) mentioned the importance of preparing the family for what to expect regarding the patient's condition before entering the room. They prefer greeting the family at the ICU entrance rather than directly in the patient's room.

« Souvent, j'aime ça, aller les chercher moi-même. Dans le sens où je les prépare à ce qui les attend, [...] je leur explique déjà sur le chemin en arrivant jusqu'à la chambre pour pas qu'il y ait de surprise. » (P. 4)

This approach allows them to introduce themselves, establish a bond of trust with the family, and provide information on the patient's condition before entering the room.

« Moi j'aime bien aller accueillir les gens (familles) à l'entrée, [...] ça me permet de me présenter, de créer tout de suite un petit lien de confiance avec la famille. Puis de donner des nouvelles avant de rentrer dans la chambre, les préparer, j'aime les préparer avant de rentrer dans la chambre du patient. » (P. 6)

Nurses can inform family members of the comfort they can provide the patient through simple gestures, such as holding the patient's hand, speaking softly to them, and reassuring them that the surgery is over, and they are currently in the ICU.

« [...] dès qu'ils arrivent aux soins intensifs, je leur demande de tenir la main, de parler doucement à la personne, de lui rappeler qu'elle est à l'hôpital, que l'opération s'est bien déroulée » (P. 2).

While they recognize the importance of respecting privacy of the patients during specific medical procedures (e.g., bronchoscopy) and intimate care (e.g., bath time), they don't invite families during these times.

« Moi, je suis plus pour la famille ou la visite en permanence, sauf dans les soins intimes du patient. » (P. 1).

« À moins de faire des soins spécifiques comme les changements de pansement, un examen comme une bronchoscopie [...] il y a certaines choses qu'on va faire que la famille peut pas être au chevet. [...] mais sinon, s'il n'y a pas d'urgence dans la chambre puis, si la situation le permet, je favorise la présence de la famille. » P. 6

4.2.2.2 Sub-theme 2.2. Sharing information with the family when delirium occurs.

The nurses can engage families by asking about their observations of the patient's condition, then provide a simplified explanation of delirium, deliberately avoiding technical jargon to ensure clarity and understanding.

All nurses (n=6) stated that they do not typically discuss delirium complications after cardiac surgery with the family if the patient has not experienced it, and this include delirium.

« Si le patient est pas en délirium, j'en parle pas, j'en parlerai pas nécessairement. » (P. 6).

However, once signs and symptoms of delirium arise, they inform the family about the condition.

« C'est au moment où ils développent des symptômes de délirium qu'à ce moment-là, on va leur expliquer ce que c'est, pourquoi la personne a ce type de comportement. » (P. 2).

Their approach involves asking the family members about their observations regarding the patient's situation. Afterward, they give a simplified explanation of delirium by avoiding scientific terms such as delirium.

« Je vais pas dire le mot délirium. [...] Quand je suis dans mon sevrage de médicaments, anesthésie, analgésie, je leur explique que le réveil peut être aussi bien agité ou confortable par rapport au fait de la longue chirurgie qu'ils ont eu en fait de la CEC (circulation extracorporelle) qu'ils ont eu. » (P. 1)

4.2.2.3 Sub-theme 2.2. Educational materials may be used to facilitate nurses' work.

The use of educational materials by nurses, including pre-prepared documents, can be important as informational support for the family. Accordingly, a few nurses mentioned (n=2) that they utilize a pre-prepared document, such as a brochure, available in the ICU to enhance the educational process.

« Ce que je fais généralement, c'est qu'on a de la documentation en avant que je leur invite à lire sur le délirium. Puis après, on en discute ensemble [...]. » (P. 6).

Despite nurses providing explanations to families, some individuals still resort to the Internet for additional information. This may result in a decreased understanding or exposure to inaccurate information, potentially leading to adverse outcomes.

« Même si on donne des explications, il y en a des fois qu'ils vont chercher sur Internet, donc des fois c'est encore pire parce que là, ils comprennent encore moins, ou alors ils ont vu quelque chose de particulier » (P. 4).

4.2.3 Theme 3. Family input is helpful to nurses for the detection of delirium.

ICU nurses acknowledge the diverse manifestations of delirium and the challenges of promptly identifying its occurrence. They note its potential to manifest in short, reversible forms or as hypoactive (marked by drowsiness or sluggish responses) and hyperactive (characterized by aggression, incoherence, hallucinations, and nightmares) states. Consequently, families can play a crucial role in recognizing abnormal behaviors and confirming delirium when it occurs. Our findings suggest that family members can be instrumental in delirium detection, particularly when nurses lack familiarity with patients' baseline characteristics. Their presence at the bedside can serve to validate the presence of delirium following cardiac surgery.

4.2.3.1. Sub-theme 3.1. Nurses have no prior knowledge of patients.

The nurses can place value on the insights family members provide due to their familiarity with the patient's baseline condition. Nurses (n=4) valued the presence of patients' family members at the bedside as they are more familiar with the patients' baseline condition and can readily identify any changes that occur.

« Je trouve que c'est vraiment très, très important, que les membres de la famille soient là. Parce que c'est eux qui connaissent plus le patient que nous. » (P. 3).

Nurses may not intimately understand the patient's personality and background, making family observations and insights valuable. Families' ability to recognize 'unusual behavior' is precious to nurses in cardiac patient care.

« Moi je connais pas le patient dans son contexte de tous les jours [...] je le connais pas le monsieur de base. » (P. 4)

4.2.3.2 Sub-theme 3.2. Delirium can manifest in various forms.

Nurses observe that delirium, while often temporary and reversible, presents in varied forms across patients, from aggressive and disoriented behaviors to the more subdued symptoms of hypoactive delirium like excessive sleepiness. This variability poses challenges for nurses in recognizing and managing the condition effectively.

The participants (n=3) noted that delirium could manifest differently in each individual, which challenges nurses in recognizing and managing it effectively.

« C'est jamais pareil d'un patient à l'autre [...]. » (P. 4).

Patients can experience various symptoms, including aggressive behavior, incoherent statements, hallucinations, and nightmares. In contrast, some patients may present with calm behavior, indicative of hypoactive delirium, characterized by excessive sleepiness and sluggish responses to commands.

« De l'agitation, de la méfiance ou quelqu'un de très somnolent, [...]. » (P. 6).

« On le voit dans leur état psychologique quand les propos sont incohérents, quand qu'il y a de la confusion, quand qu'ils sont désorientés. » (P. 5).

4.2.3.3 Sub-theme 3.3. Nurses refer to families to confirm the presence of delirium.

The reliance on family observations aids nurses in identifying early signs of delirium, highlighting the critical role of family in patient care and assessment. In order to determine any changes or problems with the patient's behavior or condition, nurses (n=3) valued the involvement of the family members. They specifically ask for feedback from the family when there is suspicion of delirium to validate their observations.

« Si j'ai un petit soupçon que le patient est en délirium, la famille devient un outil essentiel parce que... avec eux, je vais pouvoir déterminer s'il est vraiment en délirium ou pas. » (P. 6).

Additionally, family members know the patient's normal behavior and can help determine whether the patient is in delirium. For example, families can notify nurses when conversations with patients seem inappropriate or strange (compared to their natural behavior), and families could become early indicators of delirium.

Participants (n=2) mentioned that detecting delirium from the basic characteristics of a patient can be difficult for them. They believe that family presence can help them validate if the patients are truly experiencing delirium.

« C'est dur de trouver le moment où le patient est vraiment en délirium. La transition là, du patient qui est toute là, au délirium [...] la ligne est mince entre les 2 [...]. Puis c'est là où la famille pour moi devient utile pour déterminer : il est

vraiment en délirium en ce moment ? reconnaissez-vous votre mari ? [...] je le sens un petit peu mélangé ou donc je vais valider ça. » P. 6

4.2.4 Theme 4. Families can take concrete action when delirium occurs.

When delirium occurs in cardiac surgery patients, nurses actively involve family members by inviting and encouraging them to be present at the bedside if possible. Family involvement in delirium management benefits in two ways. Firstly, family members' presence reassures and calms the patient, potentially reducing delirium symptoms as the familiar faces provide a sense of comfort. ICU nurses highlight the family's presence as a crucial point of reference for patients, emphasizing that family members often hold a special connection compared to caregiving nurses. This familiar presence aids patients in reconnecting with reality and facilitates delirium recovery. Secondly, the involvement of family members in delirium activities becomes particularly valuable as they possess a deeper understanding of the patient's preferences and needs.

4.2.4.1 Sub-theme 4.1. Nurses rely on families to perform multiple tasks, particularly those they encounter difficulties performing.

Families are seen as crucial in performing tasks that are challenging for nurses, providing both emotional support and practical assistance in patient care. Nurses (n=4) indicated that they frequently reach out to the patient's family to offer support during episodes of delirium. Additionally, if family members desire to be involved in caring for a patient with delirium, nurses encourage their participation. This can include simple gestures such as holding the patient's hand, offering support when the patient attempts to touch or remove tubes, engaging in conversation in the maternal language, and maintaining eye contact.

« Je leur propose si par exemple, ils veulent leur tenir la main, [...] j'explique aux patients, puis après je leur propose (à la famille) d'être un peu plus présent, de tenir la main, de leur parler, de leur regarder dans les yeux. » (P. 3).

Some nurses (n=3) stated that family members are encouraged to be involved in patient care and treatment. Involving family members with patient care increases the possibility of completing tasks that nurses may find challenging.

« Mais en l'intégrant la famille, en les faisant participer souvent la famille va réussir à leur faire ce que nous, on n'arrive pas, à leur faire, faire comme activités des soins » (P. 2).

In addition, they can be a source of comfort and reassurance for patients.

« Parce que le patient est moins méfiant, quand une personne de la famille est là, ça me permet de faire des choses que je pourrais pas faire si ça conjointe ou quelqu'un de la famille était pas là, ça c'est sûr. » (P. 6).

Another way nurses involved families in patient care and reassurance is by talking to patient in their native language.

« Je leur ai demandé (à la famille) de rester pendant les soins, puis de tenir la main du patient ou d'expliquer des fois dans la langue maternelle, parce qu'on est plus amené à reconnaître les langues maternelles quand on est dans un état délirium. » (P. 1).

Few nurses (n=2) noted that many family members feel responsible when caring for their loved ones and often take over certain aspects of care when they are in the room. As family members are more aware of the patient's preferences and requirements, they can provide simple tasks like mouth care or other basic needs such as reassuring them by speaking, holding their hands, and looking into their eyes. In some cases, they may assist even in securing the patients, such as when the intubated patient tries to touch or remove the tube.

« Ils (la famille) prennent notre place dans quand ils sont dans la chambre, à certains moments de la prise en charge, par exemple, tout simplement les soins de bouche, des choses aussi simples, c'est eux qui vont prendre le relais et qui vont dire, j'aimerais bien moi lui donner les bâtonnets pour mettre dans la bouche, etcetera. Ils sont beaucoup plus à l'écoute du patient. » P. 3

Emphasizing the role of family as a consistent and comforting reference point highlights its impact on patient morale and the overall effectiveness of delirium management. According to nurses (n=3), having a familiar presence will help the patient recover from their delirium and regain a connection with reality more quickly than seeing multiple nurses who are strangers to them daily. When patients are familiar with and connect positively with the individuals providing care, it becomes more accessible to attend to their needs.

« Ils (les patients) ont un visage qui reconnaisse, quand ils reconnaissent quelqu'un qu'ils aiment ça, ça amène plus facilement à faire des soins. » (P. 4).

Nurses (2 out of 6) emphasized the importance of family members in providing reassurance. When family members are present, the patient is calmer. It makes it easier to approach the patient, provide care, and allow nurses to attend to other patients' needs.

« Quand ils (les patients) sont entourés de leur famille, ils sont moins anxieux et ils sont moins demandant des soins. Ils (les patients) sont quand même plus calmes. » (P. 3).

One participant emphasized the importance of providing patients in delirium with a familiar reference point in their care. This includes having a family member or someone the patient can rely on, which helps them establish a sense of grounding and connection to reality. This everyday reference point significantly affects the patient's morale and ability to navigate delirium.

« Dans les soins qu'on donne aux patients, au niveau de son moral, au niveau de juste se situer, par exemple un patient en délirium, si c'est essentiel d'avoir un repère de tous les jours dans sa vie, d'avoir un membre de la famille ou quelqu'un sur lequel il peut se réancrer dans la réalité, là, ça lui donne un point de repère. » P. 6

4.2.4.2 Sub-theme 4.2. *Facilitators that enable family members to be present and involved at the bedside.*

The adaptability of the ICU environment to accommodate overnight stays and the readiness of families to assist during agitation crises highlight the evolving support systems that contribute positively to patient care and recovery. Few participants (n=2) noted that if the ICU conditions allow, nurses invite family members to stay overnight. The ICU environment has changed in the past year in both research sites. New resources, such as single rooms and adapted chairs, facilitate the presence of families. During the interviews, nurses mentioned encouraging family members to remain present whenever adapted chairs were available. They demonstrate how to lower the bed railings, enabling the family to sit comfortably beside the patient for regular conversations and fostering a sense of home-like comfort.

« Les familles peuvent rester dormir la nuit dans la chambre, à côté de leurs proches, [...] j'essaie de le proposer plus souvent possible. Il y a des fauteuils adaptés pour ça. [...] Il s'assoit à côté, on baisse les ridelles, on essaie de recréer un environnement de conversation. » (P. 1).

Nurses believed that voluntary and active participation is critical in delirium. Many families are supportive and offer assistance in managing agitation crises, as they believe their presence helps keep the patient calm. The families express their willingness to be called anytime, day or night, and to stay by the patient's side and engage in conversation.

« Il y a beaucoup de familles qui nous disent [...] de les appeler à tout moment du jour et de la nuit s'il y a une crise d'agitation. [...] elles (la famille) voient bien que quand elles sont là, le patient est plus calme [...]. » (P. 1).

4.2.4.3 Sub-theme 4.3. Nurses attempt to balance the involvement of the family with the patient's needs.

Nurses should maintain a balance between family involvement and patient well-being, particularly for patients with delirium. In certain circumstances, nurses (n=3) stated that they may decide not to allow family members to remain at the bedside of delirious patients. When patients exhibit excessive aggression towards their families, nurses will not permit them at the bedside.

« Les limites, c'est les patients violents. Un patient violent peut blesser la famille, parce que des fois il les reconnaît pas, puis il peut être violent avec la famille. » (P.

4).

Instead, they will support the family, recognizing their challenges. Additionally, if nurses perceive that the family is exhausting the patient or if the family members themselves are emotionally exhausted or anxious, they may restrict their presence at the bedside.

« Ça me fait penser à des conjoints qui pleuraient de voir leur conjoint comme ça, puis qui se faisaient insulter par leur conjoint ou donc là je vais pas permettre à la famille de rester dans la chambre, faut pas que la famille vive des traumatismes là, premièrement. [...] Si le patient devient trop agressif ou agressif avec ses proches, ça, je le permettrai pas non plus. Donc je vais accompagner la famille parce que ça peut être dur pour la famille » P. 6

Nurses (n=3) noted that sometimes families could unintentionally stimulate patients, disrupt their sleep, and awaken their pain, particularly at night.

« Il y a des familles qui alimentent un peu soit l'agressivité ou la confusion, ou qu'ils sont tellement anxieux que ça se déverse sur le patient déjà confus ou délirieux. »

(P. 5).

The patient can feel their concern and anxiety, which can negatively affect their current condition and potentially exacerbate it.

« Je veux que la famille voit, mais je veux pas qu'on épuise le patient non plus parce qu'on a des choses à faire comme les premiers lever. » (P. 6).

4.2.5 Theme 5. Family involvement in delirium care is influenced by family characteristics.

Family members' involvement in delirium care can be influenced by various factors, including their characteristics. Many may feel overwhelmed by the ICU environment and the variety of medical devices surrounding their loved one, leading to limited interaction opportunities. Moreover, the stress induced by cardiac surgery itself, compounded by unexpected complications like post-surgery delirium, can heighten anxiety and raise concerns about the permanence of the condition. A lack of information about delirium exacerbates these worries. Individuals vary in their ability to cope with delirium situations; while some actively participate in care, others may feel overwhelmed and withdraw from the bedside. Additionally, older adults may exhibit less cooperation, and families who are physically distant from the hospital face additional challenges in providing support.

4.2.5.1 Sub-theme 5.1. Families are typically concerned and stressed out in the early post-operative phase of cardiac surgery.

The anxiety and stress experienced by families during the early post-operative phase of cardiac surgery can be problematic, especially while waiting for updates during surgery. The unfamiliar sight of their loved one amidst numerous medical devices post-surgery adds to their discomfort, with the fear of causing harm often deterring them from physical interaction. One participant perceived that family members anxiously wait outside the operating room during cardiac surgery

to hear updates on their loved one's condition. They are highly concerned and stressed about getting updates on the patients' progress and ensuring they recover quickly.

« Les gens (la famille) sont extrêmement stressés, [...] ces personnes-là sont hyper inquiètes, [...] c'est vraiment la chose qu'ils attendent de savoir si ça va bien ou si ça va pas bien. » (P. 2).

The post-operative state can also be stressful for the patient's family, as they may not be accustomed to seeing their loved one surrounded by numerous medical devices. The family members feel uncomfortable due to the presence of numerous wires around the patient, and fear of causing harm may prevent the family from touching or interacting with the patients.

« C'est souvent difficile pour eux (la famille), [...], la clientèle post-opératoire de chirurgie cardiaque est lourdement instrumentée. Il y a beaucoup, beaucoup, beaucoup d'inquiétudes par rapport à ça. [...] La famille ils sont comme on dit, je peux y toucher, il y a tellement de fil, y a tellement d'affaires sur lui, j'ai peur. » (P. 5).

4.2.5.2 Sub-theme 5.2. Family's anxiety is at its highest when delirium occurs.

Nurses observe that families are often unprepared for complications, leading to confusion and concern about the patient's recovery and the permanence of delirium. According to all nurses (n=6), unexpected complications such as delirium can surprise the family after cardiac surgery. Sometimes, delirium causes them to react, a state of reaction that does not allow them to comprehend what is happening.

« Ils (la famille) sont toujours très surpris et très inquiets de voir qu'ils se font pas reconnaître par leurs proches. Souvent sont en mode réaction, [...] c'est super anxiogène pour eux de le voir comme ça. [...] puis ils comprennent pas trop, ça va être un état permanent, temporaire... » (P. 5).

Consequently, they may feel unsure whether the patient will fully recover from the state of delirium they are currently experiencing and whether it will be permanent or temporary. As per nurses (n=4), every family understands delirium differently. Some families are unfamiliar with the phenomenon of delirium. However, they know it is not a normal awakening or level of agitation for the patients; it is something amiss.

« Il y a certaines familles, plus anxieuses que d'autres, mais ils comprennent qu'il faut être réassurant, le calmer, le parler et que c'est pas que c'est pas une quelque chose qui va rester dans le temps. Que ça va, se normaliser dans les suites, ça va prendre un peu de temps mais que ça va se normaliser. » (P. 3)

« Ils (la famille) comprennent qu'il y a quelque chose qui se passe mal, c'est pas un réveil normal, puis c'est pas une agitation qui est normale. Mais qu'ils associent au délirium. D'autres s'y attendent parce qu'ils ont déjà vécu ça avec ce proche là, dans d'autres chirurgies, par exemple. » (P. 1)

The level of anxiety experienced by family members can also vary. The type of delirium can influence it. For instance, delirium characterized by mild symptoms differs from aggressive delirium, in which patients exhibit physical or verbal violence and need restraint. This can be challenging for the family.

« C'est des petits symptômes de délirium. Puis, c'est plus ou moins inquiétant, mais pour des patients très agressifs qu'on est obligé de contentionner, qui sont violents aussi physiquement ou verbalement, ça c'est dur pour les familles, ça c'est vraiment dur. » (P. 6)

However, informing the family of their patients' delirium may cause stress and concern. Some family members do not fully comprehend or agree with the information provided. Re-explaining the situation can be challenging, as even with additional explanations, the concept may remain unclear to them.

« Des fois, ils sont pas d'accord sur ce qu'ils ont compris. [...] Mais c'est vrai que c'est pas facile de la réexpliquer parce que même si on leur explique pour eux c'est pas concevable. » (P. 4).

Also, it depends on the individual. For example, an older adult may have a lower understanding level.

« Dépendants de la personne. Aussi, quand un membre de la famille, exemple il y a 85 ans et ça se peut que la Madame elle comprenne moins bien justement les informations, qu'on soit en train de lui donner. » (P. 5).

4.2.5.3 Sub-theme 5.3. *Some families show obvious signs of willingness to participate in delirium care.*

Families often show a readiness to engage in the care of patients experiencing delirium. Nurses (n=5) noted that active family participation in care is often evident when they observe family members consistently asking questions, regularly checking in for updates on their loved ones, being present at the bedside, and displaying a high level of attentiveness toward meeting the patient's needs.

« Quand qu'ils (la famille) posent des questions, quand ils se montrent impliqués, quand ils prennent la peine d'appeler pour prendre des nouvelles, quand ils sont au chevet, puis ils sont vraiment attentifs aux besoins du patient [...] quand on sent un intérêt de leur part. » (P. 5).

Some families actively offer to take on a mission-like role. They are willing to try various tasks and responsibilities to ease the burden on nurses, understanding the challenging nature of the situation.

« Souvent, les familles vont aussi dire est-ce que je peux t'aider à quelque chose ? » (P. 2).

« Si la famille est réceptive, si on sent qu'on a affaire à quelqu'un qui est capable de prendre, cette responsabilité là, ça peut être un bon recours. [...] Il y en a qui se proposent directement de venir [...] il y en a qui prennent ça comme une mission, parce qu'ils trouvent leur mari horrible. » P. 4

4.2.5.4 Sub-theme 5.4. *Some families tend to refrain from participating in the care of a patient with delirium.*

The intense environment of delirium care can deter some families from participating. According to half of nurses (n=3), the distressing situation can be overwhelming for some family members, making them feel burdened and unable to provide support.

« Une famille qui veut pas ou qui en a peur. » (P. 1).

Consequently, they may opt to leave without offering assistance. They may believe they cannot provide significant assistance in such circumstances.

« Il y a ceux qui sont complètement perdus, puis qui pleurent juste de de voir la personne comme ça. Puis qui se disent, je suis pas d'une grande aide pour vous. »
(P. 4).

It can be particularly challenging for families to witness their loved ones exhibiting aggression and verbally insulting or being physically restrained to bed. Such conditions can significantly increase their stress levels.

« Parfois on voit qu'ils sont épuisés, ont l'air épuisé [...] Quand on voit qu'ils sont dépassés par la situation. [...] Il y en a qui sont trop sous le choc de cette situation-là, trop émotifs, sont pas aidants non plus, puis demain, ils vont quitter le chevet de dire, moi, je peux pas le voir comme ça, ça me fait trop de peine et se mettre à pleurer, puis ils vont quitter et ils vont pas rester. » P. 2

The family may lack sufficient information about delirium, leading to a lack of understanding regarding the situation and how they can assist.

« Elle est le manque d'information, compréhension de la situation, c'est qu'on comprene pas c'est quoi un délirium, c'est ils comprennent pas si savent pas ce qu'ils peuvent faire comme soin auprès de la. » (P. 2).

Depending on how far they live from the hospital, family members may be physically unable to be present at the bedside.

« Ils sont pas là physiquement [...] parfois la famille habite loin. » (P. 2).

Chapter 5: Discussion

To the best of our knowledge, this is one of the first studies to examine nurses' perspectives on family involvement in delirium care in the early postoperative days of cardiac surgery in the ICU. Overall, results show that ICU nurses have a positive attitude towards family involvement in nursing care surrounding delirium. However, some areas of improvement regarding clinicians' misconceptions, communication with families, and creating a welcoming environment have been identified. This chapter summarizes the research results and discusses each question, considering the existing scientific and theoretical literature. Finally, the chapter concludes with a comprehensive summary of recommendations for nursing practice, education, and research.

5.1 First research question

The first research question aimed to describe nurses' perceptions of the barriers and facilitators to family involvement in delirium care in the early postoperative days of cardiac surgery in the ICU. Based on the interview analysis, three of the five identified themes directly relate to this topic. The themes are: Families can be involved in delirium care once patients have reached hemodynamic stability and neurocognitive orientation (Theme 1), Family involvement can be facilitated by nurses focusing on sharing information (Theme 2), and Family involvement in delirium care is influenced by family characteristics (Theme 5).

Through these three complementary themes, our results show that early family involvement is often limited in the first hours following ICU admission due to cardiac surgery patients' clinical condition. Once the patients have reached clinical stability, families' fears and anxiety are another major barrier to their involvement. On the other hand, organizational measures such as sharing information and open visiting hours can facilitate family involvement in delirium care in the early postoperative days of cardiac surgery in the ICU. Some families are willing to participate in standard routine care, and sometimes nurses help them participate in the care process. An overview of the main barriers and facilitators identified by nurses' participants regarding family involvement in delirium care in the ICU post-cardiac surgery are listed in Table 6, discussed in detail afterwards.

Table 6. Main barriers and facilitators identified by nurse participants for family involvement in delirium care in the ICU post-cardiac surgery.

Barriers	Facilitators
<ul style="list-style-type: none"> • Patient unstable post-operative state • Patient somnolence, confusion or aggressive behaviors • Care and procedures requiring patient privacy • Family emotional and physical state 	<ul style="list-style-type: none"> • Family preparation • Creating a comforting ICU environment • Family willingness to be involved

5.1.1 Barriers to family involvement in delirium care after cardiac surgery in the ICU.

Patients' unstable hemodynamic condition was unanimously perceived by nurse participants as a significant barrier to early family involvement in ICU routine care following cardiac surgery. Nurses closely monitor patients who have undergone cardiac surgery, particularly within the first 24 hours when hemodynamic instabilities may arise. Their priority lies in initiating the primary admission routines, including conducting blood tests, performing physical examinations, and comprehensively assessing the patient's condition. Once all necessary care procedures are completed by the nurses, they proceed to inform the patient's family members about the patient's current status and keep them updated on the post-operative condition. The primary focus on patient's hemodynamic stability is in line with two large-scale ICU studies conducted in Australia reporting that high patient acuity restricts family involvement in care (Mackie et al., 2015). In one of the studies, most nurses prioritized their tasks, emphasizing the assessment and treatment of patients' physical conditions, and often preferred not to actively involve family members during these activities (Mackie et al., 2018). Similarly, in other qualitative study, nurses expressed their concern for the patient's care as their primary focus in critical care (Naef et al., 2021).

Aside from hemodynamic stability issues, cardiac surgery patients' tendency to experience drowsiness, memory loss, or confusion in the ICU, was also identified as a barrier to family participation in delirium care. Although these alterations in neurological state are often linked to the presence of delirium, they are also common side effects of the sedative medications received

in the ICU. In our study, nurses emphasized that patient's altered neurological state can be challenging and stressful for families when their loved ones cannot recognize them, leading them to be less inclined to get involved in care. Contributing to this phenomenon, the study of Lange and colleagues (2022) underscored that patients experiencing delirium were perceived as different individuals, causing fear and anxiety among their relatives. It even caused discomfort and unease the interactions of family members with the patient (Lange et al., 2022).

Other barriers identified by nurse participants related to the invasive medical procedures and moments of intimate care that necessitate privacy, which may lead to restricted family visitation. As highlighted by McConnell and Moroney (2015), nurses' preference for having relatives step out during patient care activities, especially for unstable and complicated patients with multiple invasive lines, could be linked to their belief that untrained family members may unintentionally disconnect or dislodge an invasive line (McConnell et Moroney, 2015). On one hand, such a concern by nurses is understandable as preventing harm and adverse events has remained a persistent challenge in the ICU through the years (Rothschild et al., 2005). On the other hand, we could not find any empirical evidence supporting that belief. Furthermore, evidence-based recommendations point out that family involvement should be the foundation of any quality improvement initiatives in the ICU (Thornton et al., 2017).

Aside from the medical procedures, families' characteristics play an essential role in their ability to take part or not in delirium care in the early postoperative days of cardiac surgery in the ICU. Our study showed that of all characteristics, families' emotional distress was identified as the main barrier to their involvement in the care of patients recovering from cardiac surgery in the ICU. This is understandable as family members visiting ICU patients often experience fragility and vulnerability (McConnell et Moroney, 2015). Families' emotional distress when a loved one faces delirium is not exclusive to the cardiac surgery ICU and appears generalized. Family caregivers caring for older adults with delirium experienced "feeling of unfamiliarity" and "distress" with developing anxiety symptoms and depression. The distress was more pronounced in cases of the hyperactive subtype of delirium, characterized by increased motor activity and aggressiveness (Shrestha et Fick, 2020).

Taken altogether, these barriers capture the underlying message behind several assumptions of the FSN theory. Indeed, FSN theory points out that family members' responses during a life-threatening illness can vary (assumption #4), depending on their coping capabilities (assumption #6), even to the point of altering family dynamics (assumption #5). According to our study participant nurses, family members' responses vary depending on their prior experiences with delirium. Individuals encountering delirium for the first time after cardiac surgery may react with anger, denial, or active involvement in care. ICU nurses play a crucial role in integrating these family members into the care team, helping them adapt to their loved one's delirium episode. Emotional distress and the stress of early post-operative phases further complicate family involvement in delirium care after cardiac surgery. Some may feel overwhelmed and distance themselves from the bedside, while others may take on proactive roles in prevention and management. Recognizing these varied responses, ICU nurses must address both emotional and practical needs to facilitate effective family participation in delirium care.

5.1.2 Facilitators to family involvement in delirium care after cardiac surgery in the ICU

Regarding facilitators, most nurse participants mentioned that they believed in properly preparing families for visiting their loved ones after cardiac surgery in the ICU. To achieve this, they aimed to establish a strong “*bond of trust*” with family members, which could be achieved by effectively informing them about the patient's condition status. In a recent scoping review, adequate preparation and education for both primary physical care (e.g., skin massage, eye care, help walking, oral feeding, position change and etc.) and non-physical care (e.g., physical presence, emotional support, cognitive support and psychological support) were identified as essential prerequisites for the active involvement of family members in the ICU (Heydari, Sharifi et Moghaddam, 2020). While family preparation could be crucial to facilitate family participation in delirium care in the context post-operative cardiac surgery, our nurse participants mentioned refraining from explicitly naming or discussing delirium with families if it had not yet occurred in their loved ones. To this end, a qualitative study conducted by Bohart, and colleagues (2019) revealed that relatives of critically ill patients in the ICU had limited knowledge or awareness of the term "delirium". Some participants had never heard of the term, while others had various pre-existing understandings of what delirium meant. In Bohart's study, family members expressed

their desire for more detailed information and explanations about delirium, specifically regarding the nature of the condition, potential treatments, and possible underlying causes (Bohart et al., 2019). According to Smithburger and colleagues (2017), delirium education is perceived by family members as beneficial when it comes to assisting them in reorienting and reducing confusion when they interact with their loved ones experiencing delirium (Smithburger et al., 2017). By not speaking to family explicitly about delirium, ICU nurses that have participated in the study may be a missing opportunity to educate and prepare families for the possibility of such complications.

On a larger scale, providing a welcoming ICU environment was also identified as an important aspect to facilitate family involvement in delirium care during postoperative cardiac surgery. To this end, several organizational measures were identified to create a welcoming environment and facilitate family involvement in delirium care in the ICU's early postoperative days of cardiac surgery, including having a family designated resting room and opening visiting hours. This echoes ICU best practice recommendations promoting open visitation (AACN, 2016; Davidson et al., 2017). In a review conducted by Ning and Cope (2020), several advantages of open visiting hours (any visiting policy that aims to reduce the previously existing restrictions on ICU visitation and increase family presence in the ICU) were documented. These included a decrease in the occurrence and duration of ICU deliriums, increased patient satisfaction, improved levels of family satisfaction with care, and reduced anxiety and depression among family members (Ning et Cope, 2020). However, as per our results, even if the ICU promotes open visiting hours, nurses may still feel concerns about families being at the bedside from time to time during specific medical procedures (e.g., bronchoscopy) or intimate care moments (e.g., bath time), for instance. To this end, Goldfarb and colleagues (2020) observed that during invasive procedures in the ICU, healthcare providers might be hesitant to allow family members at the bedside due to various concerns. These concerns include worries about potential distractions, the impact on trainee education, maintaining sterility, and medicolegal considerations (Goldfarb et al., 2020). Based on the family perspective, assisting with procedures like suctioning the patient's airway, which can be painful and distressing for the patient, and taking blood or other body fluid samples were perceived as distressing experiences for families (Wong et al., 2020).

According to our nurse participants, family members demonstrate a voluntary and enthusiastic commitment to actively participate in delirium care. They express their readiness to be available at any time, whether day or night and to remain beside the patient, engaging in meaningful conversations. Understanding the challenging nature of delirium situations, some families take on various tasks and responsibilities to alleviate the burden on nurses, and they actively offer to take on a “mission-like” role in the care process. Similarly, Racine and colleagues (2019) conducted a quantitative study on delirium burden in patients and family caregivers. Delirium burden (defined as the awareness of delirium symptoms, situational stress, and emotional response) is experienced by patients and their family members. The findings revealed that the burden of delirium was influenced not only by delirium severity but also by factors such as delirium subtype (hypoactive vs. hyperactive), emotional lability, and functional impairments (Racine et al., 2019). Also viewed from a qualitative perspective, the results of Schmitt's work on family caregivers' perspectives on delirium experience and its burden revealed that delirium symptoms, such as disorientation and hallucinations, and the uncertainty surrounding the duration of these symptoms, were perceived as the most challenging aspects for family caregivers while observing their loved ones (Schmitt et al., 2019).

In accordance with the second assumption of the FSN theory, "Family Members' Beliefs about a Life-Threatening Illness Influence How They and the Patient Cope with the Situation," coping with the unexpected complication of a patient after cardiac surgery can manifest as a mission-like role for some family members. In response, they often assume responsibilities, actively engaging in the care process and undertaking various activities to manage the challenges associated with delirium effectively. This mission-oriented approach reflects their commitment to being integral contributors to the patient's well-being during a critical health situation, such as delirium in the ICU post cardiac surgery.

5.2 Second research question

The second research question aimed to explore ICU nurses' perspectives on the benefits of family involvement in terms of delirium care post cardiac surgery. Our findings demonstrate that nurses generally perceived early family involvement as yielding significant benefits in delirium care during cardiac surgery recovery in the ICU. This aspect was supported by two additional

complementary themes: (Theme 3), Family input is helpful to nurses in detecting delirium, and (Theme 4), Families can take concrete action when delirium occurs.

5.2.1 Ways in which Family involvement proves advantageous in the assessment, prevention and management of delirium.

An aspect of family participation that was found particularly beneficial by ICU nurses' participants was that families can play an essential role in detecting delirium in patients recovering from cardiac surgery. This is not surprising as numerous studies have explored various family-based delirium detection methods (Flanagan et Spencer, 2016 ; Krewulak et al., 2019 ; Parsons Leigh et al., 2021), recognizing families' significant role in detecting delirium when working alongside the healthcare team (Fiest et al., 2020; Mailhot et al., 2020). Our results suggest that as cardiac surgery ICU nurses typically don't know the patients' baseline cognitive functioning, most of them emphasize the importance of family observations as a critical element in identifying alterations in a patient's baseline characteristics, especially when the patient is transitioning into a state of delirium. In the recent years, the fact that nurses recognize families as experts of the patient's baseline cognitive function translates into the development of several delirium detection tools focussed families (Fiest et al., 2020; Rosgen et al., 2018).

Aside from delirium detection, a majority of the nurse participants believed in involving the patient's family during delirium episodes and encouraging them to be part of the supportive care team. The family serves as a source of comfort and reassurance, acting as a "point of reference" and a reliable presence for the patient. This support helps establish a sense of grounding and connection to reality when the patient is in delirium. Nurses have observed that patients are calmer when accompanied by family members. These results align with Bohem's study (2021) that families placed importance on active engagement and inclusion in the patient's orientation process. When the clinical team involved the family in basic care tasks for a patient experiencing delirium, it fostered a sense of purpose and utility for both the patient and the staff (Boehm et al., 2021).

In addition, our results showed that another care activities such as bringing photos by family members can serve as a reminder of shared memories and experiences with the family, thereby helping patients cope with delirium. Furthermore, this approach can be effective in preventing

delirium in ICU patients post cardiac surgery, particularly when their ICU stay is prolonged due to complications such as bleeding, arrhythmias, and other post-surgical related issues (Ball, Costantino et Pelosi, 2016; Järvelä et al., 2018; Peretto et al., 2014; Seese et al., 2020). Nurses actively encourage family members to bring photos or valuable items for patients, recognizing the positive impact such personal belongings can have on the well-being and comfort of the individuals under their care. Components such as flexible visiting hours to encourage family presence, using picture boards and photographs for orientation and communication, and creating normality through activities like mobilization and music were considered facilitators for delirium management in critically ill patients (Bannon et al., 2018). Even without photographs, family visits positively impacted patients' psychological well-being and reduced delirium, providing emotional support and connection to the outside world (Pandhal et Van Der Wardt, 2022).

Nurses of our study emphasized that when patients are surrounded by their families in the ICU, their anxiety levels decrease, and their need for care becomes less demanding. Moreover, patients tend to feel calmer, particularly during agitation crises. In these moments, the family's ability to remain at the bedside can effectively encourage delirious patients to engage in reorientation efforts. Accordingly, our nurse participants firmly advocate for the involvement of family members in the management of delirium in the post-cardiac surgery ICU setting, as they believe it can alleviate the symptoms associated with delirium. A study by Eghbali-Babadi and colleagues (2017) demonstrated that structured and regular family visits significantly reduced delirium incidence by 21%, highlighting the potential for these visits to mitigate post-cardiac surgery delirium (Eghbali-Babadi et al., 2017). Regarding this subject, MENTOR_D including nursing interventions to involve family members in delirium management was developed and assessed for postcardiac surgery patients demonstrating its potential in improving families' self-efficacy, reducing anxiety, and enhancing patient recovery outcomes and length of stay (Mailhot et al., 2017; Mailhot et al., 2022).

5.3 Study limitations

While the utilization of qualitative descriptive methodology with semi-structured interviews yielded valuable insights into the perceptions of ICU nurses regarding family involvement after cardiac surgery in the context of delirium, our study had some limitations.

The research project relied on a modest sample of 6 participants from two different hospitals' cardiac surgery ICUs in Montreal. The small sample size restricts the diversity of perspectives that could have been obtained from a larger and more varied participant pool. Consequently, the findings may not encapsulate the full spectrum of viewpoints that exist among ICU nurses in these settings. On the other hand, data redundancy was observed, and converging themes could be identified with these 6 interviews. Additionally, the study's focus on ICU nurses in two specific francophone hospitals in the urban Montreal area may limit the transferability of the findings to other healthcare settings (namely anglophone institutions) or geographic regions. Due to the topic's sensitive nature, nurse participants might have hesitated to openly express certain opinions or experiences. This could lead to a potential underrepresentation of certain perspectives or the avoidance of discussing more complex aspects of family involvement and delirium management, although this has probably been minimized by the fact that the student researcher was not associated professionally with any of the research sites.

Moreover, the study's reliance solely on semi-structured interviews (compared to focus groups) might have restricted the depth of exploration into certain aspects of family involvement in the context of delirium. However, our attempts to recruit nurses for participation covered various work shifts, including day, evening, and night rotations. However, it's possible that the recruitment process inadvertently omitted certain nurses with distinct perspectives or experiences concerning family engagement in the context of delirium following cardiac surgery. Likewise, the perceptions and experiences of ICU nurses may have evolved or changed over time. The study captures a snapshot of perceptions at a particular moment, and thus, it may not reflect shifts that could occur in the future due to changes in healthcare policies, advancements in medical practices, or alterations in family involvement practices.

Despite these limitations, this qualitative descriptive research's findings provide valuable insights into ICU nurses' perceptions regarding family involvement in the context of delirium after cardiac surgery. The study contributes to the understanding of this complex issue. It serves as a foundation for future investigations and potential interventions aimed at enhancing family involvement and patient care in similar settings.

5.4 Recommendations

Based on the results of the study regarding family involvement in delirium care within cardiac surgery ICUs, several practical recommendations, suggestions for further research, and considerations for nursing education and practice can be drawn:

5.4.1 Recommendations for Management

5.4.1.1 Family preparation

Recent studies indicate the significance of educating families about patient delirium, yet there is no consensus on the most effective method of delivering this information (Bohart et al., 2019). Some research suggests that standardized written materials, such as brochures, can enhance understanding and reduce anxiety among family members (Goldfarb et al., 2020). Our findings revealed that nurses often use paper documents and face-to-face communication to ensure comprehension. Video-based education has also shown promise, although preferences for information delivery methods vary among caregivers (Bull, Boaz et Sjostedt, 2016). Printed content remains a predominant learning tool (Lee et al., 2023), but exploring innovative approaches for educational interventions is essential.

5.4.1.2 Creating a comforting ICU environment

Based on our findings, the presence of family members at the patient's bedside positively impacts patients with delirium, making them more cooperative, calmer, and better connected to reality. Creating an environment that simulates a home-like sense and providing quiet spaces can contribute to a calming atmosphere that reduces stress for both patients and their family members. To achieve this goal, we recommend the implementation of a 24/7 family presence policy in the care plan, not only for delirium patients but also for other critical patients, to prevent delirium onset at an earlier stage. This policy should remove restrictions on visiting hours, visit frequency,

visit duration, the number and age of visitors, as well as the relationship of the caregiver to the patient.

5.4.2 Recommendations for Nursing Education

Comprehensive delirium education must be integrated into nursing curricula across all academic levels. Nursing students should receive thorough instruction in the detection, management, and prevention of delirium, placing strong emphasis on evidence-based approaches. Furthermore, nursing students should be educated about the imperative role of family involvement in ICU patient care, specifically delirium care.

Simulation exercises that merge family-centered care principles with delirium cases are recommended to accomplish these objectives. These simulations should immerse students in interactions with standardized or virtual patients and their families, allowing them to refine practical skills and enhance their communication techniques. Additionally, students should be actively encouraged to participate in interdisciplinary training sessions and case studies that involve various healthcare professionals. This collaborative experience will underscore the significance of a team-based approach to delirium management and family-centered care provision.

Practicing nurses should be provided with ongoing opportunities for continuing education and workshops that specifically focus on the latest developments in the delirium context and the principles of family-centered care. These opportunities should include updates on best practices and emerging research findings. In both study sites, as mentioned earlier, family detection tools like FAM-CAM are not known among the nurses working in post-cardiac surgery units. Moreover, these tools are not implemented as a protocol in the ICU units. Consequently, it is crucial to consider and implement educational programs and sessions for both nurses and nurse educators to familiarize themselves with these tools in post-cardiac surgery units. Additionally, it is advisable to establish mentorship programs in which more experienced nurses can guide their less-experienced colleagues, particularly in applying family-centered care principles in delirium cases. Such mentorship programs foster the transfer of knowledge and the development of essential skills.

Regular evaluations and assessments should be conducted for both nursing students and practicing nurses to assess the effectiveness of delirium education and the integration of family-centered care practices. Furthermore, nursing professionals need access to up-to-date resources, guidelines, and tools related to delirium and family-centered care. This access can be facilitated through online resources, peer-reviewed journals, and expert webinars, serving as valuable sources of information.

5.4.3 Recommendations for Future Research

The long-term effects of family involvement in delirium care on patient outcomes, including recovery, rehospitalization rates, and overall quality of life, should be investigated.

Future research can explore how various family characteristics, such as cultural backgrounds, socioeconomic status, and family dynamics, influence the effectiveness of family involvement in delirium care. Furthermore, the dynamics of nurse-family collaboration in the context of delirium care could be studied. In addition, future nursing research projects can examine the effectiveness of different interventions aimed at educating families about delirium, including workshops, written materials, and multimedia resources. Also, it will be essential to include patients' and their families' perspectives in future studies to gain a more holistic understanding of the impact of family involvement on patients' experiences and outcomes.

5.5 Conclusion

In conclusion, this research project discussed family involvement in delirium care in cardiac surgery ICUs. The findings from our study provide valuable insights into understanding the role families play in the care journey of patients experiencing cardiac surgery delirium.

The findings underscored the importance of a strategic approach to family involvement, highlighting critical junctures such as hemodynamic stability and neurocognitive orientation as pivotal moments for initiating family involvement. The study illuminated the critical impact of effective communication on facilitating family involvement, as nurses assumed the role of conduits for information exchange between healthcare settings and families. It became evident that family

input not only aids nurses in delirium detection but also empowers families to take concrete actions when delirium episodes transpire.

Moreover, the study underscored that family involvement is a dynamic process influenced by various family characteristics, such as family emotional distress. This suggests that family involvement needs to be tailored to the individual family, considering their specific needs and resources. Furthermore, family involvement should be considered a long-term investment rather than a one-time event.

This comprehensive view resonates with the evolving paradigm of patient-centered care, where families emerge as integral partners in fostering holistic healing.

As we conclude, the implications of this study cascade across nursing practice, education, and research. The recommendations laid out provide actionable steps for healthcare institutions to fine-tune their protocols, enhance nurse-family communication, and cultivate an environment where family involvement is not just an option but an inherent aspect of care. Nursing education stands to evolve by incorporating family-centered care principles, nurturing future nurses to effectively navigate the intricate landscape of family involvement in patient care. Concurrently, the research front widens, with opportunities to explore the lasting impact of family involvement, dissect the interplay of diverse family characteristics, and delve into the deeper intricacies of collaborative care.

Recognizing the vital role of families in patient care, particularly in addressing complications like delirium following cardiac surgery, is essential for critical care units within healthcare systems. We can create a more compassionate and effective healthcare environment by offering advanced family-oriented interventions, promoting comprehensive family inclusion, and establishing family-friendly protocols. Healthcare providers, especially nurses, must be open to these changes and align their practices with evidence-based approaches to ensure the best possible care for patients and their families.

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Appendix I: ethical research approval

Centre intégré
universitaire de santé
et de services sociaux
du Nord-de-
l'Île-de-Montréal

Québec 

Le 02 décembre 2022

Caroline Arbour, inf., Ph. D
Soins intensifs
Hôpital du Sacré-Coeur de Montréal
Centre intégré universitaire de santé et
de services sociaux du Nord-de-l'Île-de-Montréal

N^oréf.: MP-32-2023-2575

Objet : Approbation éthique finale de votre projet de recherche - Résultat positif de l'examen éthique et de l'examen scientifique du projet de recherche

Titre du projet de recherche : Perceptions des infirmières sur la participation de la famille dans les soins entourant le délirium chez les patients se rétablissant d'une chirurgie cardiaque à l'Unité des Soins Intensifs (USI).

CHERCHEUR PRINCIPAL CIUSSS NIM: Caroline Arbour, RN, Ph. D

AUTRE CHERCHEUR : Tanya Mailhot, RN, Ph. D. (ICM)

ÉTUDIANTE : Dina Azimzadeh, maîtrise en soins infirmières (Université de Montréal)

CENTRES PARTICIPANTS DU RSSS : CIUSSS du Nord-de-l'Île-de-Montréal (CIUSSS NIM)
Institut de Cardiologie de Montréal (ICM)

FINANCEMENT : Fonds de recherche en santé du Québec

TYPE DE RECHERCHE : Multicentrique, Recherche en sciences humaines et sociales

NOMBRE DE PARTICIPANTS RECRUTÉS : 20

ÉVALUATION SCIENTIFIQUE CIUSSS NIM : Comité restreint

ÉVALUATION ÉTHIQUE CÉR CIUSSS NIM : Comité restreint

CÉR CIUSSS du Nord-de-l'Île-de-Montréal:

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DATE DE L'APPROBATION ÉTHIQUE FINALE DU PROJET : 2 décembre 2022

DATE D'EXPIRATION DE L'APPROBATION ÉTHIQUE : 2 décembre 2023

Madame,

Le Comité d'éthique de la recherche du CIUSSS du Nord-de-l'Île-de-Montréal (CÉR) s'assure de l'évaluation et du suivi éthique du projet mentionné en rubrique. Le CÉR a pris connaissance des documents que vous lui avez fait parvenir

NAGANO Approbation du projet par le comité d'éthique suite à l'approbation conditionnelle
CÉR CIUSSS NIM

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en réponse aux commentaires soulevés dans sa lettre d'approbation conditionnelle. Il a également évalué les réponses à ses commentaires subséquents.

C'est avec plaisir que le CÉR, qui agit comme CÉR évaluateur, vous informe que la qualité des réponses et les modifications apportées aux documents ont été considérées satisfaisantes et déclare par la présente que le résultat de l'examen éthique de ce projet de recherche est positif et vous transmet son **approbation éthique finale**.

Notre CER confirme également que vous avez déposé les documents requis pour établir le **résultat positif de l'examen scientifique** de votre projet;

DOCUMENTS SOUMIS, RÉVISÉS OU AJOUTÉS ET APPROUVÉS PAR LE CÉR CIUSSS NIM :

- *Formulaire demande d'évaluation d'un projet de recherche formulaire F11-26342, en date du 29 septembre 2022*
- *Protocole, version corrigée en date du octobre 2022*
- *Formulaire d'information et de consentement, HSCM, version française, en date du 26 octobre 2022*
- *Questionnaire sociodémographique version française en date du 29 septembre 2022*
- *Guide d'entrevue semi-dirigée version française en date du 29 septembre 2022*
- *Annonce pour le recrutement pour HSCM et ICM, version française, en date du 29 septembre 2022*
- *Protocole d'interventions en cas de découvertes fortuite en date du 3 octobre 2022*
- *Formulaire délégation des tâches, attestation des cochercheurs et engagement du chercheur signé*
- *Budget*
- *Formulaire d'évaluation budgétaire*
- *Lettre d'octroi de fonds des FRSQ (subvention d'établissement jeune chercheur no 280248) en date du 12 juin 2019*
- *Formulaire soutien projet (soins intensifs soins chirurgicaux) en date du 28 septembre 2022*
- *Formulaire soutien projet (soins intensifs CPO) en date du 27 septembre 2022*
- *Lettre appui étudiante en date du 3 octobre 2022*
- *Formulaire réponses aux conditions du CÉR formulaire F20-26659, en date du 26 octobre 2022*

Une copie du formulaire d'information et de consentement approuvée a été déposée dans Nagano sous l'onglet Mes Projets/Fichiers/FIC de votre projet de recherche. Une autre copie WORD réseau pour les établissements qui auront à faire des ajustements locaux est également déposée.

Si la réalisation de cette recherche se poursuit pendant plus d'un an, notre CER en confirmera à chaque année l'acceptabilité éthique, à la date anniversaire de la présente lettre, à condition que vous déposiez auprès du CER avant la date anniversaire (2 décembre 2023) un rapport annuel décrivant dans son ensemble la réalisation de la recherche.

Dans l'éventualité où vous n'auriez pas répondu dans les 3 mois suivant la date de la dernière approbation éthique annuelle, le CÉR procédera, sans autre préavis, à la fermeture du dossier.

Cette approbation suppose également que vous vous engagiez à respecter les demandes qui ont été fixés par le CER évaluateur pour le suivi éthique continu de ce projet :

- à tenir une liste des participants pour une période d'au moins un an après la fin du projet et s'assurer que les modalités fixées en regard du mécanisme d'identification des participants de recherche sont respectées;
- remettre au CER un **rapport annuel** faisant état de l'avancement de la recherche, dans son ensemble, avant la date de renouvellement annuel de l'approbation éthique, tel que mentionné précédemment;
- soumettre au CER, aux fins d'approbation préalable, toute modification autre qu'administrative apportée au projet de recherche, sauf si la modification est nécessaire afin d'éliminer un danger immédiat pour les participants de recherche. Dans ce dernier cas, le CER en sera avisé dans les meilleurs délais;

- à notifier au CÉR dans les plus brefs délais de tout incident/accident en cours de projet;
- notifier au CER, dans les meilleurs délais, tout nouveau renseignement susceptible d'affecter l'éthicité du projet de recherche ou, encore, d'influencer sur la décision d'un participant de recherche quant à sa participation au projet (ex : conflit d'intérêts d'un membre de l'équipe de recherche) ;
- communiquer au CER, dans les meilleurs délais, toute suspension ou annulation d'autorisation relative au projet qu'aura formulée par exemple un commanditaire, un organisme subventionnaire ou de réglementation;
- communiquer au CER, dans les meilleurs délais, toute modification constatée au chapitre de l'équilibre clinique à la lumière des données recueillies ;
- communiquer au CER, dans les meilleurs délais, tout problème constaté par un tiers au cours d'une activité de surveillance ou de vérification, interne ou externe, qui est susceptible de remettre en question soit l'éthicité du projet, soit la décision du CÉR;
- remettre au CER, dans les meilleurs délais, un rapport concernant l'interruption prématurée, temporaire ou définitive, du projet dans un site, rapport dans lequel il indiquera la nature et les motifs de cette interruption ainsi que les répercussions que celle-ci aura sur les participants de recherche, le cas échéant;
- remettre au CER, dans les meilleurs délais, un rapport final faisant état des résultats de la recherche.
- conserver de façon adéquate et pour la durée déterminée au début du projet de recherche, aux fins du suivi continu, les documents se rapportant à la recherche.
- Lorsqu'une activité de suivi continu entraîne la modification d'un document lié à la recherche, faire parvenir le nouveau document ainsi qu'une copie de l'ancienne version annotée de façon à mettre en évidence les modifications apportées et qui ont été approuvées par le CER, à la personne qui a autorisé la recherche dans chacun des établissements mis en cause.

COVID-19 Veuillez-vous assurer que la mise en œuvre de cette approbation respecte les directives sanitaires émises par la Direction de la recherche et de l'innovation du CIUSSS NIM en lien avec la COVID-19. Veuillez consulter les dernières directives disponibles sur le site web de la Direction de la recherche et de l'innovation pour prendre connaissance des détails à ce sujet.

Comme le prévoit l'article 11.1 du *Cadre de référence des établissements publics du réseau de la santé et des services sociaux (RSSS) pour l'autorisation d'une recherche menée dans plus d'un établissement*, vous pouvez déposer une copie de la présente lettre de notre CER auprès des établissements publics du RSSS à qui vous demanderez l'autorisation de réaliser la recherche dans leurs murs ou sous leurs auspices.

Si un établissement vous demande d'apporter des modifications administratives à la version finale d'un document qui a été approuvé par notre CER, veuillez vous entendre avec cet établissement pour que notre CER reçoive une copie du document modifié indiquant clairement les modifications apportées. Une version réseau du formulaire d'information et de consentement est approuvée par le CÉR et seules les sections surlignées en jaune peuvent être modifiées par les autres établissements participants.

Sur demande d'un établissement qui a autorisé la réalisation de cette recherche, nous lui fournirons les extraits de nos procès-verbaux se rapportant à ce projet.

Le Cadre de référence établi, à l'article 11.2, que vous pouvez fournir une copie de la présente lettre à un autre chercheur qui veut demander à son établissement l'autorisation d'y mener la même recherche. Lorsque vous fournirez ainsi une copie de cette lettre, veuillez :

1) rappeler au chercheur qu'il doit, si ce n'est déjà fait :
s'identifier et identifier son établissement auprès de notre CER,
fournir à notre CER les documents démontrant sa compétence pour la réalisation du projet;
et
fournir à notre CER l'information utile au sujet des populations et des conditions locales qui serait susceptible d'avoir une incidence sur l'évaluation de l'acceptabilité éthique du projet de recherche.

2) indiquer à ce chercheur que notre CER lui demande de déposer à chaque année, avant la date d'anniversaire, un rapport d'étape sur le déroulement de la recherche dans son établissement.

L'omission par le chercheur d'un établissement de déposer ce rapport ne compromettra pas le renouvellement annuel de l'approbation éthique couvrant l'ensemble de ce projet de recherche. Notre CER évaluateur pourra cependant demander à la personne qui a autorisé la réalisation de la recherche dans cet établissement de suspendre l'autorisation donnée à un chercheur qui n'a pas déposé le rapport d'étape demandé.

Le Comité d'éthique de la recherche du CIUSSS du Nord-de-l'Île-de-Montréal poursuit ses activités en accord avec les normes et les règlements québécois et canadiens applicables.

- Le CÉR du CIUSSS NIM est désigné par le gouvernement du Québec (MSSS) pour les fins d'application d l'article 21 du Code civil du Québec;
- Le comité d'éthique de la recherche exerce ses activités d'une manière conforme aux Bonnes pratiques cliniques (ICH) et aux directives publiées dans la version en vigueur de l'EPTC2 : Énoncé de politique des trois conseils : Éthique de la recherche avec des êtres humains (2018), conformément au Code Civil du Québec, conformément au *Plan d'action ministériel en éthique de la recherche et en intégrité scientifique (MSSS 1998)*;

Vous pourrez commencer le projet de recherche uniquement lors de la réception de toutes les approbations requises : convenance, scientifique, éthique ainsi que la lettre d'autorisation de réaliser le projet par la personne formellement mandatée de l'établissement). De même, lorsque cela s'applique, le projet ne peut débuter avant la finalisation et la signature du contrat.

Les membres du CÉR seront informés de cette décision lors de la prochaine réunion plénière.

Il est à noter qu'aucun membre du comité d'éthique participant à l'évaluation et à l'approbation de ce projet n'est impliqué dans celui-ci.

Veuillez recevoir, Madame, l'assurance de nos salutations distinguées.

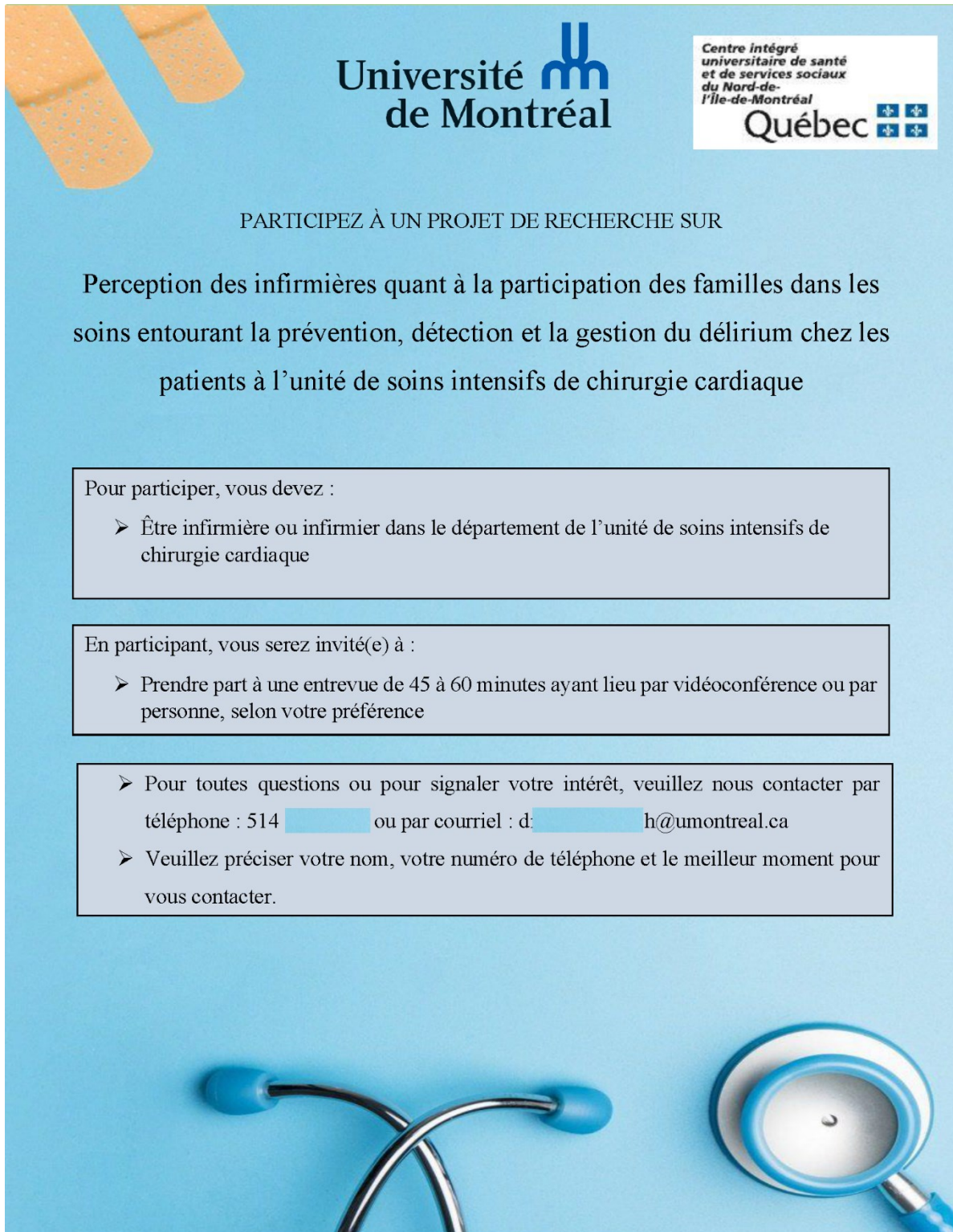
Décision prise par :
Élodie Petit, présidente du CER du
CIUSSS du Nord-de-l'Île-de-Montréal



Julie Hammanji
Coordonnatrice du CER
pour la
présidente ou vice-présidente du Comité d'éthique de la recherche
CIUSSS du Nord-de-l'Île-de-Montréal

Signé le 2022-12-02 à 14:17

Appendix II: Annonce de recrutement



Université de Montréal

Centre intégré
universitaire de santé
et de services sociaux
du Nord-de-
l'Île-de-Montréal
Québec

PARTICIPEZ À UN PROJET DE RECHERCHE SUR

Perception des infirmières quant à la participation des familles dans les soins entourant la prévention, détection et la gestion du délirium chez les patients à l'unité de soins intensifs de chirurgie cardiaque


Pour participer, vous devez :

- Être infirmière ou infirmier dans le département de l'unité de soins intensifs de chirurgie cardiaque

En participant, vous serez invité(e) à :

- Prendre part à une entrevue de 45 à 60 minutes ayant lieu par vidéoconférence ou par personne, selon votre préférence

- Pour toutes questions ou pour signaler votre intérêt, veuillez nous contacter par téléphone : 514 [redacted] ou par courriel : d: [redacted] h@umontreal.ca
- Veuillez préciser votre nom, votre numéro de téléphone et le meilleur moment pour vous contacter.



PARTICIPEZ À UN PROJET DE RECHERCHE SUR

Perception des infirmières quant à la participation des familles dans les soins entourant la prévention, détection et la gestion du délirium chez les patients à l'unité de soins intensifs de chirurgie cardiaque

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- Prendre part à une entrevue de 45 à 60 minutes ayant lieu par vidéoconférence ou par personne, selon votre préférence

- Pour toutes questions ou pour signaler votre intérêt, veuillez nous contacter par téléphone : 514 7 [redacted] ou par courriel : d [redacted] 1@umontreal.ca
- Veuillez préciser votre nom, votre numéro de téléphone et le meilleur moment pour vous contacter.



Appendix III : FORMULAIRE D'INFORMATION ET DE CONSENTEMENT



Centre intégré
universitaire de santé
et de services sociaux
du Nord-de-
l'Île-de-Montréal



FORMULAIRE D'INFORMATION ET DE CONSENTEMENT

Projet de recherche : # MEO-32-2023-3222

Titre du projet : Famille-Délirium

Perceptions des infirmières sur la participation de la famille dans les soins entourant le délirium chez les patients se rétablissant d'une chirurgie cardiaque à l'Unité des Soins Intensifs (USI).

Chercheuse principale : Caroline Arbour inf. Ph. D. Professeure Agrégée Facultés des sciences infirmières de l'Université de Montréal et Chercheure régulière Hôpital du Sacré-Cœur de Montréal-CIUSSS-NÎM

Co-Chercheuse principale : Tanya Mailhot, inf. Ph. D. - Responsable local du projet Professeure Adjointe Faculté des sciences infirmières de l'Université de Montréal et Chercheure régulière à l'Institut de cardiologie de Montréal (ICM)

Étudiante co-chercheuse Dina Azimzadeh, inf. clinicienne en charge de l'étude : Étudiante chercheuse en charge du projet. Étudiante à la maîtrise en sciences infirmières — Option expertise conseil. Faculté des sciences infirmières de l'Université de Montréal

Financement : Fonds de démarrage chercheur boursier J1 -FRQS (octroi C. Arbour)

PRÉAMBULE

Nous sollicitons votre participation à un projet de recherche parce que vous êtes un infirmier ou une infirmière œuvrant aux soins intensifs de l'Institut de Cardiologie de Montréal. Cependant, avant d'accepter de participer à ce projet et de signer ce formulaire d'information et de consentement, veuillez prendre le temps de lire, de comprendre et de considérer attentivement les renseignements qui suivent.

Ce formulaire peut contenir des mots que vous ne comprenez pas. Nous vous invitons à poser toutes les questions que vous jugerez utiles à l'étudiante chercheuse responsable du projet ou aux autres membres du personnel affecté au projet de recherche et à leur demander de vous expliquer tout mot ou renseignement qui n'est pas clair.

NATURE ET OBJECTIFS DU PROJET DE RECHERCHE

Le delirium est l'une des complications les plus fréquentes chez les patients se rétablissant d'une chirurgie cardiaque à l'unité de soins intensifs. Alors que les traitements pharmacologiques sont peu efficaces dans le traitement du delirium, plusieurs recherches montrent l'importance de l'implication de la famille comme stratégie non pharmacologique pour la prévention, la détection et la gestion de cette condition chez les patients gravement malades ayant subi une chirurgie cardiaque.

L'objectif de cette recherche est de décrire les perceptions des infirmières quant à la participation des familles dans les soins entourant la prévention, la détection, et la gestion du délirium chez les patients à l'unité de soins intensifs de chirurgie cardiaque. Le but de cette étude est d'en faire ressortir les barrières et les facteurs facilitateurs de l'implication de la famille dans les soins entourant le délirium dans les premiers jours post-opératoires d'une chirurgie cardiaque à l'unité de soins intensifs. Cette étude vise également à proposer des pistes d'améliorations concernant l'approche à la famille sur ce type d'unité.

DÉROULEMENT DE L'ÉTUDE ET MÉTHODES UTILISÉES

Une méthode qualitative descriptive avec une approche narrative et des entretiens semi-structurés a été choisie pour la conduite de cette étude. Un échantillon ciblé de 12 à 20 infirmiers et infirmières avec une expérience professionnelle diversifiée auprès de patients ayant subi une chirurgie cardiaque sera recruté.

Plus spécifiquement, tout(e)s les infirmiers et infirmières (incluant les gestionnaires) ayant au moins une expérience dans la prise en charge des patients en période postopératoire de chirurgie cardiaque pourront participer à l'étude. Les personnes qui ne maîtrisent pas la langue française, qui n'acceptent pas d'être audio-enregistrées lors des entrevues individuelles semi-structurées, ou qui sont dans l'impossibilité de se libérer pour une rencontre en personne ou une plateforme Web sécurisée (Zoom, Teams, etc.) seront exclues.

Votre participation consistera à répondre à un questionnaire écrit concernant certaines informations personnelles (questionnaire sociodémographique) et de participer à une entrevue individuelle virtuelle ou en présentiel (entrevue semi-dirigée) traitant sur la participation des familles dans les soins entourant la prévention, la détection, et la gestion du délirium chez les patients à l'unité de soins intensifs de chirurgie cardiaque. Deux à trois minutes seront nécessaires afin de remplir le formulaire sur les données sociodémographiques. La durée prévue pour l'entrevue est de 45 à 60 minutes. L'entrevue sera enregistrée afin de faciliter la prise de note durant la rencontre. Des questions ouvertes vous seront posées en lien avec l'étude.

AVANTAGES ASSOCIÉS AU PROJET DE RECHERCHE

Il se peut que vous retiriez un bénéfice personnel de votre participation à ce projet de recherche, mais on ne peut vous l'assurer. Par ailleurs, les résultats obtenus contribueront à l'avancement des connaissances scientifiques dans ce domaine.

RISQUES ASSOCIÉS AU PROJET DE RECHERCHE

Il y a peu de risques liés à votre participation. Toutefois, il se peut que les questions posées vous amènent à vous remémorer des souvenirs douloureux concernant un ou des expérience(s) de soins que vous avez vécus. Si vous ressentez un malaise, n'hésitez pas à en parler avec l'équipe de recherche qui pourra vous diriger vers le programme d'aide aux employés (PAÉ) ou d'autres ressources appropriées.

Les inconvénients à votre participation concernent également le temps exigé pour répondre au questionnaire de données sociodémographiques et de réaliser la rencontre.

CONFIDENTIALITÉ

Durant votre participation à ce projet de recherche, les chercheurs principaux recueilleront, dans un dossier de recherche, les renseignements vous concernant et nécessaires pour répondre aux objectifs scientifiques du projet de recherche. Ces renseignements peuvent comprendre les informations contenues comme votre identité, votre titre d'emploi, votre sexe, votre âge, ainsi que votre origine ethnique.

Tous les renseignements recueillis y compris les enregistrements audios demeureront confidentiels dans les limites prévues par la loi. Pour cela, les questionnaires que vous remplirez seront dénominalisés au moyen d'un code chiffré et conservés sur un serveur sécurisé muni d'un mot de passe. Les enregistrements audios seront retranscrits sous forme de verbatims, qui seront également dénominalisés au moyen d'un code chiffré et conservés sur un serveur sécurisé muni d'un mot de passe. Le fichier audio sera enregistré sur un ordinateur dont l'accès est protégé par un mot de passe dont seule l'équipe de recherche connaît. Le fichier audio sera détruit après 10 ans. Seules les chercheuses principales (C. Arbour, T. Mailhot) et l'étudiante-chercheuse (D. Azimzadeh) auront accès aux données non codées qui seront conservées sous clé dans le bureau de la chercheuse principale (C. Arbour) pendant 10 ans à partir de la fin du projet de recherche. Les données de recherche pourront être publiées ou faire l'objet de discussions scientifiques, mais ne permettront pas de vous identifier.

En lien avec les entretiens qui seront réalisés par vidéoconférence, nous employons une vidéoconférence qui est sécurisée et encryptée selon les plus hauts standards de l'industrie, de manière à protéger les informations personnelles. Cela dit, bien que ces plateformes (Zoom ou TEAMS) offrent un degré élevé de protection, il est important de garder en tête qu'aucun moyen

de télécommunication n'offre une garantie absolue contre l'intrusion, malgré toutes les mesures prises par l'équipe de recherche. Il est de votre responsabilité de choisir un emplacement où vous serez seul et non dérangé de manière à préserver cette confidentialité. Il est aussi important d'utiliser une connexion Internet sécuritaire (par exemple à domicile) plutôt qu'un point d'accès WiFi public/gratuit.

À des fins de surveillance, de contrôle, de protection et de sécurité, votre dossier de recherche pourra être consulté par une personne mandatée par l'établissement ou le comité d'éthique de la recherche. Ces personnes adhèrent à une politique de confidentialité.

Vous avez le droit de consulter votre dossier de recherche pour vérifier les renseignements recueillis et les faire rectifier au besoin.

Par ailleurs, l'accès à certaines informations avant la fin du projet de recherche pourrait impliquer que vous soyez retiré du projet afin d'en préserver l'intégrité.

CLAUSE D'UTILISATION SECONDAIRE DE DONNÉES

Avec votre permission, il se peut que les renseignements que vous fournirez soient utilisés, avant la date prévue de destruction, dans le cadre de quelques projets de recherche (2-3) qui porteront sur l'approche centrée sur les patients et leurs entourages. Ces projets éventuels seront sous la responsabilité de la chercheuse responsable locale et seront autorisés par le Comité d'éthique de la recherche du CIUSSS NIM. L'équipe de recherche s'engage à maintenir et à protéger la confidentialité de vos données aux mêmes conditions que pour le présent projet.

EN CAS DE PRÉJUDICE

En acceptant de participer à ce projet de recherche, vous ne renoncez à aucun de vos droits et vous ne libérez pas le chercheur responsable du projet de recherche et l'établissement de leur responsabilité civile et professionnelle.

PARTICIPATION VOLONTAIRE ET DROIT DE RETRAIT

Votre participation à ce projet de recherche est volontaire. Vous êtes donc libre de refuser d'y participer. Vous pouvez également vous retirer de ce projet de recherche à n'importe quel moment, sans avoir à donner de raisons, en informant le chercheur responsable du projet de recherche ou un membre de l'équipe de recherche.

Votre décision de ne pas participer à ce projet de recherche ou de vous en retirer n'entraînera aucune conséquence sur votre emploi ou sur votre relation avec votre employeur, votre équipe de travail, le chercheur responsable ou les autres intervenants.

Le chercheur responsable de ce projet de recherche, le comité d'éthique de la recherche peuvent mettre fin à votre participation, sans votre consentement. Cela peut se produire si de nouvelles découvertes ou informations indiquent que votre participation au projet de recherche n'est plus dans votre intérêt, si vous ne respectez pas les consignes du projet de recherche ou encore s'il existe des raisons administratives d'abandonner le projet.

Si vous vous retirez du projet ou êtes retiré du projet, l'information et le matériel déjà recueillis dans le cadre de ce projet seront conservés aux fins d'analyses du projet.

Toute nouvelle connaissance acquise durant le déroulement du projet de recherche qui pourrait avoir un effet sur votre décision de continuer à y participer vous sera communiquée rapidement.

COMPENSATION

En guise de compensation pour le temps alloué à cette étude en raison de votre participation à cette dernière, vous recevrez 100\$ (un montant unique de 100\$ vous sera versé à la fin de votre entrevue). Si vous vous retirez du projet (ou s'il est mis fin à votre participation) avant qu'il ne soit complété, la compensation sera proportionnelle à la durée de votre participation.

COMMUNICATION DES RÉSULTATS

Les résultats du projet seront diffusés en tant que données générales pour l'ensemble des participants. Cela signifie que vous ne pourrez pas obtenir vos résultats individuels. Si vous souhaitez obtenir un résumé écrit des résultats généraux de la recherche, veuillez indiquer une adresse (courriel ou postale) où nous pourrions vous le faire parvenir.

IDENTIFICATION DES PERSONNES-RESSOURCES

Si vous avez des questions ou éprouvez des problèmes en lien avec le projet de recherche, ou si vous souhaitez vous en retirer, vous pouvez communiquer avec l'étudiant-chercheuse responsable du projet ou avec une personne de l'équipe de recherche au numéro suivant :

Dina Azimzadeh :

Courriel : *****@umontreal.ca

Téléphone : (***) ***_****

Tanya Mailhot :

Courriel : t.mailhot@umontreal.ca

Téléphone : (514) 376-3330 poste : 4012

COMMISSAIRE AUX PLAINTES

Pour toute question concernant vos droits en tant que participant à ce projet de recherche ou si vous avez des plaintes ou des commentaires à formuler, vous pouvez communiquer avec :

La Commissaire locale aux plaintes et à la qualité des services

Institut de Cardiologie de Montréal

5000, rue Bélanger

Montréal (Québec) H1T 1C8

Téléphone : 514 376-3330, poste 3398

SURVEILLANCE DES ASPECTS ÉTHIQUES DU PROJET DE RECHERCHE

Le comité d'éthique de la recherche du CIUSSS du Nord-de-l'Île-de-Montréal a donné son approbation éthique au projet de recherche et en assurera le suivi.

FORMULAIRE DE CONSENTEMENT

Projet de recherche : # MEO-32-2023-3222

Titre du projet : Famille-Délirium

Perceptions des infirmières sur la participation de la famille dans les soins entourant le délirium chez les patients se rétablissant d'une chirurgie cardiaque à l'Unité des Soins Intensifs (USI).

Chercheuse principale : Caroline Arbour inf. Ph. D. Professeure Agrégée Facultés des sciences infirmières de l'Université de Montréal et Chercheure régulière Hôpital du Sacré-Cœur de Montréal-CIUSSS-NÎM

Co-Chercheuse principale : Tanya Mailhot, inf. Ph. D. - Responsable local du projet Professeure Adjointe Faculté des sciences infirmières de l'Université de Montréal et Chercheure régulière à l'Institut de cardiologie de Montréal (ICM)

Étudiante co-chercheuse : Dina Azimzadeh, inf. clinicienne en charge de l'étude : Étudiante chercheuse en charge du projet. Étudiante à la maîtrise en sciences infirmières — Option expertise conseil. Faculté des sciences infirmières de l'Université de Montréal

Financement : Fonds de démarrage chercheur boursier J1 -FRQS (octroi C. Arbour)

SIGNATURE DU PARTICIPANT

J'ai pris connaissance du formulaire d'information et de consentement. On m'a expliqué le projet de recherche et le présent formulaire d'information et de consentement. On a répondu à mes questions et on m'a laissé le temps voulu pour prendre une décision. Après réflexion, je consens à participer à ce projet de recherche aux conditions qui y sont énoncées, incluant l'utilisation de mes données personnelles.

Nom du participant Signature Date (jj-mm-aaaa)

J'accepte que les renseignements que je fournis soient utilisés avant leur destruction dans le cadre de projets de recherche (2-3) ultérieurs visant à approfondir l'implication des proches dans les soins directs aux soins intensifs.

Oui Non Initiales : _____

SIGNATURE DE LA PERSONNE QUI OBTIENT LE CONSENTEMENT

J'ai expliqué au participant le projet de recherche et le présent formulaire d'information et de consentement et j'ai répondu aux questions qu'il m'a posées.

Nom de la personne qui Signature Date (jj-mm-aaaa)

obtient le consentement

ENGAGEMENT DU CHERCHEUR RESPONSABLE

Je certifie qu'on a expliqué au participant le présent formulaire d'information et de consentement et que l'on a répondu aux questions qu'il avait.

Je m'engage, avec l'équipe de recherche, à respecter ce qui a été convenu au formulaire d'information et de consentement et à en remettre une copie signée et datée au participant.

Nom du chercheur responsable Signature Date (jj-mm-aaaa)

N.B. : Une copie signée et datée du présent formulaire d'information et de consentement sera gardée par le chercheur principal et une copie remise au participant.

Appendix IV : Données sociodémographiques des infirmiers et infirmières

Questionnaire sociodémographique

Date :

Code du participant :

Titre d'emploi :

Veillez cocher si vous êtes :

- Infirmier(ère)
- Infirmier(ère) gestionnaire(e)
- Infirmier(ère) praticien(ne) spécialisé(e)

Information générale :

Âge :

Genre :

- Homme
- Femme
- Autre
- Ne souhaite pas répondre

Niveau de scolarité :

- Diplôme d'études collégiales
 - Baccalauréat
 - Maîtrise
 - Doctorat
 - Autre (s)
- diplôme (s), précisez :

Année d'expérience à l'unité de soins intensifs de chirurgie cardiaque :

Origine ethnique :

- Blanc
- Noir
- Latino-Américain
- Arabe

Asiatique (précisez) :

Peuple des Premières Nations (précisez) :

Autre (précisez) :

Autres expériences de travail pertinentes :

Appendix V: Qualitative Semi-Structured Interview Logbook Entry Example

Date: 2023-03-08

Interviewee Information:

- Participant ID: P1
- Demographics: Female, 25 years old
- Occupation: RN, B.S.c
- Setting: HSCM
- Consent form no. 1

Interview Details:

- Start Time: 6:00 AM
- End Time: 6:45 AM

Technology Use:

- Recorder no. 1
- Cellphone recording no. 40
- Has the experience of working in France. Night nurse: had a cardiac surgery patient last night who developed a mild transient delirium.
- Nurse had informed the family about delirium in the night.
- Not having stress during the interview.

Notes:

- préfère admettre le patient sans la famille au chevet
- préserver le cycle circadien au maximum
- l'évaluation du Glasgow
- recadrer
- faire une éducation de délirium
- une discussion avec la famille
- une montagne d'émotions pour tout le monde

Appendix VI: Interview Guide

French version

Guide d'entrevue semi-dirigée

Introduction :

1- Accueil des participants : Bonjour, je m'appelle Dina *****, étudiante à la maîtrise en sciences infirmières de l'Université de Montréal et je vais diriger l'entretien aujourd'hui.

2- Rappel de l'objectif de la rencontre : Nous sommes réunis pour discuter de votre perception quant à la participation des familles dans les soins entourant la prévention, la détection et la gestion du délirium chez les patients se rétablissant d'une chirurgie cardiaque. Je désire connaître les facteurs pouvant faciliter et limiter la participation des familles dans ce contexte.

3- Informations relatives au déroulement de la rencontre : Il s'agit d'une rencontre entre vous et moi, d'une durée d'environ 45 à 60 minutes comprenant des questions ouvertes. Il se peut que je vous demande de préciser certains points afin de bien comprendre le fond de votre pensée. N'oubliez pas qu'il n'y a pas de bonnes ou de mauvaises réponses. Le but est de recueillir votre point de vue.

4- Réitération des considérations éthiques : Votre participation est entièrement volontaire. Vous pouvez choisir de mettre fin à l'entretien à tout moment, et vous êtes libre de ne pas répondre aux questions posées.

Je tiens à vous rappeler que cet entretien sera enregistré et des notes seront prises à des fins d'analyse.

Les données vous concernant seront conservées par l'équipe de recherche de façon confidentielle. Il ne sera pas possible de vous identifier. L'enregistrement audio de la rencontre servira à rédiger le verbatim (transcription écrite de la rencontre).

Les enregistrements et la transcription finale seront sauvegardés sur un serveur sécurisé et une clé USB protégée par un mot de passe.

Avez-vous des questions concernant le document d'informations et de consentement que vous avez signé ? Nous pouvons commencer ?

1. Pouvez-vous me parler de votre routine de soins avec des patients qui se rétablissent d'une chirurgie cardiaque ?

- Selon votre expérience, quel est le moment approprié pour accueillir la famille au chevet ?
- Avez-vous remarqué si des différences existent dans votre routine de soins entre un patient qui est accompagné d'une famille et un patient qui n'est pas accompagné ?
- Quelle est votre conversation habituelle avec les familles lorsqu'ils rendent visite à leur proche après une chirurgie cardiaque ?
- Cette conversation inclut-elle des informations sur le délirium ?

2. Quelle est votre expérience avec le délirium en général chez les patients qui se rétablissent d'une chirurgie cardiaque?

- Que faites-vous pour prévenir cet état ?
- Sur quels signes vous basez-vous pour identifier cet état?
- Que faites-vous concrètement lorsque le délirium survient chez cette clientèle ?

3. Quelle est votre perception de la préparation des familles par rapport au délirium chez les patients qui se rétablissent d'une chirurgie cardiaque?

- Selon-vous, dans quelle mesure les familles comprennent-elles ce qui se passe en situation de délirium?
- Quels sont les signes qui vous indiquent qu'une famille désire participer dans les soins en général et ceux entourant le délirium plus particulièrement?

4. Comment entrevoyez-vous la participation des familles dans les soins entourant le délirium?

- Avez-vous déjà pensé inviter la famille à participer aux soins entourant le délirium ? Si oui, comment vous vous y êtes pris?
- Si non, pourquoi? Est-ce qq chose qui serait envisageable ? Sous quelles conditions ?

5. Quels sont les barrières et les obstacles à la participation des familles dans les soins entourant le delirium dans l'unité de soins intensifs ?

- Qu'est-ce qui rend la participation de la famille dans les soins plus facile?
- Qu'est-ce qui rend la participation de la famille dans les soins plus difficile?

6. Enfin, y a-t-il d'autres points concernant la participation de la famille dans les soins aux patients atteints de délirium aux soins intensifs après une chirurgie cardiaque que nous n'avons pas abordés et dont vous aimeriez discuter ?

J'apprécie le temps que vous avez pris pour cet entretien. Merci d'avoir participé à cet échange !

English version

Introduction

Welcoming Participants:

Hello, my name is Dina *****. I am a Master's student in Nursing Science at the University of Montreal, and I will be conducting the interview today.

Objective Reminder:

We're here to discuss your perception of family involvement in the care related to the prevention, detection, and management of delirium in patients recovering from cardiac surgery. I would like to know what factors can facilitate or hinder family participation in this context.

Meeting Information:

This will be a one-on-one conversation lasting about 45 to 60 minutes with open-ended questions. I may ask you to clarify certain points to understand your thoughts fully. Please remember that there are no right or wrong answers. The goal is to collect your perspective.

Reiteration of Ethical Considerations:

Your participation is entirely voluntary. You can choose to end the interview at any time, and you are free not to answer specific questions.

I want to remind you that this interview will be recorded, and notes will be taken for analysis. Your data will be kept confidential by the research team, and it won't be possible to identify you. The audio recording will be used to produce a verbatim transcript (written transcription of the interview).

The recordings and final transcription will be stored on a secure server and a password-protected USB drive.

Do you have any questions about the information and consent document you signed? Shall we begin?

1. Can you describe your care routine for patients recovering from cardiac surgery?

- From your experience, when is the best time to welcome the family to the bedside?
- Have you noticed any differences in your care routine between a patient with family present and a patient without family present?
- What do you typically discuss with families visiting their loved ones after cardiac surgery?
- Does this conversation include information about delirium?

2. What is your overall experience with delirium in patients recovering from cardiac surgery?

- What do you do to prevent it?
- What signs do you look for to identify it?
- What do you practically do when delirium occurs in this population?

3. What is your perception of family preparation concerning delirium in patients recovering from cardiac surgery?

- In your opinion, how well do families understand what happens during delirium?
- What signs indicate that a family wants to participate in care, particularly in delirium-related care?

4. How do you view family involvement in delirium care?

- Have you ever considered inviting the family to participate in delirium care? If yes, how did you approach it?
- If not, why? Would it be feasible? Under what conditions?

5. What are the barriers and obstacles to family involvement in delirium care in the ICU?

- What makes family involvement in care easier?
- What makes family involvement in care more difficult?

6. Are there any other points regarding family participation in care for ICU patients with delirium after cardiac surgery that we haven't discussed but that you'd like to address?

I appreciate the time you took for this interview. Thank you for participating!