

The Experience of Intensive Care Nurses Caring For Patients With Delirium

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Abstract

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The purpose of this research was to seek a deep understanding of the lived experience of intensive care nurses caring for patients with delirium.

Delirium affects a large proportion of adult patients in the intensive care unit (ICU). Delirium has been linked to increased morbidity and mortality, longer intensive care and hospital length of stay, long-term cognitive impairments, short-term and long-term psychological distress, and increased hospital and health system costs. Critical care nurses play central roles in preventing, identifying, and treating ICU patients with delirium.

Semi-structured interviews were conducted with eight intensive care nurses working in an ICU in a tertiary level, university-affiliated hospital in Ontario, Canada. The researcher analyzed the interviews using an interpretive phenomenological approach as described by van Manen (1990).

The essence of the experience of critical care nurses caring for ICU patients with delirium was revealed to be *finding a way to help them come through it*. Six main themes emerged: *It's Exhausting*; *Making a Picture of the Patient's Mental Status*; *Keeping Patients Safe: It's a Really Big Job*; *Everyone Is Unique*; *Riding It Out With Families*; and *Taking Every Experience With You*. The findings describe how intensive care nurses find a way to help patients and their families through this complex and often distressing experience. This study has contributed to the understanding of the lived experience of ICU nurses caring for patients with delirium.

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Chapter 1: Introduction

1.1 Background

Approximately 100,000 Canadians are admitted to intensive care units (ICU) each year (Wunsch, et al., 2008). In Canada and internationally, ICUs consume a significant proportion of hospital costs (Awissi, Begin, Moisan, Lachaine, & Skrobik, 2012).

Delirium in ICU patients is common and may affect greater than 80% of adult patients. It is associated with longer ICU and hospital length of stay, as well as increased mortality (Pisani et al., 2009; Shehabi et al., 2010) in comparison with patients who never experience an episode of delirium in ICU. Other impacts of delirium include long-term cognitive impairments, greater functional dependency following hospital discharge, increased frequency of patient safety events, decreased quality of life, short- and long-term emotional and psychological distress, and increased hospital and health system costs (Barr et al., 2013; Girard et al., 2010; Ouimet, Kavanagh, Gottfried, & Skrobik, 2007; Pandharipande et al., 2013; Salluh et al., 2015; Skrobik et al. 2009, Stransky et al., 2011).

Caring for patients in the ICU with delirium is a complex process that encompasses nurse and patient dimensions, as well as environmental, system, and cultural factors. Identifying delirium in ICU patients is challenging due to a variety of communication barriers related to patients frequently having endotracheal intubation or a tracheostomy. Also, patients may be suffering from altered mental status from a wide variety of causes such as shock or the use of sedative medications (Barr et al., 2013). It is essential that clinicians be aware of delirium in ICU patients in order to identify it early on and implement care and treatment strategies. Nurse-administered assessment tools, such as the Confusion Assessment Method for ICU (CAM-ICU) and the Intensive Care

Delirium Screening Checklist (ICDSC) are recommended as effective methods for reliably identifying delirium in ICU patients (Barr et al., 2013; Balas et al., 2014; Bergeron, Dubois, Dumont, Dial, & Skrobik, 2001; Ely et al., 2001), and there are established best practice guidelines for prevention, assessment and treatment of delirium for patients in ICU (Barr et al., 2013).

In 2013 the Society of Critical Care Medicine updated their Clinical Practice Guidelines for the Management of Pain, Agitation, and Delirium in Adult Patients in the Intensive Care Unit (Barr et al., 2013). Key recommendations for the management of delirium include regular assessment with a valid and reliable tool, performing early mobilization for delirium prevention, targeting light levels of sedation, promoting sleep, and using an interprofessional ICU team approach for the delivery of care.

Increasingly, ICUs are developing and implementing complex interprofessional protocols to prevent delirium and to minimize the harm that can accompany it (Barr et al., 2013; Balas et al., 2013; Barr & Pandharipande, 2013; Reade & Finfer, 2014). Intensive care nurses organize, coordinate, and participate in implementing these protocols for the patients under their care (Balas et al., 2012; Balas et al., 2014; Skrobik et al., 2010). However, in daily clinical practice, the successful uptake of such protocols can be challenging due to a variety of organizational and human factors (Balas et al., 2013; Barr et al., 2013; Basset et al., 2015; Carrothers et al., 2013; Law et al., 2012; Skrobik et al., 2010; Soja, et al., 2008). Additionally, Belanger and Ducharme (2011) have pointed out that these protocols provide little guidance on establishing therapeutic relationships with patients in delirium, or techniques that might reduce the negative emotional consequences of the experience for patients and their families.

Caring for these patients in medical-surgical and long-term care settings has been associated with high levels of nurse strain, increased workload, mental conflicts, emotional distress, and feelings of uncertainty (Lou & Dai, 2002; Mc Donnell & Timmins, 2012; Rogers & Gibson, 2002; Schofield, Tolson, & Flemming, 2012). It is not known whether nurses in intensive care units experience similar effects when working with these patients. Studies on the nursing care of critically ill patients with delirium have tended to focus on the accuracy and use of assessment tools, risk factors, prevention strategies, pharmacological and non-pharmacological interventions, compliance with institutional protocols, and the challenges of protocol implementation (Al-Qahdeeb et al., 2013; Balas et al., 2013; Balas et al., 2014; Bassett et al., 2015; Carrothers et al., 2013; Devlin, Fong, et al., 2008; Forsgren & Ericksson, 2010; Gesin et al., 2012; Soja et al., 2008; van Eijk et al., 2011; Vasilevskis et al., 2011). Despite the frequency with which intensive care nurses encounter these patients and the key roles they play, inquiries into nurses' experiences in the ICU setting are limited. A greater understanding of the lived experience of ICU nurses caring for patients with delirium can facilitate the identification of factors which help and hinder nurses when caring for these patients and inform efforts to improve nursing care for these patients.

As an intensive care nurse, my interest in this phenomenon arose from my professional encounters with these patients. Persons in delirium are among the most vulnerable patients I have cared for in the ICU. In addition to being gravely ill, these people are often unable to participate in meaningful communication with their loved ones or the health care team; and so they run the risk of becoming marginalized, voiceless, and misunderstood. I have often wondered who the person I am caring for *is* when they are

not impaired by delirium and illness, and whether or not they will be able to *be* that person again. Intensive care nurses are in an intimate dance with these patients. From their position at the bedside, nurses have an opportunity to provide voice, dignity, and compassion when patients are in a strange and frightening place. Yet little is known about the experiences of nurses caring for ICU patients with delirium. This study aims to shed light on the experience in order to provide insights on how to improve patient care.

1.2 Definition of terms

1.2.1 Delirium

Delirium is defined as disturbance of attention and awareness that is associated with a change in cognition. It develops over a short period of time and tends to fluctuate in severity throughout the day (Adamis, Rooney, Meagher, Mulligan, & McCarthy, 2015; 2015; American Psychiatric Association, 2013). Patients with delirium may display psychomotor symptoms ranging from hyperactivity and agitation to hypoactivity and lethargy (Page & Ely, 2011). Symptoms of delirium include disorientation and agitation, as well as hallucinations or delusions. It should be noted, however, these symptoms alone are not diagnostic for delirium.

The participants in the present study frequently used the terms *delirium*, *agitation*, and *disorientation* interchangeably, which is evident in direct quotations. However, the researcher has endeavored to distinguish between these concepts in discussions and the term delirium is only used in accordance with the above definition.

1.2.2. Critical Care Nurse

Critical care nurses are registered nurses who possess specialized training and knowledge to care for patients who are experiencing life-threatening health crises

(Canadian Association of Critical Care Nurses, 2013). For the purpose of this study the terms intensive care unit nurse and critical care nurse are used interchangeably.

1.3 Purpose of the Research Study

The purpose of this research is to seek an understanding of the lived experience of critical care nurses caring for patients with delirium.

1.4 Research Question

The research is guided by the question:
What is the lived experience of critical care nurses caring for adult patients in ICU with delirium?

1.5 Research Objectives

- The objectives of this inquiry are:
- 1) To examine critical care nurses' experiences of caring for adult patients in ICU with delirium.
 - 2) To identify factors that facilitate or hinder critical care nurses caring for patients in ICU with delirium.

Chapter 2: Review of the Literature

This chapter includes a review of the literature related to delirium, its impact for ICU patients, and approaches to delirium management. The nursing care of ICU patients with delirium is presented, as well as nurses' knowledge related to delirium.

2.1 Caring For Patients in the ICU

Patients are typically admitted to ICU with life threatening and complex health problems such as sepsis or trauma. Patients may develop multiple organ failure and require mechanical ventilation, and/ or inotropic medications to support cardiac function (Cook et al., 2013). In the majority of ICUs, nursing care is kept to a 1:1 nurse-patient ratio due to the need for constant monitoring and rapid intervention. The nature of critical care nursing is intense, technological, and involves careful balancing of critical illness with the patient and family's need for safety, privacy, dignity and comfort (Canadian Association of Critical Care Nurses, 2013).

2.2 Delirium

Delirium is common in adult ICU patients and has been estimated to affect greater than 80% of mechanically ventilated patients (Barr et al., 2013). The pathophysiology of delirium in ICU patients is poorly understood. It is likely that several physiologic mechanisms are involved in its development (Page & Ely, 2012; Reade & Finfer, 2014; Salluh et al., 2015). Imbalances in the neurotransmitters acetylcholine, dopamine, serotonin, and γ -aminobutyric acid have been reported in patients with delirium, and central cholinergic deficiency appears to play a key role (Page & Ely, 2011; Reade & Finfer, 2014). Other theories of pathogenesis include neurotoxic effects from

inflammatory mediators and excess dopaminergic activity (Page & Ely; Reade & Finfer, 2014).

Researchers have investigated the role of various tests to help with delirium prediction and diagnosis, however, there are no neuroimaging or laboratory tests currently available for diagnosis (Page & Ely, 2011). ICU clinicians must therefore rely on bedside observations to identify and treat this important syndrome. The current clinical practice guidelines for caring for patients in ICU, recommend that all ICU patients be screened for delirium on a daily basis (Barr et al., 2013). This is generally accomplished with nurse-administered bedside screening tools, which are completed several times per day while the patient is being cared for in the ICU.

Delirium manifests in three motoric subtypes: hyperactive, hypoactive, and mixed. Hyperactive delirium is characterized by agitation and psychomotor hyperactivity. This form is the most familiar for many clinicians because its presentation can be dramatic and memorable but the hyperactive subtype is actually the least common. The hypoactive, or "quiet", subtype is the most common form of delirium. The incidence of this form of delirium has been estimated at 43-60% and has been associated with worse outcomes for patients than other subtypes (Barr et al., 2013; Peitz, Balas, Olsen, Pun, & Ely, 2013). These patients appear lethargic and inattentive. Studies suggest that ICU clinicians often overlook hypoactive delirium, possibly due to its "quiet" nature (Barr et al., 2013). The final subtype is the mixed presentation in which patients fluctuate between episodes of hyperactivity and the hypoactive state.

It is difficult to predict which ICU patients will develop delirium. Studies that have tried to isolate risk factors and precipitating factors sometimes produce conflicting

results (Page & Ely, 2011). More than 60 risk factors have been suggested in the current research (Page & Ely, 2011). Factors that increase the likelihood that patients will develop delirium in ICU can be divided into non-modifiable and modifiable categories. Non-modifiable factors cannot be manipulated or changed by the ICU team. Pre-existing dementia, functional dependence, previous episode of delirium, high severity of illness, age greater than 65 years, alcohol or substance use, previous benzodiazepine use, hypertension, stroke, coma, trauma, surgery, chronic hepatic or renal disease, terminal illness and multiple co-existing medical conditions have all been suggested as potential non-modifiable risk factors (Inouye, 2006; Page & Ely, 2011; Pisani et al., 2007; Reade & Finfer, 2014). Modifiable factors may include immobility, physical restraint, depression, sensory impairment, isolation, loss of day/night orientation, dehydration, malnutrition, shock, hypoxia, hyper or hypothermia, pain, emotional stress, sleep derangements, and the choice and quantity of sedative and psychoactive medications (Barr et al., 2013; Inouye, 2006; Page & Ely, 2011; Shehabi et al., 2010). The likelihood that an individual patient will develop delirium increases as the factors accumulate (Page & Ely, 2011). Patients often have more than ten risk factors for delirium in the ICU (Page & Ely). Clinicians seek to reduce the number and impact of modifiable factors, as much as is possible within the confines of the patient's life threatening illness, to reduce the incidence and duration of delirium.

2.3 The Impact of Delirium for ICU Patients

Delirium in ICU patients has been consistently associated with poorer short-term and long-term outcomes. Patients who experience an episode of delirium during critical illness are more likely to die, to be mechanically ventilated longer, to stay in ICU longer,

to stay in hospital longer, to have long-term neuropsychological and cognitive deficits, and are more likely to be discharged to a skilled nursing facility (Barr et al., 2013; Brummel et al., 2014; Ely, Shintani et al., 2004; Pandharipande, Girard et al., 2013; Salluh et al., 2015). Studies have detected these poorer outcomes up to twelve months after discharge from hospital (Ely, Shintani, et al., 2004; Pandharipande et al., 2013; Pisani et al., 2009; Van Rompaey et al., 2008). Also, longer duration of delirium in critically ill patients is independently associated with cognitive decline, decreased executive function, memory, and worse scores for activities of daily living (Brummel et al., 2014; Girard et al., 2010; Pandharipande, et al., 2013; Salluh, et al, 2015; Van den Boogaard et al., 2012). The nature of the relationship between the incidence and duration of delirium and these patient outcomes is not yet known. It is not clear whether delirium is a cause of worse patient outcomes, or whether it is a marker of severity of illness that is linked to poorer outcomes through other variables (Barr, et al., 2013; Salluh, et al., 2015). What is clear, however, is that delirium has significant implications for ICU patients and that critical care nurses and other clinicians have a responsibility to prevent, identify, and treat delirium in order to minimize its effects as much as possible.

2.4 Managing Delirium: Interprofessional, Multi-Component Approach

The decisions and practices of ICU clinicians have an influence on the incidence of delirium and the short and long-term consequences for patients (Riker et al., 2009; Pandharipande et al., 2013; Skrobik et al., 2010; Schweikert et al., 2009). The critical care community has responded to the growing body of evidence of the negative implications of delirium by developing guidelines, protocols, and tools for its prevention, assessment, and treatment. As valid and reliable tools for assessing delirium have become

more available, researchers and clinicians have been able to evaluate patient outcomes and determine which interventions might be beneficial. While there are still significant gaps in the evidence related to optimal delirium management, there are also areas of consensus. The 2013 "Clinical Practice Guidelines for the Management of Pain, Agitation, and Delirium in Adult Patients in the Intensive Care Unit", (Barr et al.) were based on a literature review of over 19,000 published studies. These guidelines represent an update to the previous version from 2002, and are the first ICU guidelines to include statements and recommendations regarding the management of delirium. The statements and recommendations included in the guidelines were developed using the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) methodology (Guyatt et al., 2008). The aim of the guidelines are to assist clinicians to develop "integrated, evidence-based, and patient-centred protocols" at the local level (Barr et al., p. 264). Interprofessional, multi-component protocols are recommended as the most effective way to mobilize best practices and to improve patient outcomes (Barr et al., 2013).

Pain, agitation, and delirium (PAD) are interrelated phenomena in the ICU. When the elements of the best practices for PAD are combined there are synergistic effects that lead to improved patient outcomes and cost reductions (Balas, et al., 2014; Barr et al., 2013, Barr & Pandharipande, 2013). However, preventing and treating pain, agitation and delirium in critically ill patients is a complex endeavor. Interventions for PAD can conflict with other clinical goals such as maintaining physiologic stability. Poor communication and lack of respect among disciplines, the challenges of coordinating care among a large interprofessional team, knowledge deficits, workload, staff turnover,

documentation burden and unit culture can negatively impact efforts to implement and sustain best practices for PAD (Balas et al., 2013; Barr et al., 2013; Carrothers et al., 2013). Clinicians must be knowledgeable about PAD as well as about barriers and facilitators in their individual practice setting to be able to adapt and apply evidence-based recommendations. The main recommendations from the guidelines include: monitor pain with valid and reliable tools; prevent and treat pain; monitor depth of sedation with valid and reliable tools; minimize sedation; target light levels of sedation; carefully choose sedative agents; promote and protect sleep; and use an interprofessional multi-component approach that includes education, institution-specific protocols, and quality checklists to facilitate uptake of the best practices.

Of the fifty-four (54) statements and recommendations in the guidelines, twenty-two (22) pertain to delirium. Recommendations are made for delirium prevention and assessment, pharmacological management, and non-pharmacological interventions. The guideline recommends routine monitoring for delirium using valid and reliable tools. Due to the fluctuating nature of delirium, patients should be assessed every eight to twelve hours. The guidelines recommend using one of two tools, the CAM-ICU or the ICDSC, for the assessment of delirium in all adult ICU patients (Barr et al., 2013).

Several recommendations are related to pharmacological management. Atypical antipsychotics, such as quetiapine, may lead to reduction in duration of delirium and should be considered. In a change from the previous clinical practice guidelines, the current guidelines state there is no published evidence that haloperidol reduces the duration of delirium in the adult ICU population. No medication was recommended for delirium prevention due to insufficient evidence (Barr et al, 2013). When sedative

infusions are necessary, the guidelines suggest that dexmedetomidine is preferred over benzodiazepine infusions to reduce the duration of delirium (Barr et al., 2013).

The non-pharmacologic intervention with the strongest evidence of benefit is early mobilization. Early mobilization has been associated with a reduced incidence and duration of delirium (Needham et al., 2010; Schweikert et al., 2009). It has also been associated with reduced depth of sedation, length of hospital and ICU stay, and ventilator dependence (Barr et al., 2013). As such, the guidelines recommended early mobilization for all adult ICU patients whenever feasible (Barr et al., 2013). Other non-pharmacologic strategies recommended were environmental interventions to promote sleep, such as moderating light, reducing noise and clustering patient care activities, as well as non-pharmacologic pain management interventions such as music therapy and relaxation techniques (Barr et al., 2013).

The Registered Nurses Association of Ontario (RNAO) developed best practice recommendations related to delirium in the older adult population (RNAO, 2010a; RNAO, 2010b). The RNAO guidelines state that basic and continuing professional education should include specialized content related to delirium and that organizational planning, support, and resources should be allocated to facilitate the use of best practices. Specifically, the RNAO recommends that nurses maintain a high index of suspicion for delirium in the older adult population; that nurses should regularly screen for delirium using the psychiatric criteria; use standard screening methods and objective tools, and should target prevention of delirium (RNAO, 2010b). Further, nurses should work with other disciplines to select and implement multi-component strategies to target the causes of delirium. Multi-component strategies may include specialist consultation;

pharmacological management; environmental and behavioural interventions in order to provide a safe environment; minimizing the use of restraints; education of self, patients, and families; maintaining physiologic stability; and maintaining therapeutic relationships with patients using communication and emotional support (RNAO, 2010a; RNAO, 2010b).

RNAO recommendations for the critically ill population include that older adults admitted to ICU should be screened for delirium using an objective assessment tool with high sensitivity and specificity every eight to twelve hours (RNAO, 2010b). The CAM-ICU or the ICDSC can be used to assess mechanically ventilated or non-verbal patients (RNAO, 2010b). Risk factors such as comorbidities, age, surgery, pain, anticholinergic medication, iatrogenesis, and psychosocial factors should be considered. Also, maintaining day-night orientation, cognitive stimulation and early mobilization, and re-orientation methods are recommended as non-pharmacologic strategies (RNAO, 2010a).

Nurses perform several key roles in preventing, detecting, and treating delirium in ICU patients. Nursing care for these patients includes assessing patients for delirium, assessing and treating pain and agitation; administering analgesic, sedative, and antipsychotic medications; as well as implementing non-pharmacologic interventions for pain, agitation, and delirium (Balas et al., 2012; Barr et al., 2013). Nurses coordinate many patient interventions, such as weaning from mechanical ventilation, early mobilization, and carrying out diagnostic tests and procedures, with other health care team members (Balas et al., 2012). Nurses also provide essential communication during interprofessional team rounds and through nursing documentation (Balas et al., 2012).

Finally, nurses support and care for the patient and family continuously at the bedside and are a link to the rest of the interprofessional health care team (Balas et al., 2012).

2.5 Delirium Assessment Tools

ICU clinicians tend to underestimate the presence of delirium in patients during routine care (Barr et al., 2013; Pandharipande et al., 2007; Spronk, Reikerk, Hohuis, & Rommes, 2009). Both the CAM-ICU and the ICDSC were adapted from the psychiatric criteria for delirium as described in the DSM-IV and are designed to be administered quickly at the bedside by non-psychiatric clinicians (Bergeron et al., 2001; Ely et al., 2001). Importantly, these tests do not require that the patient be able to speak and therefore can be used with patients who are receiving mechanical ventilation or have other communication barriers, such as tracheostomies, that are common in ICU patients.

The ICDSC has eight domains: level of consciousness, inattention, disorientation, hallucinations or delusions, psychomotor agitation or retardation, inappropriate speech or mood, sleep-wake cycle disturbance, and symptom fluctuation. Patients are screened by observation in each domain, usually over the period of a nursing shift. The patient scores one point on the checklist for each obvious manifestation of an alteration. Possible scores range from zero to eight (0-8). If the patient displays alterations in four or more domains they screen "positive" for delirium. The test has shown 99% sensitivity and 64% specificity for delirium in ICU patients (Bergeron et al., 2001), meaning that a score of four or greater will identify 99% of patients with delirium but it will also falsely identify 36% of patients who do not have delirium. For this reason, the ICDSC is considered a screening tool for delirium which requires further evaluation for a diagnosis to be made.

The ICDSC can be used by physicians or nurses with similar reliability; and many of the criteria are collected during routine care (Bergeron et al., 2001).

The CAM-ICU is designed for use at the bedside two to three times per day to assess patients' cognition (Ely et al., 2001; Ely, 2014). Any trained clinician can use the CAM-ICU but nurses typically administer it in practice (Balas et al., 2012; Balas et al., 2013; Carrothers et al., 2013). The patient is tested for the four diagnostic features of delirium: 1) acute onset or fluctuating course, 2) inattention, 3) altered level of consciousness, and 4) disorganized thinking. The first feature, acute onset or fluctuating course, is determined by considering whether the patient's cognitive status is different than his or her baseline. If a change from baseline is present it must have occurred as an acute change (i.e. over a period of hours to days) as opposed to a gradual onset (i.e. weeks to months) (Ely, 2014). The second feature, inattention, is assessed by asking the patient to squeeze the assessor's hand when the letter "A" is read from a list of letters. If the patient has impaired hearing an alternative picture-based test can be used. In the picture-based test the patient is asked to remember images of common objects and then indicate which images he or she remembers by squeezing the assessor's hand. The third feature, altered level of consciousness, involves using a numerical scale that ranges from comatose to hyperactive. The fourth feature, disorganized thinking, requires the use of a specified set of questions designed to test cognition (e.g. "Will a stone float on water?"). Alternately, the patient is asked to follow specified two-step commands. If both features 1 and 2 are present along with feature 3 or feature 4, the patient is considered to be "CAM-ICU positive," meaning that they have delirium.

2.6 Nursing Care of ICU Patients with Delirium

A literature review was undertaken to understand the state of knowledge related to the nursing care of ICU patients with delirium. The search terms "intensive care" OR "critical care" AND "delirium" AND "nurs*" were entered into CINAHL, and PubMed using keywords and mapped subject headings (MeSH). Hand searches of reference lists and selected critical care journals were also performed. The search was limited to studies published from 2001 to the present. The year 2001 was chosen because validated delirium assessment tools for use at the bedside (CAM-ICU and ICDSC) became available that year. Primary studies on nurses, nursing, or nurse-mediated factors related to delirium in adult ICU patients were included. The resulting fourteen (14) research studies were grouped into four categories: nurses' assessments of delirium; nurses' perceptions, attitudes and beliefs; nurses' knowledge; and nursing care related to non-pharmacologic interventions. At the time of preparing the research proposal, only one study had been conducted on nurses' experiences of caring for patients with delirium in the ICU setting.

2.6.1 Nurses' assessments of delirium.

Assessing patients for delirium with a valid and reliable tool is a best practice recommendation for effective delirium management. Nurses' assessment of delirium (i.e. using CAM-ICU or ICDSC) was investigated in nine studies (Devlin, Fong, et al., 2008; Eastwood, Peck, Bellomo, Baldwin, & Reade, 2012; Gesin et al., 2012; Law et al., 2012; Mistarz, Eliot, Whitfield, & Ernest, 2011; Reade, Eastwood, Peck, Bellomo, & Baldwin, 2011; Soja et al., 2008; van Eijk et al., 2011; Vasilevskis et al., 2011). While psychiatric evaluation remains the gold standard for delirium assessment, nurse-administered

assessment tools enable early delirium detection and treatment. The CAM-ICU and ICDSC have been shown to be more reliable for identifying delirium in ICU patients than clinical impression alone (Barr et al., 2013; Mistarz, Elliott, Whitfield, & Ernest, 2011).

Researchers have also investigated the use of the CAM-ICU outside of study conditions. Van Eijk and colleagues (2011) aimed to investigate the effectiveness of the CAM-ICU under everyday practice conditions. In their study, delirium assessments conducted by teams of experts including psychiatrists, geriatricians and neurologists, were compared to delirium assessments completed by bedside nurses using the CAM-ICU. Data were collected from ten ICUs of university, teaching and rural hospitals in the Netherlands. All of the ICUs had implemented the CAM-ICU within two years of participation in the study. A variety of educational strategies, including written materials, lectures and bedside teaching for nurses, had been used during the implementation phase. The study found that nurses using the CAM-ICU did not detect as many cases of delirium as the expert assessors. Out of 181 patient assessments, the CAM-ICU maintained high specificity (98%, 95% CI: 93-100%), but sensitivity of only 47% (95% CI: 35-58%), which was lower than previously reported. The authors hypothesized that the reduced level of sensitivity could be related to inadequate training or incomplete implementation, and lack of motivation of the nurses to use the CAM-ICU if it was not standard. They cautioned that, under everyday practice conditions, the CAM-ICU might not perform as well as previously reported.

In contrast, Vasilevskis and colleagues (2011) found good levels of agreement between assessments of delirium made by bedside nurses using the CAM-ICU in everyday practice and the assessments made by specially trained research nurses

(weighted kappa = .67, 95% CI: .66-.70). The researchers collected data in two ICU's in a single 900-bed teaching hospital in the United States. Over a three-year period, the researchers compared 6,880 paired assessments. The bedside nurse assessments demonstrated 81% sensitivity (95% CI: 78-83%) and 81% specificity (95% CI: 78-85%). The authors concluded that bedside nurses' assessments using the CAM-ICU were reliable and sustainable over time.

Reade and colleagues (2011) questioned whether the number of patients diagnosed with delirium would increase after the implementation of the CAM-ICU in a 20-bed mixed medical surgical ICU in a university affiliated, tertiary care hospital in Australia. The study was conducted in two phases. In the first phase, nurses assessed patients for delirium using unstructured assessments. In the second phase, the nurses assessed patients for delirium using CAM-ICU following an intensive educational program, which included lectures, bedside tutorials, and supervision. The researchers reported nurses' assessments using the CAM-ICU detected a lower proportion of patients with delirium compared to the unstructured assessments (21% versus 36% respectively). The authors hypothesized that the nurses might have detected more delirium in the unstructured assessments because their assessments reflected the nurses' impression over the course of the shift. In contrast, the CAM-ICU is meant to assess the patient at a specific point in time. The authors concluded that the CAM-ICU might be less sensitive in daily practice than in validation studies.

2.6.2 Nurses' perceptions, attitudes, and beliefs about delirium assessment.

Three studies focused on nurses' perceptions, attitudes, and beliefs about delirium and delirium assessment (Devlin, Fong, et al., 2008; Eastwood et al., 2012; Law et al.,

2012). Devlin, Fong, and colleagues (2008) surveyed nurses in 16 ICUs in five hospitals in Massachusetts. The response rate was 55% (331 respondents out of 601 nurses surveyed). The researchers found that 40% of the respondents were unaware that their institutional sedation protocol included regular delirium assessment. Most respondents ranked delirium assessment as less important than pain assessment, level of consciousness, and proper placement of an invasive device. Delirium assessment was more common in medical intensive care units and in academic versus non-academic hospitals. Intubation, complexity of assessment tools (CAM-ICU, ICDSC) and level of sedation were identified as barriers to delirium assessment.

Eastwood and colleagues (2012) surveyed critical care nurses about their attitudes to delirium assessment before and after they were introduced to the CAM-ICU. The majority of the participants in this study considered delirium assessment important (73% and 89% pre and post CAM-ICU respectively). The CAM-ICU was considered "quite" or "very hard" to use by 33% of the respondents. However, the majority indicated a desire to continue using the CAM-ICU and thought that the medical staff valued the CAM-ICU results. The researchers recommended using the CAM-ICU as a method to improve communication between physicians and nurses about delirium.

In contrast, in a study by Law and colleagues (2012), the perception that physicians were indifferent to nurses' delirium assessments was found to be a barrier to the ICDSC assessment. The aim of the study was to examine nurses' perceptions of the ICDSC. On four medical oncology units that included a mixture of general care, intermediate and critical care patients, respondents indicated that the ICDSC was useful and that they had confidence in it. However, limited knowledge of delirium, lack of time,

feedback on performance, as well as physician indifference were considered barriers to delirium assessment and treatment.

2.6.3 Nurses' knowledge of delirium and educational interventions.

Two surveys of nurses found knowledge gaps and lack of uptake of current best practice recommendations for delirium prevention, assessment and management in ICU (Forsgren & Eriksson, 2010; Hamdan-Mansour, Farhan, Othman, & Yacoub, 2010). Forsgren & Eriksson (2010) sent a questionnaire to every adult ICU in Sweden with the aim to determine the awareness, observation and interventions for delirium, and whether these elements would differ according to the category of hospital. Surveys were mailed to the head nurses of 82 ICUs. Fifty-five surveys (67%) were completed and returned to the researchers. Respondent ICUs included county, regional, and university hospitals with medical and surgical populations with a median number of beds of eight. Only one respondent reported that a validated delirium assessment tool (CAM-ICU) was in use in their ICU. Thirty-three of the survey respondents (60%) reported using other methods for assessing delirium, usually clinical observation. Non-pharmacological interventions for delirium that were reported included family contact, maintaining sleep and diurnal rhythm, individual care, stimulation and orientation, calm environment, maintaining oxygenation, nutrition and hydration, sensory aids, person present when anxious. Common medications used included haloperidol (96%), propofol (90%) and benzodiazepines (76%). Fourteen (25%) ICU's reported having a written delirium protocol for medications. The authors concluded that there was a lack of awareness about delirium in the surveyed ICUs and recommended implementing standardized delirium assessments and providing education about best practices for delirium.

Hamdan-Mansour et al., (2010) conducted a survey to investigate critical care nurses' knowledge of delirium and of delirium management in Jordanian ICUs. Nurses (n=232) working in ICUs in government, military, and private hospitals were recruited using convenience sampling. Respondents completed a two-part self-report questionnaire. Nurses' knowledge of delirium, was measured using a twenty-five item scale adapted from the CAM-ICU (Ely et al., 2001) and the delirium continuing education test (Devlin, Fong et al., 2008). The second section of the questionnaire was related to nursing practices for patients with delirium, such as pain management and re-orientation techniques. Nurses identified effectiveness of the practices used to manage patients with delirium on a 100-mm visual analogue scale with scores categorized from very low level of skill (0-25) to high level of skill (91-100). The findings of the study indicated that nurses in Jordan demonstrated low to moderate levels of knowledge about delirium in patients in ICU (mean=64.4, SD=6.5). Higher levels of knowledge correlated positively with more effective nursing practice, but the correlation was low ($r=.20$, $p < .001$). The respondents indicated a need for knowledge and skills specific to delirium management for patients in ICU. The authors recommend that nurses receive education on delirium assessment and treatment and that regular education programs, as well as research efforts, focus on nursing care and patient outcomes related to delirium.

Two studies evaluated educational interventions related to nurses' knowledge of delirium, and of delirium assessment following the implementation of structured delirium monitoring (Gesin et al., 2012; Soja et al., 2008). Soja and colleagues (2008) conducted a prospective, observational trial of the implementation, reliability, and compliance with delirium monitoring using the CAM-ICU in a tertiary, university-based trauma ICU in the

United States. The implementation phase consisted of education for nurses about delirium and the CAM-ICU using web-based teaching modules and group in-services. Following the implementation phase, nurses' assessments for delirium using the CAM-ICU were compared with those of an expert evaluator on randomly assigned days over a ten-week period. Compliance with delirium monitoring was measured as the proportion of CAM-ICU scores completed by the bedside nurse during spot checks. A post-implementation survey was used to evaluate the nurses' understanding of delirium, as well as their comfort and satisfaction with the CAM-ICU.

The researchers found good agreement between the nurses' assessments with CAM-ICU and the expert evaluators ($\kappa = 0.77$, 95% CI, 0.721-0.822, $p < 0.0001$) (Soja et al., 2008). Compliance was also considered to be high with more than 85% of the expected CAM-ICU scores completed during the monitoring period. In the post-implementation survey ($n=42$), the majority of respondents (66%) indicated that they understood delirium, had received adequate education to use the CAM-ICU, were confident when using the CAM-ICU tool, and thought that their delirium assessments were accurate. However, barriers to implementation were also revealed including nursing time and lack of physician response. Many of the nurses thought that patient care was not enhanced by the use of the CAM-ICU and that the physicians did not value the results (47% and 54% respectively). The researchers speculated that the physician teams that rotated through the unit at the time of the study might have lacked formal training in delirium monitoring. Based on the post-implementation feedback, the implementation team instituted additional in-services for nurses on delirium assessment; incorporated it

into nursing orientation and six-month competency assessments; implemented education for physicians as well as a delirium algorithm to guide intervention and treatment.

In a three-phase implementation study Gesin and colleagues (2012) investigated the impact of a delirium screening tool, with or without an educational intervention, on nurses' knowledge and perceptions of delirium in a surgical-trauma ICU. Nineteen (19) nurses participated in all three phases of the study. In the first phase, the nurses were asked to evaluate whether their patient had delirium using the method of their choice, no education was provided. In the second phase, nurses were provided with "minimal education" which included a paper-based ICDSC screening form and the original paper describing the validation of the ICDSC. Nurses were then asked to assess their patients for delirium using the ICDSC. In the third phase, nurses participated in a multi-faceted educational program that included a pharmacist-led lecture about delirium, delirium assessment, and the ICDSC, a web-based presentation of the same content, and in-person bedside demonstration of ICDSC use. Again, the nurses were then asked to assess their patients for delirium using the ICDSC. The bedside nurses' assessments of delirium, with and without the ICDSC, were compared with that of an expert assessor, a specially-trained clinical nurse, who always used the ICDSC. Nurses' knowledge of delirium was evaluated during all three phases using a multiple-choice questionnaire and their perceptions of delirium and delirium assessment were evaluated using a Likert-scale based questionnaire.

The results of this study indicated that the nurses' knowledge of delirium was similar in the first two phases of the study but increased following the multi-faceted education intervention in the third phase (Gesin et al., 2012). Paired delirium assessments

between the bedside nurses and the expert evaluator showed increased levels of agreement in phase 2 (kappa = 0.62, 95% CI, 0.39-0.69) and phase 3 (kappa= 0.74, 95% CI, 0.69-0.95), when education was provided. The perception that delirium was challenging to assess decreased from phase 1 to phase 3. However, two-thirds of respondents still considered delirium challenging to assess in ICU patients during phase 3 (63%). The proportion of nurses who agreed that the ICDSC made delirium easier to identify increased as the phases progressed. The authors concluded that the ICDSC should be accompanied by multi-faceted education strategies, including pharmacist-led teaching and nurse-led bedside training.

2.6.4 Nursing care related to non-pharmacologic interventions for delirium.

Colombo and colleagues (2012) conducted a two stage prospective observational study of a nurse-mediated reorientation strategy in a single medical-surgical ICU in Italy. The re-orientation intervention involved nurses frequently cueing patients to their name and the caregivers' names, location, illness progression, date and time of day. The patients also received environmental, acoustic and visual stimulation with clocks, books, music, or radio; light and noise were modulated to maintain a day/night cycle. Delirium was identified using the CAM-ICU. A multivariate analysis revealed that the patients who received the re-orientation intervention (n=144) were less likely to develop delirium than the patients in the observational group (n=170) (Cox's Proportional Hazard Model, Hazard Ratio: 0.504, 95% CI: 0.313-0.890). The authors conclude that re-orientation strategy was independently correlated with lower occurrence of delirium however caution is needed in interpreting the findings of this single-centre, observational study.

Currently, early mobilization of ICU patients is the only non-pharmacologic strategy recommended for delirium in the clinical practice guidelines for management of pain, agitation, and delirium in adult ICU patients from the Society of Critical Care Medicine (Barr et al., 2013). Early mobilization has been associated with reduced incidence and duration of delirium as well as other beneficial patient outcomes such as length of stay and improved functional status (Needham et al., 2010; Schweickert et al., 2009). Patients participate in mobilization as early as possible in their critical illness, often while undergoing mechanical ventilation and other invasive therapies (Needham et al., 2010; Schweickert et al., 2009). In many ICUs, mobilizing patients is a collaborative intervention involving nurses, physiotherapists, and other care providers. However, nurses are central players to facilitate, coordinate and participate in safely mobilizing patients along with other members of the interprofessional team.

2.7 The Experience of Caring for ICU Patients with Delirium

Jung and colleagues (2013) explored the experience of nurses caring for surgical ICU patients with delirium and the use of the CAM-ICU as a delirium assessment tool. The researchers conducted a qualitative analysis of focus group interviews with nurses in a large university hospital in Korea. The nurses perceived the CAM-ICU as difficult to use at first but easier with practice. Some nurses thought that the number of pictures (10) could be burdensome for the patients. The nurses reported needing ten minutes to complete the CAM-ICU, which decreased to five minutes with more experience. This is notably longer than the two minutes specified in CAM-ICU studies and educational materials (Ely et al., 2001; Ely 2014). Positive aspects of using the CAM-ICU included making delirium easier to detect, as well as increasing nurses' awareness of hypoactive

delirium and of delirium in general. Negative aspects of the CAM-ICU included nurses' lack of confidence in both positive and negative results, patients not cooperating with the test, and lack of awareness of the CAM-ICU among physicians. Participants in their study characterized patients with delirium as exhibiting violent behaviour and instability and that when they were caring for a patient with delirium they encouraged family visiting to "restore stability." These nurses found it helpful when nursing ratio was one to one, which allowed them to attend to the patient's emotional needs. Overall, the participating nurses experienced nervousness when a patient was diagnosed with delirium, feared violent patients, felt embarrassed when patients "acted out," and lacked knowledge about delirium prior to the training for the CAM-ICU.

2.8 Summary

Encountering patients with delirium is a regular occurrence for critical care nurses and nurses play central roles in the complex care of the patients. While several studies have investigated the nursing care of patients in the ICU with delirium, research to date has tended to focus on nurses' assessments of delirium, nurses' perceptions, attitudes and beliefs about delirium assessment as well as nurses' knowledge. Currently, there is limited literature about how nurses might navigate the complexities of caring for this vulnerable group of patients or about their experiences while doing so. Research is needed to examine the everyday experiences of critical care nurses caring for patients with delirium from the perspective of the nurses. The findings of this study will provide insights on what it is like for nurses to care for these patients, reveal factors that help or hinder nurses while providing care, explore nurses' use of delirium-related tools and best

practice recommendations, and enrich the knowledge base available to develop strategies to help nurses and other health care professionals, as well as patients and their families.

Chapter 3: Methods

The purpose of this research study is to gain an understanding of the lived experience of intensive care nurses caring for patients with delirium and the factors that facilitate or hinder nurses while caring for these patients. The research approach chosen, the sample, setting, process of data collection, and the protection of human rights are discussed in this chapter.

3.1 Phenomenology and Phenomenological Research

Interpretive qualitative research approaches allow the researcher to study human phenomena in a natural, uncontrolled setting (Mackey, 2005). Nursing experiences, which often take place in the realm of everyday practical activity, may be examined using these approaches (Leonard, 1994). Phenomenological research is grounded in the philosophical traditions of Edmund Husserl and Martin Heidegger, who was a student of Husserl (Polit & Beck, 2012). The Heideggerian approach to phenomenology stresses interpreting and understanding human experience (Polit & Beck, 2012). Heidegger argued that interpreting and understanding, or hermeneutics, are fundamental characteristics of human existence (Polit & Beck, 2012). This interpretive phenomenological approach, derived from the work of Heidegger and other thinkers, can be used to systematically reveal the meaning structures of everyday experiences (Polit & Beck, van Manen, 1990).

Several concepts in Martin Heidegger's philosophical work are important to the interpretive phenomenological research approach. The concepts of Dasein, Being-in-the-world, Space, Time, and Forestructures are reviewed.

3.1.1 Dasein and Being-in-the-World

Heideggerian phenomenology asks "what it means to *be* a person and how the world is intelligible to us at all" (Leonard, 1994, p. 45). He used the term Dasein to describe the state of being aware of and wondering about one's own existence, or Being (Mackey, 2005; van Manen, 1990). Being-in-the-world is the phrase Heidegger used to denote that humans cannot exist separately from their world. World here refers to the collection of "relationships, practices, and language" that we share with other human beings (Leonard, 1994, p. 43). For the phenomenological researcher the fundamental concern is seeking the meaning of being. Heidegger argues that the world is so familiar to us that it is usually invisible; and it is only through careful inquiry that it can become accessible to understanding (Heidegger, 1975 in Leonard, 1994).

3.1.2 Space and Time

Being-in-the-world means that persons exist in both space and time. Put another way, existence is both spatial and temporal (Mackey, 2005). The concept of spatiality goes beyond physical distance and geographical location (Mackey, 2005). Persons are spatially situated in relation to things that concern them (Mackey, 2005). The phenomenological researcher, through the interpretive process, pays attention to experiences that are close to the participants, as well as experiences that appear to be distant. Similarly, temporality refers to a concept of time beyond the usual idea of linear clock time. It is the human "awareness of time and the experience of being in time" (Heidegger, 1962 in Mackey, 2005). In this view, time is experienced as an awareness of the past, present, and future at once. Heidegger also considered temporality as fundamental to awareness of existence (Mackey, 2005). The phenomenological

researcher, in order to gain a more complete understanding of the phenomenon of interest, attends to the participant's experiences in space and time.

3.1.3 Methodological Assumptions

The following section discusses several important assumptions arising from the phenomenological perspective. Assumptions include: that there are essential structures underlying experiences that can be revealed through study; that the researcher will have preliminary understandings (forestructures) of the phenomenon under study; and that researchers cannot achieve an objective, neutral position in the positivist sense (Leonard, 1994; van Manen, 1990).

A central assumption of the phenomenological tradition is that there is an essential structure underlying lived experiences that can be made intelligible to human reason (Polit & Beck, 2012; van Manen, 1990). Phenomenological research always starts in the *lifeworld*, which refers to the world of everyday life as it is lived immediately, prior to reflection or theorizing (van Manen, 1990). Researchers aim to bring aspects of the lifeworld to awareness in order to understand them (van Manen, 1990). As such, the purpose of this study is to capture the everyday lived experience of critical care nurses caring for patients with delirium in order to understand the nature, or essence, of the phenomenon and to make it known.

However, researchers themselves are also persons in the world and cannot be fully objective (Leonard, 1994). A researcher studying persons in the world is also a person in the world and is therefore subject to the same bounded existence and horizons as the individuals that they are studying (Leonard, 1994). Heidegger argued that because of the nature of human existence, interpretation is unavoidable (Leonard, 1994; Mackey, 2005).

When phenomena are understood through interpretation they have meaning (Heidegger 1962 in Mackey, 2005). Heidegger described a 'circle of understanding' in which one moves between partial understandings and more complete understandings. For van Manen, the hermeneutic circle is expressed in the process of circular writing and re-writing that the researcher undertakes to reveal the deeper meaning of the phenomenon (van Manen, 1990).

Researchers will have a preliminary understanding, or *forestructure*, of the phenomenon under study (Leonard, 1994). In the interpretive phenomenological approach the researcher acknowledges her/his forestructures and utilizes them in the interpretation of experience (Leonard, 1994). The researcher explicitly acknowledges her/his "understandings, beliefs, biases, assumptions, presuppositions, and theories" in order to avoid allowing these influences to unknowingly influence his/her reflections (van Manen, 1990 p. 47). The researcher can then *use* these forestructures by making them explicit and to reflect on the nature of the phenomenon and come to a fuller understanding.

3.1.4 Researcher's Assumptions

For the researcher undertaking this current study, her understandings, assumptions, and presuppositions have been influenced by her identity and her experiences as a critical care nurse. The researcher acknowledges the following assumptions:

1. Caring for ICU patients with delirium is distressing for critical care nurses
2. Using evidence-based screening tools, such as CAM-ICU, enhances patient care

3. Critical care nurses empathize with the delirious patient as they are in that space and time in order to care for them effectively

3.2 Research Design

Van Manen's human science approach, based in the Heideggerian phenomenological tradition, provides the methodological lens for this study. Van Manen (1990) describes interpretive phenomenological research as the study of lived experience (lifeworld) and essences. Van Manen proposes six dynamically interactive activities for phenomenological research: (1) turning to a phenomenon which seriously interests us and commits us to the world; (2) investigating experience as we live it rather than as we conceptualize it; (3) reflecting on essential themes which characterize the phenomenon; (4) describing the phenomenon through the art of writing and re-writing; (5) maintaining a strong and oriented relation to the phenomenon; and (6) balancing the research context by considering the parts and whole (p. 30-31). The results of phenomenological research describe a phenomenon in a way that reveals its particular significance so persons who have had, or could have had that experience, can recognize it.

3.3 Setting

Participants in this study were recruited from a university affiliated, tertiary care academic health care center in Ottawa, Ontario. This hospital has three sites, two of which have ICUs. One ICU has 28 beds with neurosurgical, trauma, vascular, and general medical-surgical patients while the other ICU has 32 beds with primarily oncology, pulmonary, and medical-surgical patients. Both of these units have a policy of per shift delirium assessment using the CAM-ICU by the bedside nurse as well as an ICU-specific delirium protocol. The multidisciplinary team providing care for critically ill patients

consists of critical care nurses, intensive care physicians, intensive care fellows, resident physicians, medical students, and consultant physician teams, as well as respiratory therapists, physiotherapists, occupational therapists, clinical pharmacists, registered dietitians, social workers, and spiritual care professionals. The nurse-to-patient ratio is usually one-to-one but when patients become more medically stable they may be included in "double" assignments, where one nurse cares for two patients.

Patients in the ICUs are situated in single and double rooms that are separated by glass walls. Curtains may be drawn for privacy. Some patient rooms have windows to the outside; others have only artificial lighting that can be modified. The large hallway outside the patient rooms is brightly lit with artificial light during the day. Patients may have many invasive devices in their bodies such as intravenous catheters, endotracheal tubes, tracheostomy tubes, other drainage tubes, and urinary catheters. Patients are connected to a variety of technological devices such as cardiac monitors, multiple intravenous infusions, mechanical ventilators, and dialysis machines. Many of these machines make continuous noise during normal functioning as well as frequent alert sounds during usual care. The environment is busy with many health care professionals and visitors coming and going. The nurses' workstations are positioned outside each patient room at either fixed or mobile tables. Nurses maintain near-continuous observation of the patient, monitors, and devices throughout each twelve-hour shift. When nurses must leave the bedside, either for care-related activities or on a break, a "covering" nurse will assume responsibilities for care, observation, and monitoring of the patient for that period of time. Generally, this covering nurse will also be caring for his or her own assigned patient at the same time. Family visiting is restricted to two family

members at a time at the patient's bedside. There are designated visiting times throughout most of the day, however visiting is restricted during nursing handover.

3.4 Sample

Phenomenological studies typically include eight to ten participants in order to obtain rich data for analysis (Polit & Beck, 2012). A purposive sample of eight critical care registered nurses was recruited for this study. A pilot interview, conducted before the main study to test the interview guide and develop the researcher's interviewing technique, was included in the study data.

3.4.1 Eligibility Criteria for Participants

The key criterion for participation is having experienced the phenomenon under study. (See Table 1: Inclusion and Exclusion Criteria.)

Table 1. Inclusion and Exclusion Criteria

Inclusion Criteria	Rationale
1. Critical care nurse (RN) who has cared for intensive care unit patient(s) with delirium in the last 12 months	To ensure that the nurse has had recent experience with the phenomenon of interest.
2. Employed full or part-time in the intensive care, with greater than 1 year intensive care experience	To ensure that the participants have had the opportunity to become familiar with the context of critical care, and factors which help or hinder caring for patients with delirium
3. Fluent English	The researcher is not fluent in any other language
Exclusion	
Does not meet ALL of the above inclusion criteria.	

3.4.2 Characteristics of the Participants

The participants' age groups ranged from 21 to 60 years. The participants' years of nursing experience ranged from one to 37 years and their years of ICU nursing experience ranged from one to 28 years. Participants had worked in the study ICUs

between one and 28 years. Five participants were male and three were female. (See Table 2: Characteristics of the Participants)

Table 2. Characteristics of the Participants

Pseudonym	Age group	Gender	Years of Experience as a Nurse	Years of Experience in ICU	Years of Experience in Present Unit
Alan	41-50	Male	18	18	6
Ben	21-30	Male	1	1	1
Steven	31-40	Male	6	6	6
Joanne	41-50	Female	21	6	6
Donald	21-30	Male	5	1	1
Gail	51-60	Female	37	28	28
Gary	41-50	Male	16	7	7
Jessica	41-50	Female	13	10	10

3.5 Process of Data Collection

3.5.1 Main Study

Prior to data collection, the researcher and thesis supervisor met with the Nurse Managers and the Clinical Nurse Educators for each unit. The purpose of the research study and the data collection methods were reviewed and questions were answered. Verbal assent was obtained for posters (See Appendix E: Study recruitment Poster) to be displayed in designated staff areas and for the researcher to be present on the unit and recruit participants. The clinical nurse educator also sent out an informational email on the researcher's behalf that outlined the purpose and methods of the study. Potential participants were invited to contact the researcher by phone or email. Ultimately, all of the participants were recruited in person by the researcher. Interview times were arranged at the participant's convenience. Data collection proceeded over a three-week interval. The researcher transcribed each interview and the transcription was reviewed with the

research supervisor prior to conducting the next interview. Selected interviews were provided to the thesis committee for review. Recruitment of participants continued until rich descriptions of the phenomenon were revealed in patterns (Munhall, 1994). By the eighth interview, the supervisor and thesis committee agreed that sufficient richness and depth of the data had occurred.

3.5.2 Interview Process

One-to-one interviews of approximately one hour were held with each of the participants in a private, quiet space in the ICU. All of the participants opted to conduct the interview while they were on duty. The researcher used open-ended questions (See Appendix D: Interview Guide) to help reveal the participant's experience. Open-ended questions such as: (1) "Can you tell me what it is like to care for intensive care unit patient(s) with delirium?" allowed the participants to relate their experiences of caring for these patients. Participants were invited to share personal stories or anecdotes to stimulate their recollections and to provide rich data. The researcher also used prompts such as "Tell me more about...?" and "How do you mean...?" to maintain a conversational flow (van Manen, 1990).

Interviews were recorded with a digital recorder and transcribed by the researcher within twenty-four hours then checked for accuracy against the recording. Demographic data such as age, years of experience in nursing, in intensive care nursing and in the study unit were collected. The researcher took field notes during and immediately after the interviews in order to preserve impressions and collect additional data about each interview. A reflexive journal was maintained to record methodological decisions as well as initial assumptions and impressions throughout the data collection process.

3.5.3 Member Check Interview

One additional phone interview was scheduled following data analysis to allow the participants to reflect on the study findings. Two participants responded to the request for follow-up interviews. These interviews were not recorded. Participants listened to a three-page overview of the study findings and provided feedback to the interviewer.

3.6 Data Analysis

The researcher analyzed the interview transcripts (text) to reveal the essence of the lived experience of critical care nurses caring for ICU patients with delirium. The process of data analysis was based on the process described by van Manen (1990). In this process, there are three approaches to textual analysis: (1) Wholistic approach: The researcher read the transcript (text) as a whole to try to capture a sense of its overall significance. (2) Detailed approach: The researcher read every line of the text and asked what is revealed about the phenomenon. (3) Selective approach: The researcher returned to the text regularly to situate emerging themes within the participants' statements.

Through the process of writing and re-writing, the researcher organized meaning units into meaning clusters, which were aggregated into themes. The researcher consulted with the research supervisor and thesis committee members during all phases of data collection and analysis.

3.7 Methods to Ensure Rigor

Trustworthiness of the findings were established using the criteria outlined by Lincoln & Guba (1985): credibility, transferability, conformability, and dependability.

3.7.1 Credibility

Credibility or the truth value is here defined as the extent to which the findings can be considered to be "truth" by the participants and within the context of the study (Lincoln & Guba, 1985). Several techniques were employed to ensure credibility. Member check interviews were conducted with two participants who agreed that the study findings represented their experience of caring for ICU patients with delirium. No additions or deletions were required as a result of the follow-up interviews. Credibility was enhanced through consistent consultation with the members of the thesis committee, who had expertise in nursing, delirium, critical care, and qualitative research.

3.7.2 Transferability

Transferability refers to the degree to which the research findings might be applicable in similar settings (Lincoln & Guba, 1985). In this study, providing detailed descriptions of the setting and context have been presented, as well as descriptions of participants, to enhance transferability. Thick descriptions and direct quotations have been provided to substantiate themes.

3.7.3 Confirmability

Lincoln and Guba define confirmability as the assurance that the study results represent the data provided by the participants and not the biases or the perspective of the researcher (1985). Confirmability is demonstrated when the findings accurately reflect the participants experiences. Quotes from the participants were used to explicate each theme. Confirmability was also enhanced by having the thesis supervisor read all the transcripts and assist in the development of the themes. The themes from the analysis were verified and agreed upon by the thesis committee. Additionally, the researcher

employed a reflexive journal to record the researcher's reflections on the study data, so that personal feelings did not overshadow the experiences of the participants.

3.7.4 Dependability

Finally, dependability refers to the stability of the data over time (Lincoln & Guba, 1985). It may be considered as the degree of consistency that the study findings would have if the study were replicated in a similar context with similar participants. The researcher maintained a decision trail to record methodological decisions as well as decisions related to data analysis during the research process. Sandelowski (1986) states that a study is dependable when another researcher can follow the decision trail.

3.8 Protection of Human Rights.

Ethical approval was obtained from The Ottawa Health Science Network Research Ethics Board. Participation was voluntary and confidential. Potential participants were notified of the study and its purpose through an introductory email delivered by a neutral intermediary, and on-site posters. Individuals were invited to participate during an on-site in-service by the researcher and given the opportunity to respond confidentially by phone or email. An information letter (Appendix A) outlining the purpose of the study was given to participants prior to the interview. At the start of the interview, the interviewer reviewed the purpose of the study, the participants' right to refuse or withdraw at any time, the confidential use of information including direct quotations, the potential risks and benefits of participating in the study. Informed consent was obtained and participants were given the opportunity to ask any questions they had (See Appendix B and C: Consent Forms). A copy of the consent form was provided to the participant.

Unique identifier codes were used on all study documents to maintain the participants' privacy and anonymity and pseudonyms were used in transcribed quotations. A key file including participants' names, and consent forms was stored separately from other study documents. Electronic materials were stored in an encrypted file on the researcher's password-protected laptop. Interview recordings were deleted from the mobile device after being transcribed. In accordance with the policies of the University of Ottawa for the conservation of research data, audio recordings will be destroyed after two years; all other study materials were securely stored in the research supervisor's office at the University of Ottawa.

Chapter 4: Findings

The following chapter describes the experiences of critical care nurses caring for patients experiencing delirium. Factors that the nurses found challenging or that facilitated caring for patients with delirium are presented.

4.1 Overview of the findings

The essence of the experience of critical care nurses caring for patients with delirium can be described as "*finding a way to help them come through it.*" Nurses were challenged to find ways to provide safe, person-centered care in order to help patients come through the temporary state of delirium. Six themes emerged: 1) It's Exhausting; 2) Making a Picture of the Patient's Mental Status; 3) Keeping Patients Safe: It's a Really Big Job; 4) Everyone is Unique; 5) Riding it Out with Families; and 6) Taking Every Experience With You.

The theme *It's Exhausting* captured the draining nature of the nurses' encounters with these patients. Participants described feeling mentally and emotionally exhausted by the effort required to manage patients with symptoms of disorientation and/or agitation. There were four categories in this theme: *It Can be Frustrating for the Nurse and the Patient* described trying to meet patient needs. *Not Being Able to Give Optimal Care*, was related to not being able to provide interventions when the patient was uncooperative. *Being on Guard* concerned safety issues for nurses, while *Feeling Challenged* brought forth how care could be rewarding.

Making a Picture of the Patient's Mental Status was a dynamic process that nurses continually engaged in during their encounters with these patients. This theme had three categories. *Assessing the Patient as a Whole* considered the patient's medical history and

current illness. *Filling in the Picture: Moment by Moment* involved the continuous assessment of the signs and symptoms of altered mental status. *Using Tools but Using Judgment* described the various strategies that nurses used to assess their patients.

The theme *Keeping Patients Safe: It's a Really Big Job* reflected the challenges nurses faced when the patients were disoriented, agitated, or unable to protect themselves. This was more challenging with physiologically unstable patients, and when patients had multiple indwelling devices that could be dislodged. Two categories emerged. *Keeping an Eye on the Patient* was a continuous requirement and made delivering nursing care and other duties, such as covering other patients, difficult. *Knowing When and How to Respond* involved the nurse using his or her judgment to know when to intervene on behalf of the patient's safety, and how to prioritize interventions. This category also includes nurses' descriptions of using chemical and physical restraints.

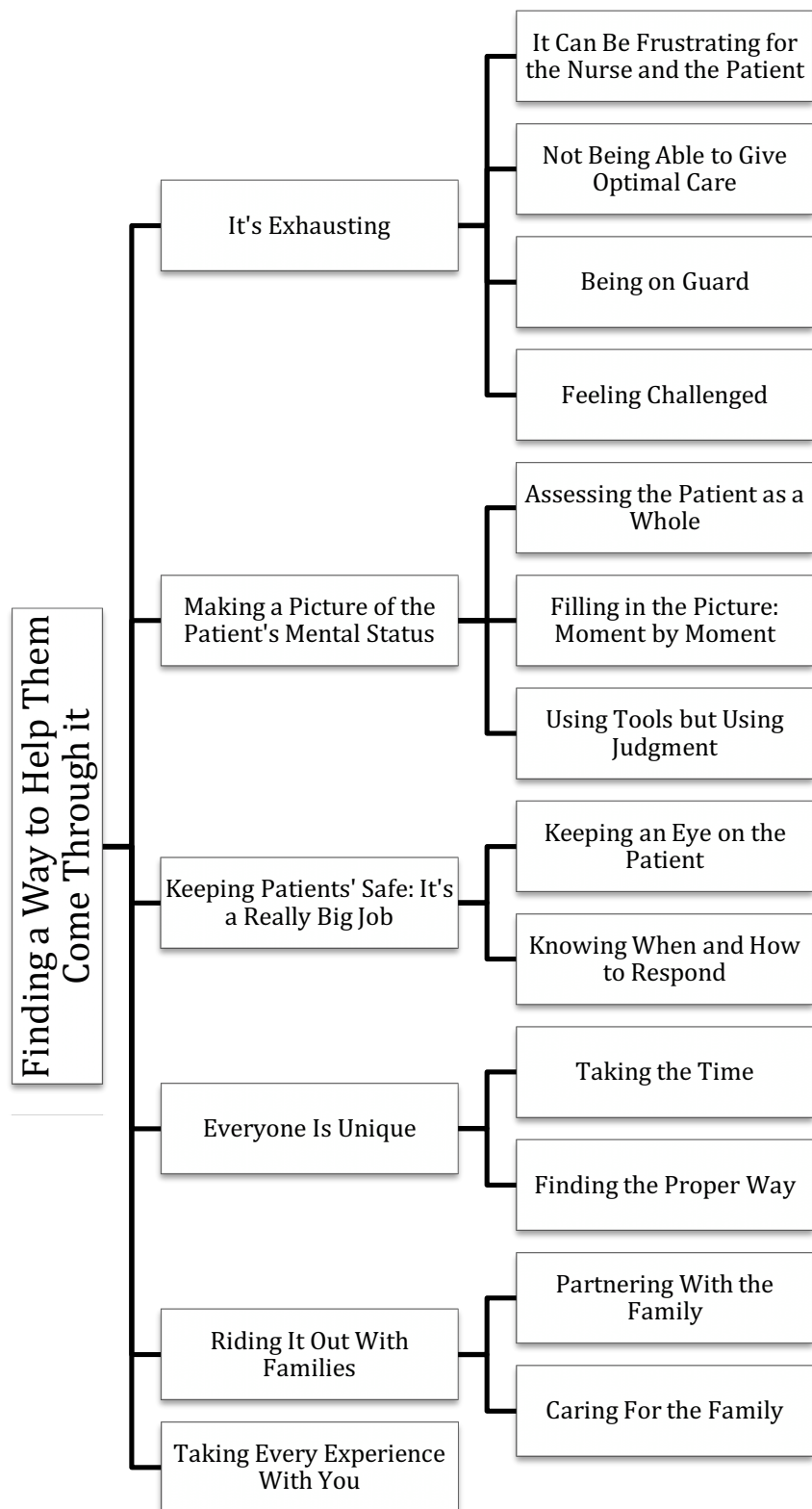
The theme *Everyone is Unique* captured the efforts nurses made to provide person-centered care. Two categories emerged. *Taking the Time* involved the efforts nurses made to understand these patients and who the patient was at that moment in time. *Finding the Proper Way* represented the process of trial and error nurses used to find effective strategies for the patient's individualized care needs. This process included using knowledge, clinical judgment, and expertise to tailor standardized practices, such as the institutional delirium protocol, to patients' individual needs.

Riding it Out With Families captured the experiences that nurses shared with families. *Partnering With the Family*, as a category, described nurses and family members working together to care for the patient more effectively. *Caring For the Family* involved nurses providing direct emotional and educational interventions for

family members. Participants described moving back and forth between these roles, but knowing when and how to do so could be difficult.

Finally, *Taking Every Experience With You* captured the process of learning to care for these challenging patients through experience. Nurses used their experiences to inform the nursing care they would provide and to develop their skills and expertise over time. (See Figure 1. Overview of Themes and Subthemes)

Figure 1. Overview of Themes and Subthemes



4.2 It's Exhausting

Nurses described the experience of caring for these patients as an exhausting day at work. Joanne stated, *"I find it difficult when you have a delirious patient. You get home and you're exhausted because you had a really hard day."* Participants described feeling mentally, emotionally, and physically exhausted when they cared for disoriented, agitated and combative patients. These patients were uncooperative with interventions, unpredictable, and at times put themselves and the nurses at physical risk. Participants described hectic shifts when *"you didn't stop for two days"* (Joanne), feeling *"tired"* (Joanne), *"worn out"* (Gail), and *"frustrated"* (Steven, Joanne, Gail, Donald, Gary, Jessica). The additional mental, emotional, and physical effort required to care for these patients could still lead to unpredictable results for the patient. Gail stated simply, *"I think it's very difficult in caring for them because you are never quite sure what's going to happen in a day to them."*

On the one hand, nurses described a variety of reactions during their difficult days caring for these patients including feeling frustrated, feeling unable to provide the care, and being on guard. On the other hand, several participants described feeling energized by the challenges of caring for these patients and satisfaction when they felt they were able to help the patient.

4.2.1 It Can Be Frustrating for Nurse and Patient

It Can be Frustrating for the Nurse and the Patient described the experience of declining patience on both sides as nursing responsibilities, patient care needs, and the patients' desires continually conflicted over the course of a shift or several shifts.

Participants shared many examples of encounters with disoriented, agitated and combative patients and gave vivid descriptions of challenges and mishaps:

She was wild. Absolutely wild. Despite having arm restraints she managed to get out the end of the bed. Trying to smash her aircast onto the ground. Then we were having trouble with her blood pressure, with her heart rate. She was totally incoherent and you couldn't reason with her at all and she had no clue that she was doing any of it. (Gail)

Steven summarized the familiar experience of caring for these patients:

Most of the stories are all the same. The worst one is when they have no idea of where they are and their main goal is getting home. It doesn't matter what you tell them or what they're hooked up to, they're climbing out of bed. And when they're hooked up to art lines and central lines and if any of these get pulled out they're going to bleed and it could be dangerous. So you're constantly going back to the bedside. It doesn't matter if there are physical restraints or chemical restraints. They have one mission. It's getting out of bed.

In addition, Steven described how the frustrations could accumulate over the course of a day:

You just feel drained. Your patience is gone. Your ability to tolerate it just slowly declines and you get angrier and frustrated and at the end you've had enough. You think that if you had to do another hour you just couldn't. You'd have to just walk away. I think the worst part is you'll slowly start to lose your patience. It's frustrating for the patient and for you.

Participants emphasized the importance of getting help from colleagues when they were caring for these patients:

It gets tiring very quickly. I remember looking at my watch and it being about 9 a.m. and at that point I already had two other nurses come in, I think three other nurses plus an orderly. There's already about four of us in there. (...) Yeah, it's good to have support because even if you're only one to one. Still, you're responsible. You do need help. (Ben)

Joanne described some of the reactions from the patients:

Well, it's frustrating. It's frustrating and it's sad because I know it's very scary when you wake up in the ICU. Especially when you're intubated. With all the drugs - all the side effects - you wake up you don't know anybody. You don't know where you are. It's scary for them.

Other participants echoed Joanne's comments. Gail described "feeling sorry for patients because it's not their fault". Gary stated, "It's really hard at that point. You know they're not normally like that and personally I find it's really difficult."

Several participants expressed relief when they could get a break from these patients both during the shift and for consecutive shifts:

I do OK with them. Not for four shifts though. I think you get really mentally and physically worn out. Two shifts is fantastic whether you get a handle on the patient or not but when you step away from the bedside there's a relief. 'Thank God I'm done with that patient!' It's always good to have someone follow you and give a different perspective.

Some participants reported that being able to request a change of assignment for a subsequent shift was helpful (Gail, Steven, Joanne).

4.2.2 Not Being Able to Give Optimal Care

Participants stated that they were sometimes unable to deliver optimal nursing care for these patients due to the patient's inability to communicate meaningfully, and/or the patient's restlessness and lack of cooperation. Jessica stated:

Normally [you identify patients' needs] through communication and by the body language and by the way they look. If I find the patient's in the delirious stage, I'm not sure whether that's what they really need. There may be some hidden needs that are very necessary that I can't identify. I would not be able to give them the best care that I could so I find this is quite hard.

Not being able to give optimal care left nurses with a sense of dissatisfaction, or "not having done their job". Jessica stated, "*When [the patient is] all over the place it seems like you have not done your job (...) you did not meet the needs.*" Gary described how he was bothered that he might not be able to provide optimal care, "*I know at one point there could be trouble. At one point I will not be able to provide my care properly. I know that if something happens, 'Well I'm his nurse. I'm supposed to be there.'* (...) *You feel responsible for that.*"

Another reason two participants believed they could not give optimal care was due to lack of team consensus on how to manage restless, agitated and/or combative patients. Donald felt distressed about patients being "stigmatized." He stated:

I find that people are quick to stigmatize them. (...) I would get report that this person is 'crazy'. 'Excuse me!?' You cannot say that. It's almost an ethical thing. I personally have a hard time with that because I think it's not right.

Donald described feeling "unsupported" at times and disagreed with interventions of some other team members, "*I don't believe the proper assessments are in place. I feel they [other nurses] over-intervene, excessively intervene with medications and restraints.*" He was further frustrated because, "*I have no idea how to address it.*" Alan expressed similar concerns about the need for a cohesive team approach to maintain continuity of care for challenging patients. It was important, though not always easy, to gain consensus among health care team members on a plan of care. He stated:

You also have to sell it to your colleagues who then come on the day shift or the night that, when you're not there say, 'Can we please all try and do that same?' So we have the consistency there?' You have to sell it to your colleagues. Hopefully you get someone there with experience as well, and who has a good set of nerves and who (laughing) has a willingness. (Alan)

4.2.3 Being on Guard

Participants described 'being on guard' when caring for disorientated, agitated, and combative patients in order to maintain their personal safety as well as the patients' safety. However, being on guard sometimes meant keeping a physical distance and could interfere with providing optimal nursing care. Gary stated:

It's really difficult because we're trying to give care to help the patient but with delirium it's really hard because they fight with us or be a danger for themselves and to us at the same time. It's time consuming, emotional, and we're always on

guard every time that we need to do something. Sometimes the care is not being done and it could be harmful to the patient.

Steven described this as "watching yourself"

If you get report that this patient is going to be fighting you and aggressive. You just get this feeling, 'Oh this is going to be a long day.' You know that it's going to be a lot of watching yourself. When you get close to the bed you're a little more cautious of where his feet are if he's going to be kicking or spitting and all that stuff.

4.2.4 Feeling Challenged

Nurses also expressed positive reactions to caring for these patients. They described "challenging" and "rewarding" experiences when they felt they were able to manage the patients successfully, even if the patient's symptoms of disorientation, or agitation didn't fully resolve. Alan stated, *"I find it is a challenge but I like that challenge because I find it very rewarding and I can just calm my patient with talking."* Taking on the challenge was easier when the nurses felt they had support and "a plan" for managing the patient:

If they've been delirious for a few days now and they have been receiving treatment for it. You can say, 'OK I already have my Haldol order. I don't have to chase anyone down to prove a point and get orders for Haldol. So that's already on board. I have a plan for this'

Several nurses described the experience of caring for these patients as "rewarding" or "satisfying" when the patient's behaviors became more cooperative, or when the patient began to show signs of improvement. Steven stated, *"It's satisfying when*

you can see them coming out of this fog. You feel you've accomplished something." Ben recalled the rewarding experience of seeing a patient's agitation resolve:

It's nice to see immediate results of your actions. Being able to make a change that you feel was for the better. Even if she is still delirious because I think she still was. Whatever was in her system was still in her system. So yes, she's still delirious but she's not unhappy anymore. It sounds dumb - as simple as making someone happy. They're content now. They're in a strange place that they don't know of but at least they're not unhappy. Everything medical aside. Back to being a basic human being. That difference was made.

Overall, several participants considered care of these patients as just a part of nursing. These participants affirmed their enjoyment of their work while they were recalling their experiences. Donald felt good about his work when it was difficult: *"It's frustrating. You've tried a few things and it's not working. It's frustrating. 'What else can I do?' But I feel wonderful that I get to take care of them. Mixed feelings but mostly good. I enjoy my job."* Joanne expressed similar feelings about enjoying her work, *"I know I'll have a busy day but you can't always have a perfect day. And my goal is to help them get better."* Alan echoed this sentiment, *"It's being a professional. I am here to help and care for a patient and it's something I feel very strongly about."*

4.3 Making a Picture of the Patient's Mental Status

Making a picture of the patient's mental status was a dynamic process that extended beyond the four hourly assessments mandated by the ICU routine, into nearly any interaction with the patient. Nurses assessed the patient as a whole by considering their current mental status in the context of the patient's medical history, clinical course,

and current plan of care. Nurses drew upon professional knowledge and their previous experiences with patients as well as additional information from family members to augment their assessments and observations. Nurses filled in more details of this picture by taking careful note of behaviors and monitoring for signs of altered mental status during their encounters with these patients. Tools for assessing mental status, such as the CAM-ICU, were used differently by different participants. Those participants who used the CAM-ICU to assess their patients described needing to exercise judgment in order to obtain reliable results. Considered together, all of this information helped nurses to make a picture of a patient's mental status in the moment. This picture was continually revised and updated as new information became available. Alan described his overall approach to making a picture of the patient's mental status:

We have our tools in the ICU like our CAM score or our Richmond Agitation Scale...But also by just observing the patient. See how he is responding. When you see family at the bedside and how the patient is interacting with their family. Like if they're starting to wake up and you just ask a couple questions see how oriented they are. Can they answer simple questions to date and time? Or to what's the year? Where are they? And you sort of start making a picture of how their mental status is.

Participants observed that the term "delirium" did not sufficiently describe a patient's mental status. Nurses sought out additional information, performed repeated assessments, and kept close observation in order to care for these patients. Ben stated that he considered "delirium" to be like an umbrella that triggered him to ask even more questions:

Yes, I'm dealing with a patient who is delirious that kind of brings up an umbrella, but what end of the spectrum are we at with that? Is this an acute change? Has this patient just been admitted? Where everything's still up in the air? We still don't know what's going on? Or is this someone who's been here a while? Have they been trached? They're on a low amount of sedation and we can give them Haldol if we need it? How do I feel when I come on when I have a patient who's delirious? I think if anything it brings more questions to mind. [It] doesn't really label you as well, there's still a lot more to it. Like say you're treating a patient with MODS [multiple organ dysfunction syndrome]. Great they have MODS. Well which systems are affected? What was the primary cause? What are we doing about it?

4.3.1 Assessing at the Patient as a Whole

Assessing the patient as a whole encompassed the empirical knowledge and previous experiences that the nurses used to make a picture of the patient's mental status. Holistic assessments included baseline level of function, medical history, current mental status, current illness and clinical trajectory, as well as past and present medical and nursing treatments. Additional information about the patient, such as their baseline cognitive status, was frequently sought from family members. Jessica describes her thought process when assessing the patient as a whole:

I go through head to toe. Is there anything bothering him like headache or other things? I check to make sure the physically is comfortable, all the needs are being met by the body language. If the patient is having a hard time breathing - the delirium could be due to hypoxia. It could be metabolic imbalance. It could be

some electrolyte imbalance. It could be some physical need and it could be medication. Review medication, go through head to toe physical assessment, check when was the last time they had a bowel movement, any urinary retention. So I would rule out all these and say 'Ok, are all these met? Is the patient safe? Is the patient stable?' So along with the medical team and the nursing team we just wonder about all these. Maybe this acute delirious stage is due to acute psychosis due to environment changes. Maybe the combination of medication side effects or maybe the new onset of sepsis. Along with that, in my mind I just look at the patient as a whole - physically, mentally and psychosocially - and see what we can do to correct it while we buy some time to protect the patient's safety.

Nurses obtained additional information on patients' baseline functioning from family members to know "*what is normal for him*" (Gary). Gary further described how he engaged patients' family members to help him assess and monitor his patient's mental status:

Well sometimes I'm going to ask them [family members] to ask just basic questions. If they are a close member of the family I say, 'Just ask him if he remembers your birthday when you talk to him.' Like basic communication; not something too complicated. Like 'I feed your cat, do you remember your cat's name?' and all that stuff. Sometimes they do sometimes they don't [remember the cat's name]. So as soon as the family finds that he's confused they come to tell me.

Many participants identified through their experiences those groups of patients whom they considered to be at the greatest risk for developing delirium. These included those with trauma (Alan), brain injuries (Alan, Gail), psychiatric history (Gary), alcohol

and substance use (Gary, Jessica, Gail), chronic pain, older patients (Gary, Gail), as well as patients who had prolonged intubation (Alan) and/or poor sleep (Gail) during their ICU admission.

I think that ties back to experience. You look back in the chart; see how long a patient was intubated. You look at the patient's age. You look at their type of injury or illness and the circumstances of their admission. If someone has a trauma (...) and they suddenly wake up in an ICU they've been...they've got tube down their throat, they can't talk, they don't know where they are. Those patients tend to be a lot more delirious than someone who comes in for an elective surgery. (Alan)

4.3.2 Filling in the Picture: Moment by Moment

Participants emphasized that patients' mental status could fluctuate over the course of hours or days and that changes for the better and worse were often sudden and unpredictable. Nurses continually observed patients for signs and symptoms of altered mental status to fill in the details of the picture. Assessing mental status in patients with decreased level of consciousness from critical illness, as well as those with communication barriers from endotracheal intubation, was challenging. However, nurses noted the subtle signs when their patients were "*not understanding*" what was happening; when patients were agitated, resistant, or combative, and when patients were disoriented.

Nurses took note of disorientation during their interactions with patients, even when patients were oriented to person, date, and time. Engaging patients' families for additional information also helped nurses to fill in the picture. Steven described one such scenario:

You're finding out if they know why they're here and what's happened to them. Like ask questions about the family and see if they get questions right. Sometimes they'll talk about their kid as if they're still five but they're actually 30 or 40. You know that their timeline is all just dis-conjugated because they might get the date right and think that their kid is five years old but they're not. Sometimes they can get all that right and you ask them about something about the country or the prime minister but they don't know - things that they should know. They might answer three questions perfectly fine and you might chart down that they're not delirious but then they'll say weird things too, 'What's that there tractor on the ceiling?' You answered all the [orientation] questions right but you think there's a tractor up there? I don't know if it's just the different states that delirium can take.

Filling in the picture included assessing the patients' behavior, which could range from confused but calm and "fine" to agitated combative patients who could be "wild". Ben recalled his experience of caring for a confused patient who was no longer agitated:

She was fine. Then she started re-telling stories about her past and I sat there and listened. And you think 'This is nice'. I asked her questions. She's very happy. You tell her where she is and she's fine with it. She'd tell you the same story four or five times. Was she still delirious at that point? Yeah probably, she was telling me the same story four or five times... the acute aggression was gone.

On the other hand, many participants gave examples of encounters with agitated, combative, or aggressive patients. Gail stated:

He wouldn't obey commands. Didn't know he was in the hospital. Always fought you even with turns and was always resistant. And of course he was 280 pounds.

You had to be careful where his arms were because he could at least use one arm at that time so you were never sure if he was going to come out swinging with that arm. By the third shift he hadn't slept at all, so we were going on three days and now what? Because he was still being ventilated. But even his eyes, he just looked wild. He would look at you and had no understanding at all. 'I'm your nurse. I've been looking after you' and it didn't matter at all.

Nurses described how a patient could go through several changes over the course of ICU admission:

I've had patients...we'll extubate them and they'll be clear one day and without any changes in the medications the next day they're confused and spend a week being confused before they clear back up. I've had that happen a few times actually. (Steven)

Nurses made note of small improvements in patients' mental status such as the patient becoming increasingly oriented to place or time or situation, or becoming less combative over the course of a shift or a few days. These signs were often subtle but they indicated that the patient was "coming to." Joanne described the signs that a patient was improving: "They're calmer. They're less confused. They don't hallucinate as much. They start to remember more things. Their vital signs are better. They're just calmer and not as confused." Again, information from family members helped to fill in the details of the picture. Steven described his observations and those of a patient's wife:

He was calmer. Things seem to start to come back as to why he was in the hospital. Start to recall the surgery that he had whereas before he didn't know what he had, where he was. But all of a sudden he knew what had happened and

then he was able start getting the date right. Sort of turned into just your standard questions date, time, place. The wife's background stories too. Yeah, the wife would say 'He's starting to remember when this happened'. She would say too that she could tell he was coming to.

Some participants described difficulty communicating these moment by moment assessments of the patients' mental status to the medical team. This was particularly problematic when the lack of recognition of the nurses' assessment by the medical team that led to delays in the patient's treatment. Gail described not being able to "get through" to the medical team when caring for a patient with episodes of severe agitation and physiologic deterioration:

I just couldn't get through to them because whenever they came by she was sleeping. Could never capture the moment when she was going out the end of the bed or talking gibberish or screaming. No one was ever around (. . .) It's not like we have someone around that we can capture that moment. They finally - like it took all day - until 6:30 at night when she wasn't looking well at all and it was like 'Oh my goodness!' that they believed you. 'No, you were right'. 'Well yeah, I told you that.'

Nurses used different strategies to communicate with the medical team. Gail would call the physician to the bedside to "capture the moment" whereas Ben used the CAM-ICU findings to help him communicate more effectively. He stated, "I get people to believe me by objective evidence [emphatic tone- laughs]. So, using your CAM tool" (Ben).

4.3.3 Using Tools but Using Judgment

Evidence-based tools such as the CAM-ICU, when used, required additional considerations and expertise to be applied effectively. For example, not all participants described using tools such as the CAM-ICU to assess mental status. Participants who did use the CAM-ICU varied significantly in how they applied it in everyday practice. All of the nurses who used the CAM-ICU in any way supplemented the findings with other assessments to make a picture of the patient's mental status.

Alan didn't find the CAM-ICU helpful to assess patients' mental status. He associated the CAM-ICU tool with "*a data collection thing*" and expressed frustration with the requirement to use the CAM-ICU:

I always have a hard time with getting so much paperwork in nursing care. We have to fill out forms, we have to sign here we have to sign there. It becomes sort of a cookie cutter nursing. Where is my professional autonomy here? I've trained to become a nurse. I've got work experience. Where has all that gone to? If I just follow a sheet and have to answer some pre-written questions and tick them off and add up the numbers and I say, 'That patient is delirious.' But every patient can fake an answer. It's not the real world. Where is my professional opinion if I'm just adding up numbers? (. . .) We suddenly have to fill out all those forms and you get reprimanded: 'You haven't filled out this form. You didn't do this. You didn't use that tool to assess the patient.' We are doing a lot of data collection in the ICU now.

Steven used the CAM-ICU to assess patients but mistrusted the results. He stated, "*For some reason I don't have a lot of faith in that CAM.*" He gave an example of when the CAM-ICU results appeared to contradict his other assessment findings:

I guess there are patients that'll be fine on the CAM and - whether there's been a change or not (. . .) but they could get all the questions right but still be seeing things everywhere, confused (. . .) There was one patient who was passing all the CAM tests but then was saying all those weird things like, 'my driver's downstairs' [mimics a conversation] 'Do you know where you are?'/ 'Oh yeah, I'm at the hospital.'/ 'Remember why?'/ 'Oh yeah I had surgery.'/ 'But you think your driver's downstairs waiting for you?'/ 'Oh yeah, yeah, my driver was coming by to pick me up at 2 so we can do something..' So even though they were able to squeeze your hands when you said an 'A', they didn't quite seem all there - even though they were CAM negative.

Gary noted a similar circumstance when he had sought additional information from family members, who thought the patient was confused but patient was CAM negative. "*sometimes [the patient] is negative as the CAM but, as the point of view of the family, they find [the patient] confused.*"

Joanne was uncomfortable using the CAM-ICU and recalled negative reactions from patients:

I never had the in-service on it so initially I was a little uncomfortable with it and the questions that you ask. Because sometimes you ask the patient and the patient looks at you and says 'Do you think I'm an idiot?' I've had a few patients say that.

She stated that she used the CAM-ICU with only some patients:

We're supposed to use it on everybody but I don't use it on a young person that's OK. We're supposed to ask them all those questions anyway and say they're positive or negative, but I just use it on older people and somebody who does look a little bit confused (. . .) If they're disoriented to time place person, if they're agitated, if they seem confused, hallucinating. Anything like that I do the CAM.

(Joanne)

Conversely, Donald was very positive about using the CAM-ICU to effectively assess patients' mental status. He recalled examples of when using CAM-ICU had helped him to detect delirium in patients "*And then I had delirious patients that I did not think were delirious, but through asking the questions... I thought, 'Oh my god this tool really works!'*" Donald also emphasized the importance of considering other factors that could affect the accuracy of the CAM-ICU findings, such as the patient's emotional ability to participate in the assessment. Donald described using his clinical judgment as knowing "*the right time, the right context, the right environment*" to do an assessment.

4.4 Keeping Patients Safe: "It's a really big job"

Nurses described the considerable efforts they took to try and ensure patient safety. Maintaining the safety of patients in their care was a central and pervasive concern. One participant described it simply as "*a really big job*":

But just the nighttime...when he started to get really agitated and restless. He totally could not recognize any person now and [he was] just agitated and just keep climbing out of the bed... and just keeping him safe is a really big job...

(Jessica)

Patients who were restless and disoriented were seen as at risk of seriously harming themselves by falling out of bed or pulling out medically necessary invasive devices. Several participants recalled experiences with such adverse events. Gary described the scenario following a self-extubation:

Patient extubates himself. Patient's not doing well so you need to get all the stuff ready to re-intubate the patient. You need to sedate him more to be able to re-intubate him. Then stuff happens like low blood pressure because of too much sedation. You need to start other kinds of medication... levo [norepinephrine], phenylephrine, and all that. He was doing well but because he extubated himself or pulled out line.. He had another kind of set back... and this is another kind of procedure. So it's not just time consuming for the nurse... but it's time consuming for the doctor that needs to re-intubate the patient or put back the Uldall [dialysis catheter]... or just a triple lumen [central venous catheter]... So you mobilize lots of people just because the patient pulled something.

4.4.1 Keeping an Eye On the Patient

Keeping an eye required the continuous physical presence of the nurse to ensure the patient did not remove indwelling medical devices or otherwise harm him or herself. Nurses found it necessary to maintain continuous observation of these patients. Several participants referred to this as "keeping an eye" on the patient, which was quite difficult in the context of the day-to-day realities of nursing work and it was sometimes impossible to do alone. The participants described the difficulty of maintaining patients' safety when they needed to leave the bedside for care-related activities, such as getting medications from another location.

Gary describes how "everything could happen in a minute":

And since we have lots of medications, antibiotics and all that. Some antibiotics are inside the fridge, and the fridge - we have one but its in the middle of the unit. So it takes us about a minute to go and get the stuff and come back.. and with those kinds of patients, a minute... its like... everything could happen in a minute. Sometimes you're doubled so you have two patients you need to take care of. But as soon as you give care to another one, you need to make sure that the other patient is not doing other stuff that could harm himself. Now you need to maybe ask your buddy, 'Can you keep an eye while I do this' [...] But it's sure that as soon as we don't have eye contact on the patient... and he's really confused, agitated.. that's always like a time bomb...

Nurses described using everything at their disposal to try to maintain patient's safety including partnering with family members, forgoing other duties and, at times, sacrificing breaks in order to keep an eye on the patient.

Well just because you had to be with him all the time... so you couldn't... I didn't take long breaks because I was afraid that during my break that he'd fall out of bed.. So we get him up into a chair with a table in front of him for his safety because we can't really leave him in bed and leave. So you try to find ways to make him safer... It's just giving all the meds, staying with him, talking to him... and that's it... You call the family and see if someone can come and he sees familiar faces... it helps them... So that helps a lot when the family is able to come and sit with them. You feel that he's safer. (Joanne)

A one-to-one nurse to patient ratio was described as a key facilitator to keeping an eye on patients. Nurses sometimes struggled to maintain safety when they were assigned two patients. Additionally, several nurses commented that it was safer for these patients to be in the ICU, with a one-to-one or one-to-two ratio, than for them to be transferred to lower acuity areas where nurses had to care for even more patients.

When you have to check two patients at the same time it can still be dangerous but in the ICU it's a lot better than on the floors... because you're one-to-one and you have more time to sit with the patient and you try to find ways to calm him down... and don't have to be running from room to room... But just when you're covering... or doubled with a delirious patient I find it to be very stressful and dangerous. (Joanne)

4.4.2 Knowing When and How to Respond

Several nurses described knowing what was safe for a particular patient in a particular circumstance. Nurses continually assessed the patient and drew upon past experience and knowledge in order to prioritize nursing care that was responsive to the immediate needs and safety of the patient. Alan described his thought process while caring for an agitated patient whom he was trying to calm down without medication:

You sort of know what to expect and you know their physiology that they are relatively safe. You know that they can be hypertensive for a while without causing immediate danger. I mean it has to be obviously on your radar. It has to be in the back of your mind that you don't want to get him to be hypertensive for a long time but he's safe. He's still safe to do this. (Alan)

The participants spoke of knowing what was needed for a patient "right now" and how they balanced the emotional, psychological, and medical needs of agitated or uncooperative patients:

It means putting other things aside and treating the immediate needs... I'd like to go in there, if I'm going in to do a head-to-toe assessment, or I'm going in there to give a medication,... I'd love to do that but I can't do that... I have to divert my attention to helping them with whatever is happening right now, or letting them know who I am or what I'm gonna do... and if they're uncomfortable try to reposition them I'm coming in there to give a medication but I can't do that until - technically - until they let me. Fair on their part... But at the same time if you're in ICU in critical condition... we're not able to nurse you... then that's almost negligence on my part... I can't just say 'Oh, they refused their pip-tazo [piperacillin-tazocin] or vancomycin'... you know 'Don't worry about the sepsis', That's not good. At the end of the day you have to realize what you need to do. What you can kind of put off a little bit and balance it... (Ben)

All of the participants believed that chemical and/or physical restraints were at times necessary to maintain the patient's safety:

Sometimes you just have to physically restrain them... to make it safe for him and for you... It's not nice but sometimes you have to. We'll give medications for it... hopefully calm it down... Give Haldol... start a Precedex infusions... Things like that. And that might work for a little while. But I find eventually, I don't know if they get used to the medications, but then the delirium just sort of stays there... You're just sort of back where you were struggling with them... (Steven)

The participants' opinions about the relative risks and merits of physical and chemical restraints varied as did their opinions about the timing and use of either type of restraint. In a few instances, the lack of consensus among the nursing team led participants to feel frustrated or to mistrust other nursing colleagues:

I don't think someone needs... a couple milligrams of Haldol every so many hours because they're taking a lead, a wire, off their chest... I don't think in any world that's OK. Or physically restraining them. I have personally sat beside a bed and just held someone's hand for a couple hours... while I did other stuff... I could chart with one hand... and I did not feel... I found that it was excessive, over-excessive, what this one person [nurse] did. Giving all that medication... Yeah. It's not proportional... intervention to the behavior from the patient. (Donald)

One participant identified this lack of consensus as an issue that required a larger debate among the health care team:

We need to have a discussion every now and then amongst the team as well saying that ...'When is it OK to use a chemical restraint when is it not?' (Alan)

Nurses expressed reluctance to use both physical and chemical restraints but most participants considered chemical restraint as a "last resort." Reasons participants gave for avoiding using physical restraints included further physical harm from the restraint itself (Gail), or increased levels of agitation (Gary, Ben). Reasons given to avoid using chemical restraints included side effects (Joanne, Gail), the potential for "overmedicating" (Steven), and the possibility of prolonged intubation or ICU stay (Alan).

Joanne stated that, in spite of her reservations, she had "*no choice but to give*" sedative medication after she had "*tried everything*":

Well initially after I've tried everything I mean when they're confused and hallucinating there's not much you can do... You do try to calm them down but there's not much you can do... so you don't have a choice but to give it [medication]... and then depending on the frequency... I won't go right away and give some oral ...just wait and try to calm them down and see if it's going to work before I repeat it... But sometimes I do have to give a lot of meds... and like I'm against... I don't like to be giving too many meds to anybody. There's a lot of side effects for patients so that's my number one thing, I don't like giving medications... if you don't have to... if you can find other ways... (Joanne)

4.5 Everyone is Unique

Participants considered each patient, nurse, and situation "unique." Nurses used their knowledge of each patient to tailor their interventions for these patients; often drawing upon past experiences. In all cases, nurses needed to take extra time and attention to deliver effective care.

I find that everyone is unique and every patient is unique in how you care for them. As long as you have the support behind you. We're there to help them and we're there to support them, and when you have a great team behind you, you can do it. Most patients you hope do really well. Every day you come in it's always a unique situation. Some days I love it. Some days I don't (laughs). (Gail)

4.5.1 Taking the Time

Nurses needed to "take the time" to understand these patients in order to deliver effective care. Taking the time signified both the additional time spent doing patient care or communicating with patients, as well as a particular mindset that could be characterized as using "patience," (Gail, Ben), or "accepting" who the patient was at that moment in time (Alan, Steven). Gail described taking the time as *"being a willing participant to the care that you give to your patient."* She explained further, *"Instead of rushing and getting through everything you might have to take extra time to do things with the patient... and be calm and be kind to patients too."*

Communicating *"at the moment"* with these patients required both knowing what the patient could understand, and taking the time to repeat messages. Alan compared this to caring for young children:

You sort of try reasoning as much as you can with them. What's within their scope of understanding at the moment while they're delirious. That seems to work. You have to go over and over but again... same when you have young children. You have to repeat it and repeat it and repeat it. You can't get tired of it you just have to do it. But... it worked. And I think that you just have to stick with it. (Alan)

Participants described their mindset while taking the time to care for patients in a variety of ways including *"being present"* (Alan), *"letting them do their thing"* (Steven), and *"waiting it out"* (Donald). Jessica summarized this aspect of care as trying to *"sense in their world"*:

I think overall you have to be very sensitive, you have to be non-judgmental and just deliver care. And part of delivering care, as a nursing part, I try to be non-judgmental be sensitive. To feel how they feel and try to sense in their world and see where they're at. And try to understand their body language maybe there's some hint in their language that is something that'll remind me of what they really, truly need. (Jessica)

4.5.2 Finding the Proper Way

Many participants spoke of individualizing care to each unique situation. One participant referred to this as trying to "*tailor specific interventions to what the patient would need*" (Gary).

The participants provided many examples of strategies including: using a calm voice/approach; providing familiar objects, music, or people; recruiting family members to sit with the patient; frequent verbal re-orientation; manipulating the immediate environment by modifying noise and light; maintaining a day/night orientation; providing comfort by bathing, positioning, and pain management; setting boundaries and providing structure for patients; reviewing medications; mobilizing; and providing distractions.

Joanne recalled using a variety of strategies with one patient:

I'm good for that... I'll give him a bath and wash their hair, and if they're in pain I'll give them medications, which he wasn't [in pain], he was just delirious. Just make sure he's comfortable... Open the curtains also - during the day because especially in the ICU that's what makes them - they don't know if it's day or night... So just open the curtains so they can see it's daylight. (Joanne)

Some interventions were more unorthodox, Gail recalled using a novel solution for a patient who wasn't sleeping well: *"I mean we had a patient here who hadn't slept in five or six days... they were given permission to bring their dog in... The dog climbed up on the bed. Dog fell asleep. The patient fell asleep."*

Guidelines and best practice recommendations were not frequently referred to when the participants described caring for these patients. Their nursing strategies were not attributed to guidelines, recommendations, or protocols. Rather, they seem to have been acquired through experience. Further, when protocols were used, the nurses often employed their judgment to adapt the protocol to the specific patient and situation. Gary stated, *"(sighing) well, guidelines... There's the protocol [unit-specific delirium protocol] that we follow, the CAM for delirium, that's probably it for guidelines...and other than that, it's just judgment."*

Several participants were not aware of the unit-specific delirium protocol that was available in their ICU. Steven was unsure of whether there was a protocol but thought that a protocol would be helpful for guidance with medication dosing and obtaining doctor's orders:

At one point I thought we were coming out with a protocol for delirious patients and it had proper dosing of some prn Haldol and other things. I've never actually seen it. I thought at one point there was and maybe there is and it just never gets used. But at one point there definitely was talk of doing something like that. And that would be nice. Because I find sometimes one doc is hesitant to prescribe some of these drugs, from bad experiences that they've had or something. An actual protocol would be helpful.

The participants who had positive experiences with the unit-specific delirium protocol related its helpfulness to overcoming barriers for getting medication orders (Joanne, Ben) and for guidance with medication dosages (Ben). Joanne stated, "*you didn't have to bother the doctor because the protocol was there and you just followed the protocol. I don't remember everything that was on it but it was helpful.*"

Gary described how the protocol could be individualized:

For some patients yes it is [the protocol is helpful]. I find at the same time - because we know the side effect of Haldol and if it's the first time that we give Haldol to the patient - we always watch for side effects like long QTs and all that. Even if the protocol is in it's supposed to be the right way to treat it. If we are allowed to give the Haldol every 15 minutes, for example, they're going to say instead give it every 4 hours, so we give some treatment but it's on long term. Sometimes it works but sometimes it does not work. Sometimes it's better if we do follow the protocol properly for some patients and others - like for some small lady that's really confused... a little too much Haldol it'll just do the opposite and not be proper (. . .) I do think that the protocol does help if it's well managed.

(Gary)

4.6 Riding It Out With Families

As nurses described their experiences of caring for these patients they often referred to their encounters with family members. Riding it out with families involved two distinct aspects: Nurses partnered with families in order to care for the patients more effectively. Nurses also cared directly for families by supporting, educating, and

intervening when necessary. Steven described both of these aspects when he recalled caring for a patient and his wife over several days:

It was him and his wife. She was very concerned but very accepting. I just explained to her that he would come through this. She calmed down. She was able to talk with him a little more. He could still be very confused but she didn't try to fight everything he said or disagree or constantly try to correct him. And for the next two days - me and her - we just rode it out. We sat back. We let him be confused and if he wanted to get up we could get him up and down; and try to re-orient him here and there if he was getting really confused but just know that in a couple days it'll be better. And in that time it was. You could just see it over the next - I had him for four days and on the fourth day he wasn't completely clear but he was definitely clearing up. Didn't have to intervene with a whole bunch of meds. We just sat back, let it ride sort of thing, and then he cleared up. But it was getting the wife to understand that it was temporary and then once she was able to calm down, we just rode it out and it worked out fine. (Steven)

4.6.1 Partnering with Families

Nurses partnered with family members in order to care for these patients more effectively. Family members were described as "helpful" and a "resource" for the nurses. *"They're a great resource and they know their family member best and when they showed up at around 9:30 in the morning I was happy because I still needed more support"* (Ben). Several participants stated that having family at the bedside made it "easier" to care for these patients. Joanne explained: *"What made it easier? When the family came in and I asked the family what kind of music he likes so I put the radio station that he*

usually likes. You try to put some familiar things in front of him." Gary described how patients could be "calmer" with family than with the nurse: *"Most of the time the patients don't listen to us because they think that we're trying to kill them but they are really more calm with the family. We ask the family if they can stay. That helps us"* (Gary).

However, knowing how to negotiate the line between partnering with family members and caring for them could be difficult. Ben expressed uncertainty about caring for family members:

I notice that throughout the day that the family members' coping mechanisms are going as well. And I'm pretty new to ICU too but that's one thing I have picked up quickly here - is the family component and having to educate them and reconfirm things with them. I mean they're there to help too. They're a resource. They're definitely a part of the treatment team. But in terms of getting them help - I'll admit that's probably one of my weak spots and that's something I could work on. I've never had specific training on how to talk to family members, or how or what to tell them or how or when or any of that. You just figure it out as you go. But I think at least just recognizing - you can't do anything if you don't recognize coping mechanism failure. (Ben)

4.6.2 Caring for Families

Nurses recognized that dealing with these patients was distressing for family members and cared for their psychosocial and informational needs in addition to caring for the patients. Participants described providing support, education and interventions when necessary:

"The family comes to us, they're crying and saying 'My husband is not like that normally' and they always say, 'We're really sorry about that.' We try to explain to them, 'This is not your fault and this is not him really because we've given some medications that can affect his judgment'. It's hard for the family too - trying to take care and support the patient." (Gary)

At times, the needs of the family members could conflict with the needs of the patient.

Alan described feeling "torn" in this situation:

Then you see that the family is butting heads in front of the patient it doesn't help the patient. And sometimes you're spending more time with the family and taking them outside. To the point that you have to restrict visitation because it's not beneficial for the patient's recovery. So that makes it extremely difficult then to deal with delirious patient. You become so torn because you're getting influenced by the family's behavior and then you see the patient that you work with and you're trying to accommodate both of them. (Alan)

Ultimately, the needs of the patient were the first priority for the nurses. Alan describes recruiting another member of the multidisciplinary team to assist with a distressed family:

In the end you have to make a decision, 'What am I concentrating on?' And you have to concentrate on the patient because it's my patient, it's not the family I'm here for. I have to be here for my patient before the family. So you have to find - our social worker here is really good - you have to get our social worker involved early on, or our manager, in trying to defuse that potential situation." (Alan)

4.7 Taking Every Experience With You

Participants described learning to care for these patients through their professional and personal experiences. *Taking Every Experience With You* involved building up personal resources, skills and confidence to effectively care for these challenging patients. Gail stated, " *I think you've got to take every experience with you. That's what nursing's all about and you learn something new everyday.*" Through "trial and error" (Donald) "watching someone else deal with a patient" (Gail), and "drawing from every experience" (Gail), nurses built up a store of strategies they could try with patients to find out "what works well and what doesn't" (Donald).

Some participants described personal experiences, such as having a family member in hospital or being a patient themselves, as key sources of learning. These experiences helped nurses empathize with patients and provide more sensitive, individualized care. For example, Gail made additional efforts to protect patients' sleep as a result of her personal experience. She stated, "*I've put up signs saying 'Please be quiet' because a lot of people aren't used to noise. I think if you've had the experience of being a patient in the hospital you know what the noise level is like.*"

Nurses developed confidence by taking every experience with them. Confidence was key to effective care and led to more positive encounters, even with difficult patients. Alan described how his experience and confidence helped him to enjoy the challenge of working with agitated patients:

I think it comes with experience and with confidence. I think you can manage the patient quite well. Sometimes you just have to let him kick in the bed and let him kick his legs up and maybe turn upside down. I just let them do it as long as I can

safely manage him. So as long as I can maintain an IV access, and a safe airway and stuff like that. I'm pretty relaxed about it. I just let them do it. And I find I have I've had lots of success with that. I've been doing it for years and I feel confident taking them on. It's a nice challenge. (Alan)

Participants did not report learning about caring for these patients through structured teaching and learning activities. Some participants felt that they needed additional formal teaching, "*we need more information about delirium*" (Donald). Other sources of learning included daily rounds (Ben), discussions with physician colleagues (Gail), and previous mental health training (Donald).

4.8 Summary of the Findings

The essence of the experience of critical care nurses caring for ICU patients with delirium was revealed to be *finding a way to help them come through it*. This work was exhausting but could also be rewarding. Moment by moment assessment and individualized care strategies allowed nurses to consider the patient as a whole, accept them as they were at that point in time, and allowed nurses to find a way to provide safe and effective care. Participants in this study also found a way to help families come through it by both caring for and partnering with the family as they went through the experience of having a critically ill family member with delirium.

Factors that hindered nurses when caring for these patients included communication breakdown between the interprofessional team, lack of consensus among the nursing team, high workload, not being able to keep an eye on patients, dealing with agitated and combative patients, lack of knowledge about delirium, and difficult family dynamics. Factors that helped nurses included good communication among the nursing

and the interprofessional team, achieving consensus and consistency in the approach to care, accepting patients as they were in the moment, being able to keep an eye on patients, and being able to successfully partner with family members.

Despite the challenges of caring for ICU patients with delirium many of the participants found it rewarding to work with these patients. The findings of this study revealed that critical care nurses caring for ICU patients with delirium find a way through many complexities to provide person-centered care.

Chapter 5: Discussion

5.1 Introduction

This chapter discusses the findings of the study in the context of current literature.

Discussions of the essence of the study "*finding a way to help them come through it*" and the main themes and factors which influence the complexity of caring for patients in ICU with delirium are presented. Implications for nursing practice, policy, education, and future research are put forth and the limitations of the study are described.

5.2 The Experience of Caring for ICU Patients with Delirium: *Finding a Way to Help Them Come Through It*

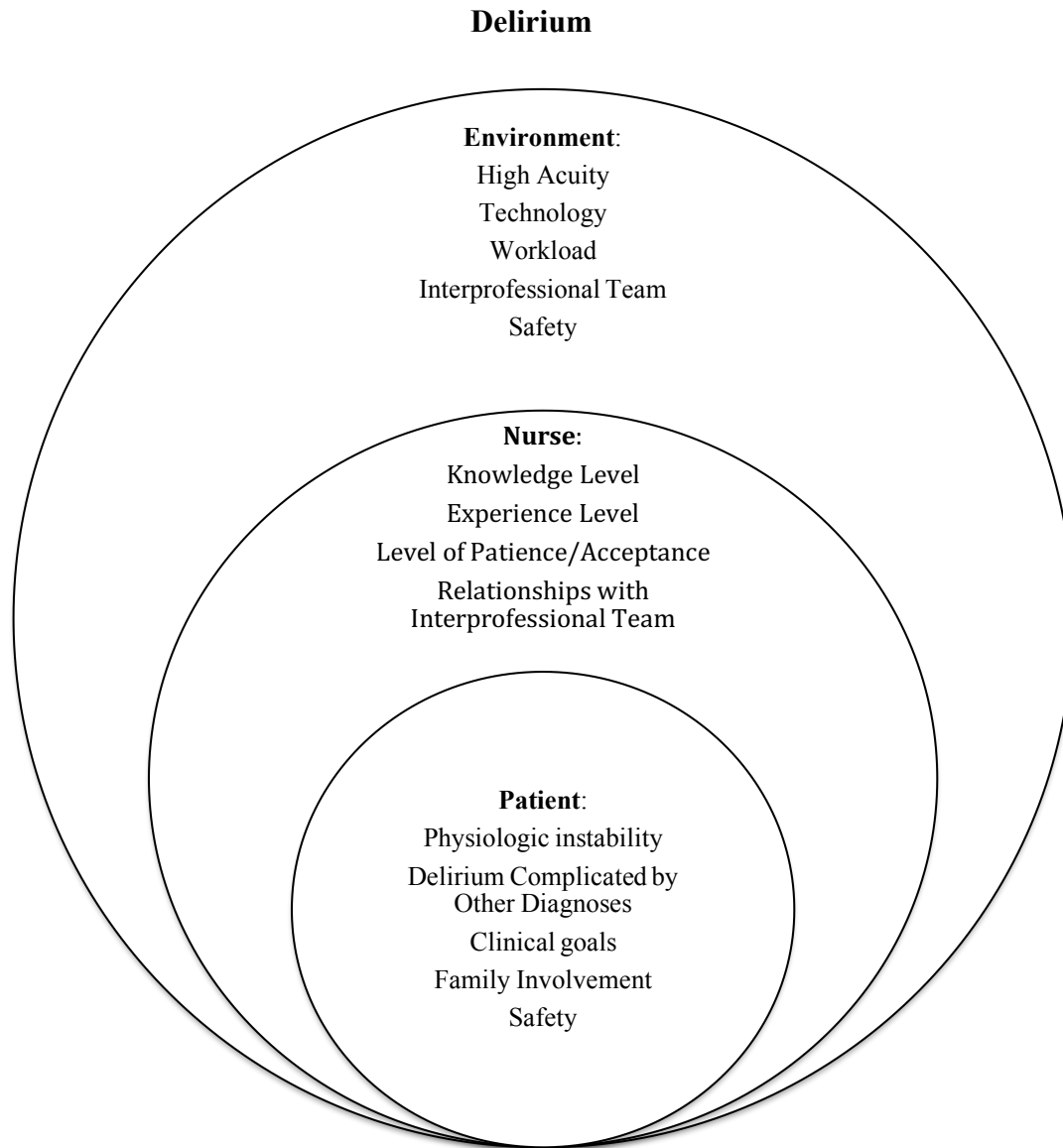
This study examined the experience of caring for ICU patients with delirium from a nursing perspective. The essence of the experience was revealed to be "*finding a way to help them come through it.*" Nurses in this study used their knowledge and expertise as well as their personal resources in order to assist patients in ICU with delirium, as well as their families, to come through an unpredictable and often distressing situation. The findings of this study reveal that caring for patients in ICU with delirium is complex due to the intensive care unit environment; the patient's critical illness, safety concerns, and the family distress; health care team dynamics and communication; as well as inconsistencies in nurses' knowledge about delirium and delirium assessment tools. Nurses found it mentally, physically, and emotionally exhausting to negotiate all of the factors that contribute to this complexity in order to provide patient-centered care, but doing so was also rewarding. Nurses assessed patients' mental status moment by moment, which sometimes conflicted with the application of the standardized delirium assessment tool required by the ICU policy. However, learning how to provide effective, patient-

centered care for patients in ICU with delirium was not limited to training and education about diagnostic criteria and standardized tools. It included learning to negotiate all of the factors that contribute to complexity as well as learning to work with families.

5.3 The Complexity of Caring for ICU Patients with Delirium

Lived experience is context specific. Therefore, the participants' personal interpretation of the experience of caring for patients in ICU with delirium was bound by the nature of the ICU being a highly technological and interventionalist space in which they worked, resources available and the relationships of team members, patients and families. Their experiences were multi-factorial and complex in nature. Participants' experiences were contextually bound and inclusive of both past and present experiences. In the present study, these contextual factors were identified and grouped into three categories: the environment of care; patient-related factors; and nurse-related factors. The researcher and thesis committee identified these factors by reflecting on the commonalities among the participants' responses as a whole. These factors, which were present in some way in all of the participant interviews, influenced the participants' experiences of caring for patients in ICU with delirium. Figure 2 illustrates the researchers' interpretation of the factors contributing to complexity of care that the nurses must navigate in order to *find a way to help them come through it*. Three distinct categories are represented in the figure as intersecting circles. The intersection of the circles indicates that these factors interact within the circle, and can also interact with factors present in the surrounding circles. In this view, the complexities of the critically ill patient interact with the complexities for the nurse caring for the patient that, in turn, interact with the complexities of the critical care environment.

Figure 2: Factors Contributing to the Complexity of Caring for Patients in ICU with



5.3.1 The environment of care.

The participants in the present study described caring for patients with delirium in ICU as "exhausting," mentally "tiring", physically and emotionally taxing, and "frustrating". These descriptions demonstrate the significant workload that is associated with managing disoriented and agitated ICU patients. All of this takes place in the context of potentially life-threatening illness, high technology, family distress, and

interprofessional team care. Every factor adds to the complexity that the nurses must navigate to meet patients unique needs.

Several participants described caring for patients who became agitated "all of a sudden." These patients sometimes dislodged essential devices such as the endotracheal tube connected to the ventilator, thus becoming a danger to themselves, or to staff by striking out. Once nurses had recognized an alteration in mental status they described feeling "on my guard", and felt the need to maintain constant surveillance, or to "keep an eye" on these patients to maintain safety for patients and themselves. This surveillance was unremitting throughout the shift or during consecutive shifts. The nurses were frequently unable to leave the bedside, even for brief activities such as retrieving medications from another location, or helping with other patients, because "everything could happen in a minute." One participant described "charting with one hand" while he held onto the patient with the other hand for much of a shift in order to prevent the patient from injuring himself. This constant surveillance was a source of strain for the participants.

The finding that nurses experience increased strain and workload when caring for these patients is consistent with the results of other studies (Jung, et al., 2013; McDonnell & Timmins, 2012; Yue, Wang, Liu & Wu, 2015). ICU nurses have reported experiencing tension, embarrassment, and lack of knowledge of delirium (Jung et al., 2013; Yue et al, 2015). Similarly, caring for delirious and confused patients in non-ICU settings has been associated with increased strain and has been recognized to be emotionally and psychologically taxing (Andersson, Hallberg & Edberg, 2003; Brietbart, Gibson, & Tremblay, 2002; Rogers & Gibson, 2002). This is especially the case when patients

exhibit hyperactive symptoms and visible emotional distress (Brajtman, Higuchi, & McPherson, 2006; Brietbart et al., 2002; McDonnell & Timmins, 2012). In spite of advancements in identifying the risk factors for delirium, and evolving recommendations for the pharmacologic and non-pharmacologic management of these patients (RNAO, 2010b; National Institute for Health and Care Excellence [NICE], 2010), a recent survey of nurses in Ireland suggests that there is still significant strain associated with caring for these patients (McDonnell & Timmins, 2012). Nurses feel responsible for patients' safety and feel empathy for patients and their families when they are distressed which, in turn, increases nurses' mental and emotional work (Andersson et al., 2002; Brietbart et al., 2002).

ICU environments are characterized by large interprofessional teams, yet interprofessional communication was a barrier to caring for patients with delirium. Nurses described not "being believed" by physicians when they communicated their assessments of the patient's mental status. Some studies have found that nurse-physician communication about delirium was improved when objective tools, such as the CAM-ICU, were used (Eastwood et al., 2012). One participant in this study used the CAM-ICU to "be believed." Conversely, several studies have suggested that physician engagement can continue to be a barrier even when nurses are using objective tools for assessment (Barr et al., 2013; Law et al., 2012; Soja et al., 2008). Nurse-physician communication is a complicated matter in hospital based systems which can support hierarchical communication processes (Crawford, Omery & Seago, 2012). Accurate delirium identification and good management can be enhanced with effective interprofessional communication and collaboration.

5.3.2 Nurse-related factors.

The nurses' level of knowledge and skills related to critical care in general, and of delirium and delirium assessment tools in particular, influenced their ability to assess and manage delirium. Personal factors, such as the nurses' ability to care for these patients with acceptance and patience, as opposed to frustration, influenced interactions with patients and the ability to establish therapeutic relationships. Nurses' relationships with their peers and the other members of the interprofessional team; their level of confidence and their ability to communicate effectively with patients, families, and other health care providers are integral to caring for ICU patients with delirium.

The nurses in this study described learning to care for these patients through experience, and with the guidance and support of more experienced nurses. However, they indicated limited formal education on care of patients with delirium. Studies about nurses' skill and knowledge acquisition in relation to delirium have tended to focus on delirium assessment tools and have investigated traditional teaching/learning methods such as lectures, webinars, and bedside in-services (Eastwood et al., 2012; Gesin et al., 2012; Soja et al., 2008). Research on the role of experiential learning for nurses caring for delirious patients in ICU, in regard to delirium assessment as well as other aspects of the care of this patient group, is lacking.

All of the participants in this study may have had knowledge gaps in relation to the complete spectrum of delirium, which includes hyperactive, hypoactive and mixed forms. They described patients who were disoriented, and agitated, or combative. Two participants used the word "wild" (Gail, Ben) in their stories, to characterize the experience of caring for a delirious patient. This powerful word evokes notions of danger,

unpredictability, and chaos and it refers to the experience of caring for an agitated, combative patient. Yet hyperactivity is identified in the literature as a state present in only a minority of ICU patients with delirium (Barr et al., 2013; Peterson et al., 2006).

Few of the participants' responses referred to patients who could be characterized as having hypoactive delirium or the "quiet" subtype, which is identified as the most common presentation in ICU and is associated with poorer patient outcomes overall (Barr et al., 2013; Peterson et al., 2006). The fact that the participants in the current study appeared to equate delirium with hyperactive symptoms signals a concerning trend. Previous research has demonstrated that many critical care clinicians continue to have the misperception that delirium is synonymous with hyperactive, agitated behaviour (Barr et al., 2013). This misperception has been identified as contributing to point-of-care clinicians' missing hypoactive delirium altogether unless they are assessing patients in ICU using an objective tool such as the CAM-ICU (Devlin, Fong, et al., 2008; Soja et al., 2008).

Participants in this study identified lack of consensus among the nursing team as a barrier to caring for these patients, particularly when managing agitation. They expressed frustration when other nurses intervened with agitated patients in a different manner than they themselves would have done. Several participants in this study stated that there was a need for an agreed-upon approach to managing agitation, both pharmacologically and non-pharmacologically, in order to maintain the best care for patients and to minimize conflict among the team. Consensus at the unit level should be sought with the aim of consistently using best known practices, in order to minimize practice variation while still

allowing the flexibility to address patient's individualized care needs (Barr et al., 2013; Belanger & Ducharme, 2011).

5.3.3 Patient-related factors.

Patient-related factors that contribute to complexity include physiologic instability, the various presentations of delirium, the difficulties in assessing patients with communication barriers, the challenges of keeping critically ill patients safe, and family involvement. The onset, the signs and symptoms, and the resolution of delirium are unpredictable and will differ from patient to patient. Participants in this study described how patients fluctuated from calm states to agitated states, and from being non-delirious to delirious and back again. Fluctuations could take place over a matter of hours in a single shift or were sometimes observed over several consecutive shifts.

Critically ill patients are usually physiologically compromised and unstable. Patients may be unable to communicate due to a low level of consciousness or because of communication barriers such as endotracheal intubation. Many patients are also too weak to write or point to a communication board. Under these conditions, alterations in cognition, consciousness, and attention are difficult for the clinician to detect.

Patients with delirium are often incapable of participating in their care, and uncooperative or combative patients can be a danger to themselves and others. These patients are at risk for removing life-supporting devices such as breathing tubes or intravenous catheters, resulting in risk of further physiological compromise and deterioration of their condition. One study of 49 ICUs in the United States found that harm occurred in roughly 25% of patients following accidental removal of a life-supporting device (Mion, Minnick, Leipzig, Catrabone, & Johnson, 2007). The accidental

removal of less critical devices, such as peripheral intravenous catheters, can be time-consuming to replace which leads to increased workload for nurses and other ICU clinicians as well as the potential for additional pain, discomfort and distress for the patient (Mion et al., 2007). The nurses in this study described the difficulties they had trying to keep these medically complex and unstable patients safe when they experienced delirium. Participants recounted experiences when patients with delirium had removed breathing tubes or intravenous and dialysis catheters, which led to bleeding and other patient emergencies. Even seemingly simple interventions could become a big challenge when patients were agitated. For example, patients sometimes refused to keep oxygen masks on, or to take important medications. One participant described needing the help of several family members and other nurses to administer an intravenous antibiotic to an agitated patient.

Interventions to prevent and treat delirium can also conflict with other clinical goals (Barr et al, 2013). For example, early mobilization is recommended for delirium prevention but it may be impossible to implement in a physiologically unstable patient. Sedative medications, invasive devices, and many other interventions are necessary during critical illness, but also increase the risk that patients will develop delirium. Conflicting goals like these were frustrating for the participants in this study and contributed to the complexity of caring for these patients. Nurses described balancing the positives and negatives of various interventions. Studies are lacking about how nurses prioritize interventions, or about how nurses balance these conflicting goals in clinical practice. Participants in this study described selecting the best intervention for the patient at a given time in the subtheme *Knowing When and How to Intervene*.

Families of ICU patients are often in crisis yet still need to participate in decision making on behalf of their loved one (Al-Multair, Plummer, O'Brien, & Clerehan, 2012). In the current study, families were at the bedside and were anxious about the patient's condition. The nurses were caring for not only the patient but also for the family; nurses worked to allay families' fears. Al-Multair and colleagues (2012), in a literature review of 30 studies on family needs and involvement in ICU, identified assurance and information as the two most important needs of family members. Although nurses are considered ideal members of the health care team to meet those needs, the result may be an increase in the complexity and workload of nurses at the bedside (Price et al., 2004; Soderstrom et al., 2003). Nurses in this study provided information about the patient's condition to family members, and helped them interact with patients. The nurses also monitored family interactions with patients and intervened when the family's distress led to increased agitation in the patient.

In addition to attending to the family members' needs, several participants in this study described partnering with them to care for patients. Studies on integrating family members into care of the ICU adult patient are limited. Azoulay and colleagues (2003) found that, while most (88.2%) ICU caregivers surveyed thought that families should be given the opportunity to participate in care of adult patients in the ICU, only 33% of the family members surveyed expressed the desire to participate. Mitchell, Chaboyer, Burmeister and Foster (2009) concluded that a nursing intervention to partner with families to provide care to adult patients in the ICU led to improved overall family-centered care. Nurses in the present study described a variety of family care and partnering activities, which were more or less successful depending on the circumstances

and the type of response from family members. Participants both cared for and partnered with families, but found switching between these roles challenging and both of these dimensions of family care added to the complexity of caring for these patients.

5.4 Nurses' Moment by Moment Assessment versus the CAM-ICU

Clinical practice guidelines recommend that patients should be assessed for delirium using a valid and reliable assessment tool at least once per nursing shift (Barr et al., 2013; RNAO, 2010a). Studies in the Netherlands, Australia, and the United States suggest that ICU physicians and nurses can miss up to three out of four cases of delirium if they are not using a delirium assessment tool (Devlin, Fong et al., 2007; Mistarz et al., 2011; Spronk et al., 2009; van Eijk et al., 2009). Further, patients in the ICU who have hypoactive delirium may be more likely to be missed (Guenther et al., 2010; Peterson et al., 2006). However, many participants in this study did not trust the CAM-ICU results, or found it challenging to use in everyday practice. Only one participant reported using it consistently. The sub-theme *Filling In the Picture: Moment by Moment* revealed that nurses in this study tended to assess patients' mental status moment by moment throughout their shifts or over consecutive shifts. They noted subtle changes and continually assessed mental status during routine interactions to evaluate whether the patient was experiencing delirium. These assessments were used to plan, implement, and evaluate nursing care, and to manage the signs and symptoms of delirium and agitation.

Participants in this study characterized patients as being on a continuum from mildly delirious to very delirious. Mildly delirious patients exhibited a few signs and symptoms of delirium, whereas very delirious patients showed many signs and symptoms, and were typically agitated as well. The nurses also tracked changes in the

signs and symptoms over time and spoke of patients who were "getting worse" or "getting better" and "coming to." The nurses used these moment by moment assessments to plan and evaluate nursing care regardless of whether the patient was CAM-ICU positive or negative. The dichotomous categorization of the CAM-ICU results clashed with the way nurses experienced these patients and the nursing assessments they used to tailor care. In spite of this tension, they were expected to communicate with the interprofessional team, in particular the physicians, using the CAM-ICU results. The participants referred to "not being believed" by the medical team when they were describing signs and symptoms of patients' altered mental status in the way that was the most relevant to them. One participant stated, "I get them to believe me by objective evidence," meaning the CAM-ICU. Delirium by its nature has a fluctuating course, one that requires perhaps this moment to moment assessment used by the nurses in this study. Whereas the medical team may be using the language of diagnosis and CAM-ICU criteria, the nurses appeared to be using the language of continuous observation and moment by moment assessment.

The nurses sometimes attempted to communicate with the medical team to help manage signs and symptoms but the medical team did not always respond unless there was a diagnosis. Eastwood and colleagues (2012) described a similar finding related to nurses' motivation to use the CAM-ICU. The nurses in that study suggested that medical staff paid more attention when the CAM-ICU was used and, despite considering the assessment tool difficult to use, they were willing to use it to improve patient care. Conversely, when physicians were perceived as disinterested in CAM-ICU results, nurses were less motivated to use it to assess patients (Soja et al., 2008). Physicians' responses

to nurses' assessments for delirium may be affected by physicians' knowledge of delirium and delirium assessment (Bassett et al., 2015; Ely, Stephens, et al., 2004; Soja et al., 2008). The findings of these studies as well as this current study highlight the need to ensure that ICUs which choose to employ structured delirium tools should provide and sustain adequate education for the entire interprofessional team (Barr et al., 2013).

Only one participant considered the CAM-ICU helpful to determine whether patients were delirious or not, which is the tool's actual purpose. Notably, this participant also emphasized the need to use good judgment as to how and when to use the CAM-ICU. Other participants had found that patients could be "CAM-ICU negative" but still display signs of altered cognition such as hallucinations. This finding could be a result of poor testing technique or fluctuations in patients' symptoms; or it could indicate subsyndromal delirium, which occurs when a patient is experiencing some of the signs and symptoms of delirium but does not fulfill all of the diagnostic criteria for the syndrome (Page & Ely, 2011; Skrobik, 2010).

Moment by moment assessments helped the participants to develop a big picture of the patient in order to provide safe care. Overall, the CAM-ICU alone did not meet the needs of the participants in this study as they cared for patients with delirium.

5.5 Finding a Way to Help Them Come Through It

5.5.1 Trying to provide patient-centred care.

The nurses in the present study sought to individualize care to each unique patient and situation. They used their moment by moment assessments of the patient to plan and evaluate nursing care. The strategies they used were based on the nurses' knowledge of the patient as well as trial and error. Results of the trial and error process then fed back

into the nurses' knowledge of the patients' responses, tolerances, and preferences. This process, revealed in the sub-theme *finding the proper way*, is an important aspect of patient-centred care. Definitions of patient-centred care differ across the literature. Kitson, Marshall, Bassett and Zeitz (2013) identified three core elements of the concept: patient participation and involvement, the relationship between the patient and the healthcare professional, and the context in which the care is delivered. Patients with delirium often have a reduced capacity to participate in their care. However, the nurses in the present study sought to develop a relationship as far as they were able in order to find the proper way to care for the patient. They focused on the individuality of the patients in their care. This became much more difficult when contextual factors arose, such as high workload, poor communication, or ineffective teamwork.

5.5.2 Individualizing nursing strategies.

Participants described using many non-pharmacologic strategies when caring for patients with delirium including several strategies that are recommended best practices. For example, nurses described frequent re-orientation to person, place, and time; modulating light and noise to promote day/night orientation; minimizing chemical and physical restraints; using music and distraction; promoting and protecting sleep; providing visual and hearing aids as necessary; promoting physical and emotional comfort; bringing family in to help with orientation and to help manage agitation. These strategies are supported by the current best practices recommendations (Barr et al., 2013; RNAO, 2010b). The goals of these interventions were to provide comfort for patients; reduce delirium, distress and disorientation; facilitate the delivery of essential therapies; maintain patient safety; and minimize the need for chemical and physical restraints. Non-

pharmacologic strategies were generally used as the first line of interventions to settle the patient's symptoms prior to turning to medication to reduce agitation. In other cases, nurses used a combination of pharmacologic and non-pharmacologic strategies to tailor interventions to a patient's needs.

The strategies described by the participants in this study are a mixture of nursing interventions that have been used and studied in ICU and non-ICU settings. A recent systematic review of non-pharmacologic nursing strategies for delirium identified 28 interventions, used alone or in combination, for delirium prevention and management (Rivosecchi, Smithburger, Svec, Campbell, & Kane-Gill, 2015). Building upon the recommendations of the clinical practice guidelines, the authors advocated the use of multicomponent, non-pharmacologic protocols that included early mobilization, cognitive stimulation and re-orientation as well as education for nursing staff (Rivosecchi et al., 2015).

The nurses in this study used their individualized knowledge of patients to select how and when to use these strategies and determined what "worked" for patients based on changes in patients' symptoms, such as reduced agitation or disorientation. However, a caution is warranted. When directly asked about recommendations for delirium management, most of the participants expressed uncertainty about the current best practice recommendations. Further, nurses in the present study focused almost entirely on hyperactive symptoms. There was little mention of hypoactive delirium and its treatment. For example, several participants described mobilizing patients as a strategy to decrease agitation, but none of the participants described mobilization as a method to prevent or reduce delirium in general. Since early mobilization is the non-pharmacologic

intervention with the strongest evidence of benefit (Barr et al., 2013), this may indicate a lack of knowledge about this recommendation or it could result from the participants not distinguishing between agitation and delirium. As Belanger and Ducharme (2011) point out, nurses' interventions for delirium may vary according to local culture and values. Comprehensive education for nurses who are caring for patients in ICU with delirium will assist nurses to prioritize and implement evidence-based interventions.

5.5.3 Taking the time.

Participants sought to understand the patient's reality, or got to know the patient, by *taking the time*. One aspect of taking the time was the additional time nurses needed to spend with patients to complete care activities when patients were uncooperative. Another aspect of taking the time was adopting a mindset that allowed the nurses to focus on the patient's present reality and to try to connect with them. The participants characterized this mindset as using patience, or trying to "sense in their world," in order to focus on the patient as a person as opposed to rushing through nursing care tasks. This process could be viewed as a method to get to "know" the patient in the midst of delirium. Zolnierek defined knowing the patient as "in-depth knowledge of the patient's patterns of responses and knowing the patient as a person" (2013, p. 3). Knowing the patient assists nurses to provide safe care, develop relationships, and utilize expertise (Zolnierek, 2013). Participants in the present study used their knowledge of the patients, gained through the process of taking the time, to provide individualized care.

5.5.4 Maintaining safety.

Participants in this study frequently described the difficulties they experienced trying to keep their patients with delirium safe. The patients were considered constantly

at risk for harming themselves by being uncooperative with care, removing invasive devices, or falling out of bed. Maintaining patients' safety while carrying out medically necessary interventions was viewed as optimal and professional care. In order to achieve this, the nurses *kept an eye on the patient* either by continuously observing the patient themselves or delegating observation to other nurses or family members when necessary. While keeping an eye on the patients, the nurses used their knowledge, expertise and clinical judgment to decide when and how to intervene in order to maintain patients' safety. Interventions ranged from verbal reorientation to using physical and/or chemical restraints. Nurses expressed ambivalence about using these restraints. On the one hand, they considered restraints necessary for maintaining safety. On the other hand, they were concerned about the potential adverse effects such as increased agitation or over-sedation, and sought to use them as little as possible.

The effectiveness of physical and chemical restraints to maintain patient safety is not clear. For example, in a recent systematic review on unplanned extubations, da Silva and Fonseca (2012) noted that many unplanned extubations occurred while patients were physically or chemically restrained (60% and 55% respectively). A case-control study in a Taiwanese ICU suggested that physical restraint increases the risk of unplanned extubation (Chang, Wang, & Chao, 2008).

Chemical restraints are also associated with negative side effects such as increased length of ICU stay and delayed liberation from mechanical ventilation and therefore, their use should be minimized whenever possible (Barr et al., 2013). Further, some sedative agents are associated with increased incidence of delirium (Pandharipande et al., 2008; Pandharipande et al., 2010). When sedatives are required, ICU clinicians

must carefully select the agent that best suits the patients' clinical situation (Barr et al., 2013).

Internationally, there is considerable variability in practice related to restraints in ICU. European ICUs typically favour chemical restraint over physical whereas the inverse is true in the United States (Benbenbishty, Adams, & Endacott, 2010). However in Canada, it was hypothesized that patients with higher levels of agitation received both physical and chemical restraint for symptom control (Luk et al., 2014). Luk and colleagues (2014) found that just over half of mechanically ventilated patients were physically restrained. In a secondary analysis of data gathered in 51 ICUs across the ten Canadian provinces, Luk and colleagues (2014) found that 53% of mechanically ventilated patients were physically restrained; higher doses of benzodiazepine, opioid, and antipsychotic use were found to be predictors of physical restraint. Agitation was also a positive predictor of physical restraint use. The nurses in the present study used moment by moment assessment, trial and error, and kept an eye on patients to judge when and how to use restraints.

Maintaining the safety of patients with delirium emerged as a major finding of a critical discourse analysis conducted by Schofield and colleagues (2012) of the written and spoken texts of nurses caring for older confused patients in an acute hospital in the United Kingdom. The authors argued that the participants in their study were influenced by societal and professional discourses of risk reduction and safety, which led the nurses to construct patients as "risk objects" (p. 165) and to focus nursing care on surveillance and containment. Considerations of the patients' self-respect and dignity were delayed until after the resolution of the symptoms of delirium. In contrast, the nurses in the

present study demonstrated an immediate regard for patients' dignity. By trying to understand the patients' reality while they were in delirium, the nurses attempted to strike a balance between protecting the patients' safety and intervening on their behalf. This process is described in the sub-theme *Knowing When and How To Intervene*. Experienced nurses (i.e. those participants with greater than 6 years of ICU experience) were more confident about knowing when and how to intervene.

Several other studies about nurses caring for delirious patients have emphasized the need to observe, surveil, or keep an eye on patients (Dalke & Phinney, 2008; Rogers & Gibson, 2002; Schmidt, 2010). In fact, safety and surveillance are often connected. The Institute of Medicine's report "Keeping patients safe: Transforming the work environment of nurses" identified nurses' surveillance as a key factor to preventing adverse events (2003). As Schofield and colleagues noted, safety is one of the major discourses influencing nurses (2012). Nurses in the present study felt a significant pressure to keep patients safe. When adverse events did occur, such as an unplanned extubation, the nurses felt personally at fault. They also indicated that keeping an eye on the patient was at times impossible and they often recruited help from other nurses, other health care professionals, and from family members to do so. Several participants remarked that caring for these patients was easier in the ICU as compared to other care environments due to the low nurse to patient ratio. However, nurses still gave up personal time (i.e. meal breaks) during their shift or needed to forgo other aspects of care to keep an eye on patients.

5.5.5 Integrating families into care.

Family members of ICU patients are exposed to a number of psychological stressors including the life threatening illness and potential death of a loved one, the disruption of the family system, and the highly technological context of ICU (Al-Multair et al., 2013; Davidson et al., 2007; Davidson 2009). Family members are at risk for anxiety, post-traumatic stress, depression, complicated grief, and postintensive care syndrome-family (Davidson, Jones, & Bienvenu, 2012). Best practice recommendations to optimize support for families in ICU include regular communication with family members, flexible visitation, and family support before, during, and after death (Davidson et al., 2007). However, little guidance is provided about how to accomplish these goals.

In the present study, the sub-themes *Partnering With the Family* and *Caring For the Family* closely echoed the findings of a recent hermeneutic study on the roles of family members of ICU patients (Frivold, Dale, & Slettbø , 2015). Frivold and colleagues described the family members' experience of being cared for by nurses and physicians as "*being in a participating role*" and "*being in a receiving role*" (p. 1). Being in a participating role involved family members feeling included by the health care team, being able to participate with care activities, and participating in decision-making on behalf of their loved one. Family members who were able to participate developed a sense of meaningfulness, and those whose psychosocial needs were met were more likely to express feelings of confidence in the health care system (Frivold et al., 2015). Conversely, Frivold and colleagues found that being in a receiving role consisted of receiving informational and supportive care from nurses and physicians. Nurses in the present study partnered with family to elicit information about the patient, facilitated

family presence at the bedside, and coached family members about how to participate in the patient's care. They described supporting family members by giving information, teaching family members about delirium, and providing psychosocial care.

Partnering with family members helped the participants in the present study to provide safe and effective care for these patients. Participants partnered with family members in several ways: they gathered additional information about the patients such as baseline cognition and functional status, learned about patients' preferences, and looked for ways to tailor their interventions to the patient's needs. Nurses also enlisted the family members help to maintain patients' safety by positioning them at the bedside to observe the patients during periods of agitation. This could free up the nurse for other work such as preparing medications or assisting with the care of other patients. Family members assisted nurses' assessments by communicating their observations of patients' changing mental status. Beneficial effects of partnering with families have been described in the literature including improved orientation, security, and calmness for patients and improved family members' outlook, support, respect and collaboration (Bergbom & Askwall, 2000; Eldredge, 2004; Gonzalez et al., 2004; Mitchell, 2009).

A nurse-facilitated, family participation intervention for delirium trialed by Black, Boore, and Parahoo (2011), involved coaching ICU patients' family members in communication strategies and nurses facilitating family presence at the bedside. This intervention leveraged the family members' desire to be included in the patient's care, as well as their knowledge of the patient and established familial communication patterns. Although there was no measurable reduction in the incidence of delirium in the intervention group, the patients in the intervention group demonstrated better

psychological and emotional wellbeing as measured by the Sickness Impact Profile (Bergner et al., 1981) during follow-up assessments at 4, 8, and 12, weeks after ICU admission. The results of the study suggested that helping the family to participate in meaningful and structured communication with delirious patients could lead to measurable improvements in patients' psychological outcomes following critical illness.

Integrating family members into the routine care of ICU patients, irrespective of delirium, has been associated with improved communication and relationships with the health care team, reduced anxiety and improved satisfaction, and the potential for enhanced patient care (Al-Multair et al., 2013). A key element to partnering with the family is gauging the family members' ability to participate, since not all family members may be able to help in the patient's care, nor will all families have the desire to do this (Azoulay et al., 2003). Nurses in the current study alternated between partnering with family members and caring for family members by providing informational and psychosocial support. Family members who required additional support were sometimes perceived as taking the nurses' time away from the patient and could be viewed as an additional strain on the nurses' workload. One participant reported feeling "torn" when needing to divide time between an agitated patient and the distressed family members. Although other members of the health care team might be available for additional family support, the nurse typically spends the most time in the presence of family when they visit the patient. As such, ICU nurses face the challenge of trying to address family members' psychosocial needs in addition to caring for the critically ill, delirious patient.

The nurses in this study used their personal and professional resources to support family members and to involve them in patient care. Despite the challenges that the

nurses faced when integrating families into care, the findings of the present study support the idea that effective partnering with families can be helpful to nurses when caring for these patients.

5.6 Learning to Care for Patients with Delirium

Nurses in the present study reported learning how to care for patients with delirium by accumulating experiences. Participants cited many personal as well as professional experiences that informed their nursing care. Personal experiences, such as being a patient themselves or having a family member as a patient, helped nurses to develop empathy for the patient and their family members. Professional experiences in mental health and elder care settings were also perceived as helpful for learning to care for these patients as well as learning from more experienced colleagues. Nurses combined these personal, professional and mentorship experiences to learn about the factors contributing to the complexity of caring for these patients. Interestingly, the participants with more experience credited their years of experience with helping them care for patients with delirium as well as for developing good coping strategies to deal with the strain of doing so. Conversely, participants with less nursing experience credited their "newness" and enthusiasm with helping them to care for these patients. All of the participants learned from each experience and carried it forward to the next one.

Experiential learning can be defined as a process of creating knowledge through the transformation of experience (Kolb, Boyatzis, & Mainemelis, 2001). As Rashotte observed in her study on the transformational journey of acute care nurse practitioners, "a linear view does not account for the intertwining, dynamic, and iterative nature of learning" (2013, p.16). She further explains that earlier experiences and new experiences

interact to produce new understandings and transform significance. The participants in the current study used their previous nursing experiences to develop a store of strategies to be called upon depending on patients' symptoms and learned by trial and error to tailor these strategies. These experiences and learnings helped nurses develop confidence, self-efficacy and, in some cases, a sense of satisfaction when they felt personally and professionally able to provide optimal care for patients.

One important finding from this study is that none of the participants credited formal teaching and learning activities when describing how they learned to care for these patients. This is problematic if nurses are lacking knowledge of delirium. Researchers have noted that clinicians are prone to overlooking hypoactive delirium unless they are specifically assessing for it (Barr et al., 2013). This might be the case in the present study, since the participants focused almost exclusively on patients with hyperactive symptoms. A few participants recalled in-services on using the CAM-ICU but most expressed some uncertainty about the concept of delirium and the best practices associated with it. None of the participants discussed clinical practice guidelines related to delirium in ICU patients. Only some of the participants were aware of the delirium protocol that was available in their ICUs. The participants who knew about the protocol considered it most useful to obtain physician's orders for antipsychotic or sedative medications. Non-pharmacological interventions described in the institutional protocol were discussed but not regarded as coming from the protocol.

5.7 Finding Care Rewarding

Several participants in the present study described positive reactions to caring for these patients. This finding was not present in any of the literature retrieved regarding the

experience of caring for delirious patients. These participants described feeling satisfied when they could see patients "coming out of the fog" or when they thought they had been able to effectively manage the patient's agitation. When nurses thought that they had been able to "make a patient more happy" they felt energized and satisfied. One participant described this as "back to being a basic human being." Nurses described feeling privileged to work with these patients, loving their work, and feeling "professional." These feelings were expressed by participants with various levels of experience and with various levels of stress related to caring for these patients. Larkner, Egerod, and Hansen (2015) described a similar theme when nurses were taking care of awake, intubated ICU patients. In their study, the theme "demanding, yet rewarding" revealed the experience of nurses needing to balance the patients' preferences and the patients' physiological and nursing care needs. This was a difficult but a rewarding part of interacting with patients. Further research would be helpful to gain a deeper understanding of the nature of this relationship.

Two studies that measured nurses' experiences of caring for patients with delirium framed the inquiry from a negative standpoint. McDonnell and Timmins (2012) aimed specifically to examine the "subjective burden" of nurses when caring for patients with delirium. Brietbart and colleagues asked the leading question, "Your patient was confused, did you find it distressing?" (2002, p. 186). However, investigations into the rewards of the experience or framing the question from a neutral or positive perspective could also be informative.

5.8 Implications for Practice, Policy, Education, and Research

5.8.1 Practice and policy.

Caring for these patients was exhausting, emotional, and frustrating but also rewarding. The key elements that facilitated this work included team cooperation and consistency, good communication among nurses and the interprofessional team, forming helpful relationships with families, and being able to "take the time" with patients. Elements that hindered this work included feeling unable to keep the patient safe, a lack of consistent approach among nursing colleagues, disagreement among the interprofessional team, communication breakdown, "not being believed" with respect to nursing assessments, trying to balance the needs of the patients with other workload issues such as doubled assignments, and dealing with challenging family situations.

Managing delirium in ICU patients is challenging to accomplish in the complex environment of critical care (Barr, et al., 2013). As has been seen in the present study, nurses navigate the complexities related to the patient's life threatening illness, high technology, family distress and interprofessional team dynamics to try to provide effective, patient-centred care for ICU patients with delirium. Policy makers and clinicians in ICU's must identify barriers and facilitators that are specific to their practice setting and address them in a thoughtful and systematic way (Barr et al, 2013; Carrothers et al., 2013). Physician engagement has been found to be a key factor to successful implementation of delirium screening and should be sought early in the process (Bassett et al., 2015; Eastwood et al., 2012; Law et al., 2012; Soja et al., 2008).

Unit-specific protocols, and "bundles" of related interventions (e.g. a pain, agitation, and delirium care bundle) with or without accompanying education, have been

found to be effective in the critical care environment (Sinuff et al., 2013). However, as seen in the present study, the existence of an institutional delirium protocol does not ensure that it will be used, or used as originally expected, in daily practice. Institution-specific delirium protocols should be developed with input from all members of the interprofessional team. Implementation and evaluation of the protocols should similarly include all team members, including meaningful input from direct care nurses and nurse leaders. Nurses play a central role in prevention, assessment, and treatment of delirium and should be involved at every stage to facilitate the uptake and sustainability of delirium-related best practices.

5.8.1.1 Integrating CAM-ICU into assessment.

The CAM-ICU and similar delirium assessment tools should not be seen as a replacement for clinical nursing assessment but as a method to assist nurses to complete the picture of the patient's mental status. Assessments using the CAM-ICU should be acknowledged to be a snapshot of the patient's mental functioning at that point in time and should be placed in the context of the continuous assessments that nurses perform as well as the overall context of the patient's clinical situation. Acknowledging the contribution of both moment by moment assessments and CAM-ICU results places the use of an objective tool within the realm of nursing judgment and not in opposition to it. This may avoid the perception that the assessment tool is a replacement for the nurse's assessment. One participant described this as "cookie cutter nursing" in which his professional autonomy was disregarded. Further, this participant regarded the CAM-ICU as simply a data collection tool, not as an intervention for patient assessment, and tended not to use it. The recommendations from clinical practice guidelines should be used as a

source of high quality evidence that can be adapted to individual practice settings by integrating local knowledge about what works and does not work at that level (Barr et al., 2014, Sinuff et al., 2013). Failure to take local barriers and facilitators into account may lead to poor uptake of best practices (Balas et al., 2013; Barr et al., 2014; Carrothers et al., 2013; Sinuff et al., 2013).

When nurses in this study noted a discrepancy between the CAM-ICU findings and their own assessments of altered mental status, they began to mistrust the tool and its results. Discrepancies such as this may arise if the CAM-ICU is used improperly; if the patient is demonstrating subsyndromal delirium; or if the patient's signs and symptoms of delirium fluctuate.

Understanding and interpreting CAM-ICU results requires knowledge of delirium and of delirium assessment. Some of the nurses in the present study reported receiving education about the CAM-ICU, however most of the participants did not integrate the tool into their ongoing assessments of the patients mental status. The marked variability in the participants' perceptions and use of the CAM-ICU tool suggest that its use in daily clinical practice could be more complicated than is usually acknowledged. Supporting structures that assist nurses to embed the CAM-ICU into their practice, such as interprofessional education on delirium assessment and management, clear documentation of assessments and structured interprofessional daily rounds may increase the uptake of delirium assessment tools (Brummel et al., 2014; Carrothers et al., 2013)

5.8.1.2 Maintaining patient safety.

Nurses in this study identified maintaining patient safety as an overarching concern as well as a significant challenge. Factors such as high workload, doubled

assignments, retrieving supplies distant from the bedside, and needing to intervene with distressed family members made keeping an eye on these patients more difficult. Nursing assignments and environments that facilitate continuous observation of ICU patients with delirium may be helpful. The additional workload associated with caring for these patients and their families could be considered in staffing allocation.

5.8.1.3 Supporting nurses to engage with families.

Nurses' interactions with family members emerged as a main theme in the present study. However, in order to effectively partner with family members the participants in this study needed to understand the family members' emotional and informational needs. Research is needed to shed light on developing partnerships with family members and the nursing interventions that could facilitate this as well as the potential effects of partnering for families and patients. Nurses may require additional education about the needs of family members in order to learn to partner with as well as care for families of patients in ICU. The time required for nurses to engage with families must be recognized.

5.8.2 Education.

All of the participants in the present study credited experience as the key factor to learning how to care for ICU patients with delirium. Experiential learning is an important aspect of nursing practice yet researchers examining nursing care of delirious patients have often overlooked how nurses learn to care for these patients in the clinical setting. Instead, research has largely focused on didactic teaching about tools and adherence to protocols (Eastwood et al., 2012; Gesin et al., 2012; Soja et al., 2008).

Participants in this study did not demonstrate knowledge of the most common form of delirium in the ICU, the hypoactive subtype. Other studies have demonstrated

that ICU clinicians in general lack awareness of delirium and are more likely to overlook the hypoactive form (Barr et al., 2013). Educational interventions for nurses about delirium should include components based on empirical evidence about the features of delirium, the incidence and impact on ICU patients, appropriate use of objective assessment tools, and inter-professional communication. Traditional educational methods, such as lecturing or bedside in-services may be helpful to disseminate didactic material. McCrow, Sullivan and Beattie (2014) found that nurses' participation in web-based educational vignettes resulted in increased knowledge and recognition of delirium, including hypoactive delirium and delirium super-imposed on dementia. In another study, a multifaceted educational program that included web-based, lecture, and bedside in-services combined improved nurses' knowledge and perceptions about recognition in clinical practice (Gesin et al., 2012). Recommendations for effective educational interventions are to include a mixture of didactic and scenario-based strategies as well as multiple presentation formats such as lecture and one to one sessions to cover a variety of learning styles (Devlin, Marquis et al., 2008; Gesin et al., 2012; Rivosecchi et al., 2015)

Nurses in the current study drew upon their own personal and professional experiences and they also learned from more experienced colleagues how to negotiate the complexities of caring for these patients. Educational interventions that create links between more experienced and less experienced nurses, such as mentorship programs, may help to improve knowledge and enhance sustainability (Hutchinson & Estabrooks, 2013). Educational activities related to caring for ICU patients with delirium should be tailored to address the barriers and facilitators present in the local context. The complex nature of delirium assessment and management should be acknowledged, and periodic

educational follow-up or outreach may be required to sustain knowledge use (Brummel et al., 2013; Gesin et al., 2012). ICUs that are implementing the CAM-ICU or similar tools should investigate the barriers and facilitators to integrating these tools into clinical workflow; including considerations of initial education, re-enforcement, documentation burden, team perceptions, values and beliefs about delirium and objective screening. Educational interventions often need to be combined with other interventions that address cultural or systematic barriers and facilitators to achieve sustainable practice change (Barr et al., 2013; Brummel et al., 2013; Carrothers et al., 2013; Dodek et al, 2012). For example, combining an educational intervention for nurses with an intervention to promote discussion of delirium during interprofessional rounds may have greater effect than either of these interventions alone.

5.8.2.1 Implementing best practices.

Using the principles of knowledge translation may help to achieve sustainable improvements in the care processes related to delirium in ICU patients (Barr et al., 2013; Straus, Tetroe, & Graham, 2013). Research has shown that didactic educational interventions are necessary, but rarely sufficient, to fully embrace best practices or to change practice (Barr et al., 2013; Carrothers et al., 2013; Dodek et al, 2012). For example, in the present study nurses negotiated the complexities arising from patient-related, nurse-related, and environment-related factors to help patients come through delirium. Only some of the barriers and facilitators related to these factors could be addressed through educational interventions. Clinicians and decision makers aiming to implement best practices related to delirium should employ a systematic approach that includes identifying specific gaps in practice, barriers and facilitators, and strategies

tailored to their own setting (Baker et al., 2015; Barr et al., 2013; Sinuff et al., 2013). Effective strategies for implementing delirium best practices will differ from setting to setting and implementation interventions should be evaluated for uptake as well as in relation to important outcomes, such as rate of delirium screenings performed and the proportion of patients who screen positive for delirium (Barr et al., 2013).

Brummel and colleagues (2013) reviewed strategies that have been shown to be helpful to mobilize knowledge of delirium, increase recognition and promote delirium screening, and facilitate interprofessional collaboration and communication. These included addressing barriers to delirium screening, using a validated delirium assessment tool, multifaceted training programs, real-time feedback of delirium screening, providing follow-up training, enhancing interprofessional communication by incorporating delirium into interprofessional rounds, using communication frameworks to describe patient's mental status, including delirium screening in documentation systems. The authors also recommended creating interprofessional teams of "delirium champions," early leadership involvement, engaging with direct care personnel, and using small changes that can be easily evaluated. These and other strategies such as multicomponent interprofessional protocols, audit and feedback interventions, reminders, bundles/checklists, and organizational and cultural interventions may be helpful to promote and sustain change (Barr et al., 2013; Bassett et al., 2015; Sinuff et al., 2013).

Interprofessional, multi-component protocols that place delirium in the context of pain, agitation, and sedation have been recommended as the most effective way to mobilize best practices and to improve patient outcomes (Barr et al., 2013; Bassett et al., 2015; Barr & Pandharipande, 2013; Sinuff et al., 2013). Institution-specific protocols

should be developed with input from all members of the health care team, as well as from patients and family members, to include a broad variety of perspectives when considering how to utilize the recommendations of clinical practice guidelines in a specific practice setting. ICU protocols should be flexible enough to allow nurses and other health care providers to utilize individualized knowledge of the patient while delivering consistent evidence-based care. Measures need to be taken to help staff examine the best practice guidelines to identify which recommendations can help nurses provide care in the ICU context. Findings from this research study such as the vigilance required to maintain patient safety may help organizational leaders to understand how best to care for these patients.

5.8.3 Research.

In the present study, the researcher asked nurses to describe their experiences of caring for ICU patients with delirium. The nurses' responses overwhelmingly consisted of recollections of and reflections on caring for patients who were disoriented, agitated, and combative. Agitation in critically ill patients is challenging for nurses and puts patients at risk of adverse events and poorer outcomes (Burk, Grap, Munro, Schubert & Sessler, 2014). Further research specifically aimed at investigating nursing care of agitated patients in ICU would be helpful to inform and guide practice. In addition, further research is needed into the contribution of the moment by moment assessments by nurses and their individualized approaches in the care of these patients.

Nurses in this study tended to assess patients' mental status along a continuum of signs and symptoms. Patients who exhibited a greater number of signs and symptoms were described as "more delirious" and patients who showed fewer signs and symptoms

over time were considered to be "getting better" or "coming to." In contrast, the CAM-ICU and other objective assessment tools dichotomize delirium into present or not present. Researchers have identified that ICU patients with "subsyndromal" delirium, that is patients who fulfill some but not all of the diagnostic criteria for delirium, may have longer ICU and hospital length of stay, and a greater chance of being discharged to a skilled nursing facility (Ouimet et al., 2007). Research into subsyndromal delirium and the nurse's role in assessing and managing it may be of benefit. Studies on ICU patients' experiences of delirium reveal that patients retain unpleasant memories, frightening dreams, as well as unreal memories, such as specific delusions or hallucinations, for months and years after ICU discharge (Lof, Berggren & Ahlstrom, 2006; Roberts, Rickard, Rajbhandari & Reynolds, 2006; Samuelson, Lundberg & Fridlund, 2007). Research on interventions to reduce the impact of these experiences may be helpful for patients.

The nurses in this study worked closely with families. Additional inquiry into how nurses are presently caring for and partnering with family members to care for ICU patients with delirium would be helpful to further define this phenomenon. Research on specific strategies, particularly on ways to promote family engagement and partnering are potentially beneficial. This is an understudied topic that warrants further investigation to develop specific strategies, skills or protocols for use in practice.

5.9 Limitations

The purpose of this study was to gain a deeper understanding of the experience of critical care nurses caring for ICU patients with delirium. The intent of phenomenological inquiry is not to develop generalizable results that are applicable in all contexts. As such,

the findings of this phenomenological study may not be representative of the experience of all nurses who have cared for ICU patients with delirium.

The participants were recruited from two ICUs in a large university affiliated hospital in Ontario, Canada. The findings of this study may not reflect the experiences of nurses in smaller, non-academic ICUs, or ICUs in other countries or contexts.

The sample of participants was non-random and therefore individuals who volunteered to participate may have had a particular interest or perspective on the topic of delirium. However, a strength of this study is that the participants varied widely in age and years of experience, and males and females were represented (five men and three women).

A final limitation of this study is that only two out of the eight participants responded to the request for a follow up interview. The purpose of the follow-up interview was to enhance credibility, or to establish the "truth-value" of the findings of the study (Lincoln & Guba, 1985). However, both participants who completed the follow-up interview agreed that the results of the study reflected their experience of caring for ICU patients with delirium. One participant stated, "*This seems very good to me. It captured the importance of working as a team and seeing the patient as a whole.*"

5.10 Conclusion

This study examined intensive care nurses experience caring for patients with delirium. The essence of the experience was revealed to be *finding a way to help them through it*. In spite of the many challenges faced while caring for these patients, nurses found a way though the complexity to provide individualized, person-centred care. The themes of this research revealed the complex and ongoing work that nurses applied to

each individual patient and family. This study demonstrated the central role of experience for the participants as they learned to care for these patients and developed their expertise and confidence over time. This learning required more than the application of an assessment tool. Despite the complexities and challenges of caring for patients with delirium, many of the nurses who participated in this study found this caring rewarding and felt privileged to do so. One participant explains:

I feel challenged and I enjoy it. It can be tiring but when you see the end result, when you see how well a patient turns around and suddenly becomes normal. And in 95% of the cases the patient turns out to be quite pleasant people. What's more rewarding than that?

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Appendix A: Letter of Information



LETTER OF INFORMATION

Title of Study: Critical Care Nurses' Experiences of Caring for Intensive Care Unit Patients with Delirium: An Interpretive Phenomenological Study

Local Site Principal Investigator (PI): Irene Oliveira, Nurse Educator, CTU Medicine

Invitation to Participate:

You are invited to participate in this study because you are a critical care nurse who has cared for one or more intensive care unit patients with delirium within the last twelve (12) months.

Purpose of the Study:

Delirium is severe state of confusion that is sudden and temporary. People with delirium are not able to think clearly, have trouble paying attention, and might see or hear things that are not there. Delirium is common in patients in intensive care units. Research shows that these patients are at higher risk of death, long-lasting mental and physical disabilities, and emotional distress. Intensive care unit nurses play several important roles in reducing the impact and severity of delirium, but studies show that there are many barriers to acting on expert recommendations in daily care. Nurses who care for patients with delirium in hospital wards other than the intensive care unit experience higher workload and emotional strain, and feelings of conflict or uncertainty. It is unknown whether intensive care unit nurses experience similar difficulties, or if these factors are important to how nurses care for these patients. This study aims to understand the experience of nurses caring for adult intensive care unit patients with delirium. The findings will shed light on the role of nursing with these patients and will help support efforts to improve patient care.

If you agree to take part in the study, you will participate in a one-to-one interview lasting approximately 60 min and one follow-up contact by phone or email within six (6) months.

Benefits:

The results of this study will help to advance knowledge about the experience of critical care nurses caring for delirious patients in intensive care units, and may contribute to improvements in quality of care for patients, and working environment for critical care nurses. Additionally, you might find reflecting on my experiences helpful for developing your professional practice.

Risks:

The risks associated with this study are expected to be small. However, during the interview you will be asked describe and reflect on caring for a delirious patient (or patients) in the intensive care unit, it is possible that this cause you to feel emotionally uncomfortable. You have the right to refuse to answer questions and may stop the interview if you choose.

Personal Information:

A unique code, not connected with your identity will be used on all study documents. A list linking participants' names with codes will be stored apart in an encrypted file. This file will only be available to the investigators.

Participation in this study is confidential. Only the investigators will use the contents of the interviews. Names and identifying characteristics of participants will not be used in any publication. Some quotations of what participants have said might be used in reports for this study, if this is the case, the quotes will be changed to remove identifying characteristics.

Interview transcripts, consent forms, research notes, and emails will be kept electronically in an encrypted file at the University of Ottawa for a period of five (5) years as required by the Research Ethics Guidelines after which time the records will be destroyed. Interview recordings will be destroyed after two (2) years.

Compensation and costs:

There is no compensation offered for participating in this study. There are no costs expected to be associated with this study aside from the time taken for the interview.

Voluntary Participation:

You have the right to choose not to answer questions and may stop the interview at any time without negative consequences. Participation in this study is entirely voluntary.

If you have any questions about this study, please contact:

Dr. Frances Fothergill-Bourbonnais Professor Emeritus School of Nursing University of Ottawa Ottawa, ON	Allana LeBlanc Masters Student School of Nursing University of Ottawa Ottawa, ON
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The Ottawa Health Science Network Research Ethics Board (OHSN-REB) has reviewed this protocol. The Board considers the ethical aspects of all research studies involving human participants at the University of Ottawa and The Ottawa Hospital. If you have any questions about your rights as a study participant, you may contact the Chairperson.

Appendix B: Participant Consent Form (English)



PARTICIPANT INFORMED CONSENT FORM

Title of Study: Critical Care Nurses' Experiences of Caring for Intensive Care Unit Patients with Delirium: An Interpretive Phenomenological Study

Local Site Principal Investigator (PI): Irene Oliveira, Nurse Educator, CTU Medicine

Participation in this study is voluntary. Please read this Participant Informed Consent Form carefully before you decide if you would like to participate. Ask the study team as many questions as you like.

Why am I being given this form?

You are being asked to participate in this study because you are a critical care nurse who has cared for one or more intensive care unit patients with delirium within the last twelve (12) months.

Why is this study being done?

Delirium is severe state of confusion that is sudden and temporary. People with delirium are not able to think clearly, have trouble paying attention, and might see or hear things that are not there. Delirium is common in patients in intensive care units. Research shows that these patients are at higher risk of death, long-lasting mental and physical disabilities, and emotional distress. Intensive care unit nurses play several important roles in reducing the impact and severity of delirium, but studies show that there are many barriers to acting on expert recommendations in daily care. Nurses who care for patients with delirium in hospital wards other than the intensive care unit experience higher workload and emotional strain, and feelings of conflict or uncertainty. It is unknown whether intensive care unit nurses experience similar difficulties, or if these factors are important to how nurses care for these patients. This study aims to understand the experience of nurses caring for adult intensive care unit patients with delirium. The findings will shed light on the role of nursing with these patients and will help support efforts to improve patient care.

How is the study designed?

This is a qualitative study using an interpretive phenomenological methodology. The investigators will conduct one-to-one interviews, which will be analyzed by the study team. There will be one follow-up phone call or email to each participant for the investigators to get feedback on the findings.

What is expected of me?

Participation involves an audio- recorded, one-to-one interview with the Co-investigator, Allana LeBlanc RN, for about 60 minutes. Interviews will be conducted in English. During the interview you will be asked to describe what it's like to care for delirious patients in the intensive care unit. There are no right or wrong answers to the interview questions. The investigator might take some notes during the interview. The place and time of interviews will be planned at your convenience with the researcher. You will also be asked to respond to one follow-up email or phone call within six (6) months of the interview in which you will be given the opportunity to review the summary of the interview and provide feedback if you wish.

Will my interview responses be used in future research?

My interview responses will only be used for this research study.

How long will I be involved in the study?

The interview will last about one hour and the follow-up phone call will last fifteen to twenty (15-20) minutes within six (6) months of the interview.

What are the potential risks I may experience?

Describing and reflecting on care provided to a delirious patient (or patients) in the intensive care unit may cause feelings of emotional discomfort. You may choose not to answer any question and may stop the interview at any time.

Benefits from participating in this research study?

You will not receive any direct benefit from participating in this study. Participation in this study will help to advance knowledge about how critical care nurses care for delirious patients in intensive care units, and might lead to improved quality of care for patients, and work environment for critical care nurses. Also, you might find reflecting on your experiences helpful to develop your professional practice.

Do I have to participate?

You do not have to participate in this study and if you choose to participate, you can withdraw from the study at any time and/or choose not to answer any questions. Your decision will not affect your current or future employment at The Ottawa Hospital.

If I agree now, can I change my mind and withdraw later?

You may withdraw from the study at any time without any impact on your current or future employment at The Ottawa Hospital. If you choose to withdraw, the investigators will only use the information you have given them with your permission. If you do not wish the investigators to use your information, the investigators will destroy it.

How is my personal information being protected?

A unique code, not connected with your identity will be used on all study documents. A list linking participants' names with codes will be stored separately from the interview transcripts in an encrypted file. This file will only be available to the investigators.

Participation in this study is confidential and only the investigators will use the contents of the interview. Your name or other identifying characteristics will not be used in any publication. Direct quotes might be used in reports for this study, if this is the case, the quotes will be changed to remove identifying characteristics.

The audio files will be deleted immediately upon transcription. The interview transcripts, research notes, and emails will be kept electronically in an encrypted file at the University of Ottawa for a period of ten (10) years as required by the Ottawa Health Science Network Research Ethics Board after which time the records will be destroyed.

Do the investigators have any conflicts of interest?

There are no conflicts of interest to declare related to this study.

Who do I contact if I have any further questions?

If you have any questions about this study, please contact:

Dr. Frances Fothergill-Bourbonnais Professor Emeritus School of Nursing University of Ottawa Ottawa, ON	Allana LeBlanc Masters Student School of Nursing University of Ottawa Ottawa, ON
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The Ottawa Health Science Network Research Ethics Board (OHSN-REB) has reviewed this protocol. The Board considers the ethical aspects of all research studies involving human participants at the University of Ottawa and The Ottawa Hospital. If you have any questions about your rights as a study participant, you may contact the Chairperson.



Consent to Participate in Research

- I understand that I am being asked to participate in a research study about the experiences of critical care nurses caring for adult intensive care unit patients with delirium.
- This study was explained to me by _____.
- I have read, or have had read to me, each page of this Participant Informed Consent Form.
- All of my questions have been answered to my satisfaction.
- If I decide later that I would like to withdraw my participation and/or consent from the study, I can do so at any time.
- I voluntarily agree to participate in this study.
- I will be given a copy of this signed Participant Informed Consent Form.

Participant's Printed Name Participant's Signature Date

Investigator or Delegate Statement

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

Investigator/Delegate's Printed Name Investigator/Delegate's Signature Date

Appendix C: Participants Informed Consent Form (French)



FORMULAIRE DE CONSENTEMENT ÉCLAIRÉ **À L'INTENTION DU PARTICIPANT**

Titre de l'étude : Les expériences du personnel infirmier en soins intensifs qui soignent des patients souffrant de délirium : Une étude phénoménologique interprétative

(Le générique masculin est utilisé sans discrimination et dans l'unique but d'alléger le texte.)

Chercheure principale sur les lieux : Irene Oliveira, infirmière enseignante, Unité d'enseignement clinique en médecine

Toute participation à cette étude est volontaire. Veuillez lire attentivement ce formulaire de consentement éclairé à l'intention du participant avant de décider si vous désirez y participer. L'équipe de recherche se fera un plaisir de répondre à toutes vos questions.

Pourquoi ai-je reçu ce formulaire?

Nous vous invitons à participer à cette étude parce que vous êtes infirmier ou infirmière en soins intensifs ayant soigné un ou plusieurs patients aux soins intensifs souffrant de délirium au cours des douze (12) derniers mois.

Pourquoi cette étude a-t-elle été entreprise?

Le délirium consiste en un état confusionnel sévère, soudain et temporaire. Les personnes souffrant de délirium sont incapables de penser clairement, ont de la difficulté à se concentrer et peuvent voir ou entendre des choses qui ne sont pas là. Le délirium est fréquent chez les patients aux soins intensifs. Les recherches démontrent que ces personnes courent un plus grand risque de mort, d'incapacité mentale ou physique à long terme et de détresse affective. Le personnel infirmier en soins intensifs joue plusieurs rôles importants dans la réduction de l'impact et de la sévérité du délirium, mais les recherches révèlent de nombreux obstacles à l'application des recommandations des experts lors des soins quotidiens. Le personnel infirmier qui soigne les patients souffrant de délirium dans des unités autres que les soins intensifs assument une charge de travail plus élevée et éprouvent davantage de stress émotionnel et de sentiments de conflit ou d'incertitude. Il est inconnu si le personnel infirmier en soins intensifs vit des expériences semblables ou si ces facteurs sont pertinents pour les soins qu'il offre à ces patients. Cette étude vise une meilleure compréhension de l'expérience du personnel infirmier soignant les patients souffrant de délirium dans l'unité des soins intensifs pour adultes. Les résultats éclaireront le rôle du personnel infirmier dans les soins de ces patients et appuieront les efforts pour améliorer les soins aux patients.

Quelle est la méthodologie de l'étude?

Cette étude qualitative suit une méthodologie phénoménologique interprétative. Les chercheurs mèneront des entrevues individuelles et les analyseront. L'équipe de recherche communiquera par téléphone ou par courriel avec chaque participant afin de recevoir une rétroaction sur les résultats.

Que dois-je faire?

Votre participation consiste en une entrevue individuelle d'environ soixante (60) minutes avec la co-chercheuse Allana LeBlanc, infirmière autorisée. Cette entrevue sera en anglais et sera enregistrée. Lors de l'entrevue on vous invitera à décrire votre expérience de soins de patients délirants dans l'unité des soins intensifs. Il n'y a pas de bonnes ni de mauvaises réponses aux questions d'entrevue. La co-chercheuse pourrait prendre des notes pendant la rencontre. L'heure et le lieu de l'entrevue seront déterminés, avec la co-chercheuse, selon vos disponibilités. On vous demandera de répondre à un appel téléphonique ou un courriel dans les six (6) mois suivant l'entrevue, ce qui vous permettra de réviser le sommaire de l'entrevue et de fournir de la rétroaction, si vous le désirez.

Mes commentaires en entrevue seront-ils utilisés dans de futures recherches?

Vos commentaires en entrevue seront utilisés uniquement pour la présente étude.

Quelle sera la durée de ma participation dans cette recherche?

L'entrevue durera une heure environ et l'appel téléphonique sera d'une durée de quinze (15) à vingt (20) minutes et aura lieu dans les six (6) mois suivant l'entrevue.

Quels sont les risques potentiels associés à ma participation?

Il se peut que l'acte de décrire et de réfléchir sur les soins offerts à un ou plusieurs patients délirants dans l'unité des soins intensifs évoque un certain malaise. Vous pouvez, en tout temps, décider de ne pas répondre à une question ou d'abandonner l'entrevue.

Quels seraient les bienfaits de ma participation à cette recherche?

Vous ne recevrez aucun bienfait direct de votre participation à cette recherche. Votre participation à cette recherche contribuera aux connaissances sur les soins offerts aux patients délirants par le personnel infirmier en soins intensifs, et pourrait mener à l'amélioration de la qualité des soins fournis aux patients ainsi que du milieu de travail du personnel infirmier. Il se peut également que l'expérience de réfléchir sur vos expériences puisse vous être utile dans le développement de votre propre pratique professionnelle.

Dois-je participer?

Votre participation à cette étude est volontaire et, si vous décidez d'y participer, vous pouvez, à tout moment, vous en retirer ou choisir de ne pas répondre à quelque question que ce soit. Votre décision n'aura aucune incidence sur votre emploi actuel ou futur à l'Hôpital d'Ottawa.

Si j'accepte de participer maintenant, puis-je changer d'idée et abandonner plus tard?

Vous pouvez vous retirer de l'étude en tout temps sans que cela n'ait aucune incidence sur votre emploi actuel ou futur à l'Hôpital d'Ottawa. Si vous décidez de vous retirer de l'étude, l'équipe de recherche n'utilisera aucune des informations que vous avez fournies sans votre permission. Si vous voulez que l'équipe de recherche n'utilise aucune de vos informations, elles seront détruites.

Comment mes renseignements personnels sont-ils protégés?

Un code unique n'ayant aucun lien à votre identité sera utilisé dans tout document lié à l'étude. Une liste associant ces codes aux noms des participants sera stockée séparément des transcriptions d'entrevue dans un fichier chiffré. Seuls les chercheurs auront accès à ce fichier.

Toute participation à cette étude est confidentielle et seule l'équipe de recherche utilisera le contenu des entrevues. Ni votre nom ni aucun autre renseignement pouvant vous identifier ne sera utilisé dans quelque publication que ce soit. Il se peut que des citations directes soient incluses dans les rapports de cette étude et, si c'est le cas, elles seront modifiées afin d'éliminer toute information pouvant vous identifier.

Les fichiers audio seront supprimés immédiatement suivant la transcription. Les transcriptions d'entrevue, les notes de recherche et les courriels seront conservés en format électronique dans un fichier chiffré à l'Université d'Ottawa pendant une période de dix (10) ans, selon les exigences du Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa. Après cette période, les dossiers seront détruits.

Existe-t-il des conflits d'intérêt liés à l'équipe de recherche?

Il n'existe aucun conflit d'intérêt à déclarer lié à cette recherche.

Qui dois-je contacter si j'ai d'autres questions?

Veillez contacter une des personnes suivantes avec toute question associée à cette recherche.

Dre Frances Fothergill-Bourbonnais Professeure émérite École des sciences infirmières Université d'Ottawa Ottawa (ON)	Allana LeBlanc Étudiante à la maîtrise École des sciences infirmières Université d'Ottawa Ottawa (ON)
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Ce protocole a été révisé par le Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa. (CÉR-RSSO). Ce conseil est chargé de l'ensemble des aspects éthiques de toute recherche impliquant la participation de sujets humains menée à l'Université d'Ottawa et l'Hôpital d'Ottawa. Pour toute question liée à vos droits en tant que participant à cette étude, veuillez communiquer avec le président du Conseil .



Consentement à la participation à la recherche

- Je comprends qu'on me demande de participer à une recherche sur les expériences du personnel infirmier en soins intensifs qui soignent des patients souffrant de délirium dans l'unité des soins intensifs pour adultes.
- _____ m'a expliqué en quoi consiste cette étude.
- J'ai pris connaissance de chacune des pages de ce Formulaire de consentement éclairé à l'intention du participant.
- Toutes mes questions ont été répondues de manière satisfaisante.
- Si je décide au cours de l'étude que je désire ne plus participer ou retirer mon consentement, il me sera possible de le faire en tout temps.
- Je consens volontairement à participer à cette étude.
- Je recevrai une copie signée de ce Formulaire de consentement éclairé à l'intention du participant.

 Nom du participant
 (lettres d'imprimerie)

 Signature du participant

 Date

Énoncé du chercheur ou du délégué

J'ai expliqué soigneusement au participant de recherche en quoi consiste cette étude. Au mieux de mes connaissances, le participant reconnaît la nature, les exigences, les risques et les bienfaits associés à sa participation à cette étude.

 Nom du chercheur/délégué
 (lettres d'imprimerie)

 Signature du chercheur/délégué

 Date

Appendix D: Interview Guide

Can you tell me what it is like to care for an intensive care unit patient with delirium?
Can you recall a specific situation that would help to describe what it is like to care for an intensive care unit patient with delirium?
What makes caring for these patients easier or harder for you as a nurse?
Can you recall a specific situation that would help to describe what makes it harder or easier?
Can you tell me how you decide if a patient has delirium?
Tell me how you care for a patient who has delirium.
Can you tell me about the tools you use while caring for these patients?
Do these tools make it easier or harder for you as a nurse?
Can you tell me about the best practice guidelines that you use while caring for these patients?
Do these best practice guidelines make it easier or harder for you as a nurse?

Interview prompts to keep focus on the level of experience (van Manen, 1990).

Tell me more about...?
How do you mean...?
How did you feel about...?
Can you give an example of...?
What was it like when...?

