

THE LIVED EXPERIENCE OF ICU FOR PERSONS
WHO HAVE EXPERIENCED DELIRIUM:
A PHENOMENOLOGICAL STUDY

KAREN WHITEHORNE



The Lived Experience of ICU for Persons Who Have Experienced Delirium:

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by

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“It is impossible to heal the body without knowing something about the soul, indeed without knowing something about the nature of the whole.” Plato

Abstract

The experience of being in the intensive care unit (ICU) frequently includes the experience of delirium. Delirium is a phenomenon that is often not recognized by nurses but has serious implications not only for the patient's mortality but also for his/her psychological well-being. Therefore, there is a need for nurses to understand the experience of ICU for patients who had delirium. The purpose of this phenomenological study is to answer the question "What is the lived experience of ICU for persons who have experienced delirium?" Study participants, seven men and three women who ranged in age from forty-six to seventy years, were identified as having delirium using a validated tool for identifying delirium, the Confusion Assessment Method for the ICU (CAM-ICU). van Manen's (1997a) method of phenomenology was used to guide this study, and data collection entailed semi-structured interviews which were audio recorded. Four themes were identified that describe the essence of the experience of ICU with delirium: *I Can't Remember, Trying to Make a Connection, Trying to Get it Straight*, and *Fear and Safety Concerns*. The first theme refers to the participants' reported loss of memory for part of the ICU stay and their reaction to the memory loss. The second theme is related to feeling disconnected from others and from reality as well as efforts to connect. The third theme means trying to make sense out of what was real or unreal such as the unusual experiences including hallucinations and disorientation in order to understand what happened to them in ICU. The final theme describes feeling safe or unsafe and the fear that loved ones were in danger. Participants identified ways that they were affected by this experience, which was at times confusing or frightening. The findings from this study have important implications for nursing

interventions for patients in ICU including the need to assess for the presence of delirium as well as the mental status for patients who have delirium, and helping patients and families learn about and deal with the psychological effects of the ICU experience. The findings from this study provide direction for nursing interventions, policy development, administration, education, and further research to improve the care of the patient who experiences ICU and delirium.

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Chapter One

INTRODUCTION

An admission to an intensive care unit (ICU) can be both a lifesaving and a life changing experience that frequently includes the experience of delirium (Morandi & Jackson, 2011). While not every patient admitted to the ICU will experience delirium, these patients have complex medical and surgical needs and their medical instability makes them vulnerable to developing delirium. In fact, researchers have identified delirium in up to eighty percent of ICU patients (Pun & Boehm, 2011). Older persons are at an increased risk for developing delirium and are admitted to ICU more frequently as medical technology continues to advance. This may result in an increase in the incidence of delirium in the future.

There has been increasing interest about the impact of an ICU admission on quality of life for patients recovering from a critical illness. Advances in medical technology and the skilled preparation of health personnel found in the ICUs allow for better physical outcomes than once was possible. However, these positive physical outcomes may come at a high psychological cost. Often during treatment in an ICU patients are sedated and or intubated which decreases their ability to communicate and express needs or describe experiences. The sense of helplessness and lack of control that can come from lying on a bed, wearing a hospital gown, and looking at the ceiling can add to patients' feelings of vulnerability. The psychological outcomes from an ICU admission may include anxiety, depression, and post-traumatic stress disorder (PTSD) (Girard, Shintani, Jackson, Gordon, Pun, Henderson, et al., 2007). Researchers have also reported an association between recall of delusional memories of ICU and the incidence of these forms of psychological distress (Kiekkas, Theodorakopoulou, Spyrtatos, & Baltopoulos, 2010).

Psychiatrists have used case reports to demonstrate that PTSD symptoms can be provoked

by the recall of distressing delirium experiences that patients had during a life threatening event in the ICU (DiMartini, Dew, Kormos, McCurry, & Fontes, 2007). These psychiatrists argue that the criteria for PTSD should include unreal or perceptually distorted experiences such as those occurring during delirium. It would follow then that patients who experience delirium while in the ICU are at increased risk for psychological distress such as found in PTSD when they recall distressing delusional memories.

The impact of an admission to ICU and the experience of delirium on quality of life for patients recovering from a critical illness is an area of interest for researchers. In order to provide evidence informed care we need to know more about the experience of ICU from the perspective of patients who experienced delirium while in the ICU. This thesis describes a phenomenological study that looks at the ICU experience from the perspective of patients who experienced delirium while in the ICU.

Background

While some survivors of critical illness recall positive memories of the lifesaving aspects of ICU, and the feelings of comfort and safety, the experience has also been reported to include both physical and negative psychological effects that can impact a person's health related quality of life for a long time after leaving ICU (Adamson, Murgo, Boyle, Kerr, Crawford, & Elliott, 2004). The impact of being critically ill, having impaired sleep, having multiple medications and procedures, as well as the vulnerability of loss of control can lead to psychological distress. In addition, delirium is common in this population and is associated with disturbances in orientation, memory, cognition, and information processing (Kiekkas et al., 2010).

Delirium is a syndrome that includes cognitive, mood, and behavioral symptoms indicative of a medical illness (Ely, Siegel, & Inyoue, 2001a) and is a form of acute brain failure (Pun

&Boehm, 2011). It is one example of the mind and body connection in which the brain is seen as an organ that is dysfunctioning. Delirium is a frequent occurrence in ICU that has been identified in 20 to 50% of lower severity ICU patients or those not receiving mechanical ventilation, and in 60 to 80% of ICU patients receiving mechanical ventilation (Pun & Ely, 2007). Despite the high prevalence of delirium in ICU, it is often unrecognized by nurses (Mistarz, Elliott, Whitfield, & Ernest, 2011). Delirium is defined by the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2000) as a disturbance of consciousness, inattention, and changes in cognition or perceptual disturbance that develops over hours or days and fluctuates over time. Hypotheses that attempt to explain the pathophysiology of the development of delirium are related to diffuse brain dysfunction, inflammation related to sepsis, genetics, biomarkers and neurotransmitter imbalance (Morandi & Jackson, 2011). Delirium is categorized according to psychomotor activity and includes three subtypes: hypoactive (43.5%), hyperactive (1.6%), and mixed (54.9%) (Peterson et al., 2006). Hypoactive delirium is observed as inattentiveness and lethargy and hyperactive delirium includes restlessness, hypervigilance, and combative behavior. Mixed delirium includes features of hyperactive and hypoactive delirium. Hypoactive delirium is more common than hyperactive delirium but is less recognized or it is misdiagnosed as sedation or depression. It is important to recognize hypoactive delirium as it has a higher mortality rate than hyperactive or mixed delirium subtypes (Peterson et al.).

Risk factors for the development of delirium have been mostly studied in general medical populations and not specifically ICU patients (Morandi & Jackson, 2011; Pun & Boehm, 2011). Specific to ICU, the following risk factors have been identified: pre-existing dementia, a history of baseline hypertension, alcoholism, and the severity of illness on admission (Pun & Boehm).

The naming of the experience that can be defined as delirium is one area in ICU literature that lacks clarity (Arend & Christensen, 2009; Belanger & Ducharme, 2011). Experiences in ICU have been labeled as dreams, memories, confusion, ICU psychosis, and encephalopathy. In some studies exploring patients' recall of the ICU experience the term delirium is not included (Lof, Berggren, & Ahlstrom, 2006; Samuelson, K., 2011). These experiences may all be examples of delirium but it is not clear because delirium is not identified in these studies. If delirium incidence is up to eighty percent of patients in ICU then at least some of the experiences that have been described in the literature about ICU admissions are likely to be during an episode of delirium.

The Confusion Assessment Method for the ICU (CAM-ICU) (see Appendix A) is a validated tool for identifying delirium in ICU (Ely, Inouye, Bernard, Gordon, Francis, & May, 2001b). This tool was designed for use in non-verbal patients as well as verbal patients and therefore allows assessment of patients who are mechanically ventilated and unable to speak. The four features that lead to a diagnosis of delirium included in this tool are: 1) acute mental status changes and fluctuating course; 2) inattention; and either 3) disorganized thinking, or 4) altered level of consciousness. Bedside nurses in ICU with no formal psychiatric training can reliably detect delirium in mechanically ventilated patients with a high degree of sensitivity and specificity using the CAM-ICU (Ely et al., 2001b). Before the development of the CAM-ICU, the lack of a validated instrument to reliably diagnose delirium in mechanically ventilated patients had resulted in patients in ICU with delirium who could not speak to be excluded from research studies (Ely et al., 2001b). The option of another tool the Intensive Care Delirium Screening Checklist that was developed in Canada (Bergeron, Dubois, Dumont, Dial, & Skrobik, 2001) was considered for use in ICUs in the facilities where this research was conducted but was

found to be difficult to use. The Intensive Care Delirium Screening Checklist required the assessment of several features of delirium by staff members with no psychiatric background and was lengthy compared to the CAM-ICU. The CAM-ICU has been chosen as a tool that is easier to use and has been implemented. Because of the complex nature of the care required by patients in ICU, the investment of resources in the form of equipment, time, money, and personnel can be greater than many other areas in health care. Delirium increases the length of stay and therefore increases costs (Pun & Ely, 2007). In the United States, delirium in ICU patients costs between four and sixteen billion dollars annually (Pun & Boehm, 2011).

There are other negative outcomes of delirium in the ICU that are significant. ICU delirium is associated with higher mortality, increased reintubation rate, and an increased risk of long term cognitive impairment (Pun & Ely, 2007). Long term cognitive impairment after ICU delirium has a negative impact on activities of daily living and the ability to return to work. Case reports have described a connection between delirium and psychological distress (DiMartini et al., 2007). Other psychosocial complications of an ICU admission that have been identified include anxiety, depression, PTSD, and disturbed sleep (Johns, Dawson, & Ball, 2010). The incidence of PTSD is 14% of all ICU admissions. It has been suggested in a review by O'Malley, Leonard, Meagher, and O'Keeffe (2008) on the delirium experience that a better understanding by health care professionals of what it means to patients to be delirious can improve recognition, management, and treatment of delirium. Because of the significant negative impact of delirium in ICU, interest in the topic has grown markedly in the past decade.

The recent development of the European Delirium Association, the American Delirium Society, and the Veterans Administration Annual Conference on Delirium are just three examples of the growing importance of this phenomenon. In the July edition of *Annals of*

Delirium (Page, 2010) there was a request for personal experiences of delirium to be used as an educational tool to improve clinicians' knowledge of delirium. Survivors of ICU can discuss their delirium experiences on the peer support website called ICU steps (<http://www.icusteps.org>). This British based resource also contains patient focused information on recovery after ICU as well as educational material for healthcare professionals. There are also websites for professionals dedicated to ICU delirium based in the United States and Great Britain (<http://www.icudelirium.org> and <http://www.icudelirium.co.uk>). Safer Healthcare Now (<http://www.saferhealthcarenow.ca>) is a grassroots campaign to enlist Canadian healthcare organizations in implementing targeted interventions in patient care. Each of the ten interventions upon which the campaign is built has an evidence base indicating that appropriate implementation and practice can lead to reduced patient mortality and morbidity. Minimizing the impact of delirium in the ICU is one of the recommended interventions for implementation. Delirium in the ICU has become an international subject of research and development.

Most research on ICU delirium originates in Scandinavian countries, the United States, or the United Kingdom. There is relatively little research completed in Canada about delirium in the ICU. Only two Canadian sources were found in my literature review (Belanger & Ducharme, 2011; Bergeron et al., 2001). Research such as my study based in Canada would provide data reflective of patients within the Canadian health care system.

The focus of this study is on the experience of ICU for patients in eastern Canada who experienced delirium. For the purposes of this thesis, ICU includes three types of adult critical care units: cardiovascular intensive care, coronary care, and medical/surgical intensive care. The coronary care unit contains private rooms and the other ICUs are open multi-bed units that may have a few private isolation rooms. ICU staff includes the multidisciplinary team of nurses,

pharmacists, occupational therapists, psychologists, pastoral care practitioners, social workers, physiotherapists, dieticians, respiratory therapists, and physicians who could utilize the knowledge of the patients' ICU experiences to guide their choices of interventions for patients and families.

Rationale

As a Mental Health Consultation Liaison Nurse in a general hospital I have interviewed many people following their transfer out of ICU when they were inpatients on medical or surgical wards. I have listened to the memories of ICU that included descriptions of unreal experiences that were very distressing from patients' perspective. Patients have sometimes struggled with determining what actually happened while they were in ICU and which of their remembered experiences were dreamed or imagined. In my clinical experience patients have expressed feeling relieved when they were told that delirium is not considered a mental illness. The symptoms that are similar to those of a mental illness bring with them a stigma about going crazy or losing your mind. Delirium can be a difficult experience to relate to if one has never had such an experience. For some, it creates a reluctance to discuss the experiences of that delirium because it may cause people to question their mental health. Listening to the descriptions of the patients' experiences helped me understand behaviors that are observed by ICU staff when patients struggle or are agitated and strike out or become withdrawn and are less interactive. Being aware of patients' inability to interpret events or attend to instructions explains the frequent need for ICU staff members to repeat information and explains the difficulty that patients sometimes have in complying with treatment. I identified that it is important for staff members to have this knowledge about patients' inability to follow instructions as it could help the staff to understand the behavior.

While the amount and type of recall of an experience of ICU and the influence it has on patient outcomes has been studied (Adamson et al., 2004; DiMartini et al., 2007; Jones, Griffiths, Humphris, & Skirrow, 2001; Lof et al., 2006; Magarey & McCutcheon, 2005; Papathanassogiou & Patiraki, 2003) there are many unanswered questions. There is a need for improved identification of patients in ICU who have delirium; as reported in previous studies between 66 to 84 percent of patients with delirium went unrecognized (Ely et al., 2001a). Slade, Hancock, and Walsh (2003) concluded that in the surveys completed by staff members in the ICU the incidence of delirium was underestimated, staff members did not regularly screen for delirium and the management plans for delirium varied. They recommended education for ICU staff on delirium. This survey was conducted in the same locations included in this current study.

I have been involved in the development and implementation of a delirium protocol that emphasizes the early recognition and treatment of delirium in ICU. In my work with patients who have been in ICU, I have seen the need for healthcare professionals to further appreciate the effect the ICU experience has on the patients, especially those who have had a delirium episode. Despite much attention internationally on the subject of delirium there is a lack of understanding about the experience of ICU delirium. I have been involved in the ICU delirium committee in the facilities where this research was done and I have had input from the ICU delirium and cognitive impairment study group of Vanderbilt University (see Appendix B). There have been many efforts to educate ICU staff about the importance of prevention, early detection, and treatment of delirium but there is still a lack of knowledge about the factors that contribute to the behavior of a person with delirium. It is for this reason that I chose a phenomenological approach to investigate this topic. This type of study may uncover issues which have not been previously explored and can highlight areas of patient care needs that require further intervention. I was

seeking to understand what it would be like to be in the ICU during an episode of delirium from the perspective of the person who has experienced it and to be able to relay that information to ICU staff members.

In phenomenology the researcher avoids generalizing by seeking to understand someone in his or her specific situation and phenomenological nurse researchers in particular focus on the subjective experience of each human being (Donalek, 2004). Through phenomenological research we challenge our assumptions (Beck, 1994). The findings of this research highlight interventions that ICU staff members are doing well, and provide direction for the areas of knowledge that need to be further explored. The findings from this research study can be applied not only to inform the practice of ICU staff members but also healthcare staff who work with patients recovering from an ICU stay in acute care hospital wards, in rehabilitation settings, and during follow up care in the community. Awareness of an individual's unique experience in ICU can provide the healthcare staff members with insight into how recovery may be affected. The findings of this study could provide support for the development of therapeutic nursing interventions such as patient and family education, counselling, and support aimed at the comfort and psychological well-being of patients who experience delirium while in ICU and after transfer out of ICU. The findings from this research can also inform the approach for all healthcare personnel who are caring for persons who are delirious. Such interventions could facilitate those patients' recovery.

In van Manen's (1998) discussion of the body's experience in illness and health he states that in phenomenology we measure our understandings and insights against the lived reality of our concrete experiences. van Manen also states that our experiences are more complex than any particular interpretation can portray and health professionals must be more involved in the way

that people live with and experience their problems in a unique manner. This is a reminder that people who live with illness are more than the ill body. Included in van Manen's (1997a) approach is a description of the patient's experience in the form of the four existentials that define the lifeworld: time, space, body, and human relations. Phenomenology is the appropriate methodology to study lived experience of ICU for patients who have had delirium as it provides rich descriptions and themes that make the experience more meaningful (Beck, 1994). Phenomenology helps people connect to an experience and have a better understanding of it as the essential description of the phenomenon must allow the reader to grasp what is central to the phenomenon (Donalek, 2004). For these reasons the method of research that I selected for this study is phenomenology as described by van Manen.

Purpose

The purpose of this research is to answer the question "What is the lived experience of ICU for persons who have experienced delirium?" This study provides descriptions from the viewpoint of the patient who has been delirious as evidenced by a positive score on the confusion assessment method for the ICU (CAM-ICU).

CHAPTER 2

LITERATURE REVIEW

There is a growing interest in the experience of an admission to ICU and the impact of delirium in the ICU as well as an increase in the literature about delirium in general in the form of clinical articles, research reports and literature reviews. A PubMed search for “delirium experience” from 1949 to 2012 yielded 493 articles. The focus of most of these articles was on the definition, prevention, assessment, causes, treatment, and pharmacological management of delirium as discussed in the background section of this paper. There were fewer articles that focused on the delirium experience. For this literature review I refined the search on PubMed and CINAHL databases by using the key words ICU, delirium, and experience in three combinations: ICU experience, delirium experience, and ICU delirium experience. I also searched the reference lists from these articles for other literature related to the ICU experience and the experience of delirium. Within these articles the impact on the patients telling the stories of the experiences of delirium was discussed. Therefore, I have included a section in the literature review on the impact of recalling the delirium experience. Out of the sixty three articles that I included in this literature review, sixteen were quantitative research studies, fourteen were qualitative research studies and nine were a combination of research methods. There were fourteen review articles, seven discussion articles and three self-narratives describing the experiences.

Because the purpose of this study is to explore the lived experience of ICU for patients who have experienced delirium I divided the literature into the following categories: the ICU experience, the delirium experience in ICU, the delirium experience outside ICU, and the impact of recalling the delirium. The following is a review of each category of the literature.

The ICU Experience

Frequently an admission to ICU is preceded by a traumatic experience or risk of death. After exploring the topic of the ICU experience, researchers have concluded that falling critically ill results in emotional responses from patients that are affected by the severity of the illness and the threat to life (Cook, O'Meade, & Perry, 2001; Fredriksen & Ringsberg, 2007; Granberg, Engberg, & Lundberg, 1998; Magarey & McCutcheon, 2005). Difficult psychological responses that have been described included anxiety, fear, panic, depression, denial, withdrawal, psychosis, and delirium. Fear of not being able to breathe, fear of dying, fear of being harmed by staff, fear of hallucinations, and not being able to communicate add to the distress. Impaired communication leads to anger and low mood for some patients (Hofhuis, Spronk, van Stel, Schrijvers, Rommes, & Bakker, 2008). Difficulty sleeping and thirst were unpleasant experiences reported by patients admitted to ICUs (Galvin & Martinez, 2009).

Psychological distress of ICU survivors has been identified and the incidence of psychiatric morbidity has been recognized. Depression rates two to three months post ICU, range from 9.8 to 30 percent, anxiety disorders have been estimated as high as 25 percent two years post ICU, and PTSD has been recognized as a specific anxiety disorder that is related to having an ICU admission (Volk & Grassi, 2009).

Theories have been developed to explain reasons for patients' difficulties with being in ICU. The stresses of the environment, the stress of the physical experiences, and the imbalance of power between patient and staff as well as being separated from loved ones have been proposed as causative factors for negative experiences in ICU. The current treatment suggestion for patients receiving mechanical ventilation is to use less sedation and to allow the patient to wake up daily (Hofso & Coyer, 2007). Now that patients are less sedated they may have more

memories of experiences in ICU. Studies that focus on sedation and memory of the ICU have suggested a dose dependent relationship between sedatives and the formation and retention of memory so that decreased sedation results in increased memories (Samuelson, Lundberg, & Fridlund, 2006).

Black, McKenna, and Deeny (1997) suggested that psychological disturbances experienced by patients in ICU are precipitated by sensory deprivation or sensory overload in the ICU physical environment and the patient's inability to achieve a balance in that environment. The authors called this concept sensoristrain and reported that such things as enforced bed rest, weakness, physical illness, invasive procedures, effects of medications and lack of control over the situation impact the patients' psychological state.

The types of stress that patients in intensive care experience were the subject of a literature review of ten previous review articles (Fredriksen and Ringsberg, 2007). A phenomenological – hermeneutic point of view was used to conduct the review of the ten articles dating from 1994 to 2003. Nine of these reviews used a qualitative approach and one used a quantitative approach. The three key areas of research that were examined by Fredriksen and Ringsberg were the experience of: 1) the body 2) the room, and 3) relationships during serious disease. Included in the ten review articles was the nurses' stress as part of the relationship experiences. The authors concluded that the different phenomena experienced by patients in ICU are not well understood and more research is required.

Physical discomfort has been identified as a major contributor to the ICU experience. Being intubated, experiencing suctioning, and being extubated are associated with pain. Often there is such a level of discomfort that the patient attempts to remove the intubation tube themselves. Physical discomfort was identified in a research study by Hofhuis et al. (2008) on

the experience of the ICU stay and the nursing care for fifty critically ill patients in ICU in the Netherlands. This study included two phases with the first phase using qualitative data and the second phase using quantitative data from a self-report questionnaire. In addition to physical discomfort, some positive experiences were also reported by the patients related to receiving support from nursing staff which in turn had positive effects on patients' psychological well-being. The patients in this case were described as experiencing a sense of safety and security because of the support from nurses that relieved fear and worries.

Recollections from ICU in the form of dreams have been examined (Magarey & McCutcheon, 2005; Papathanassiou & Patriaki, 2003; Roberts & Chaboyer, 2004; Roberts, Rickard, Rajbhandari, & Reynolds, 2006). Magarey and McCutcheon developed a questionnaire to screen ICU survivors. This questionnaire was comprised of 14 structured questions to explore memories of ICU and the distress caused by these memories. Of the fifty ICU survivors who completed the questionnaire, eight survivors were chosen to participate based on their reports of hallucinations, dreams or confusion. These eight persons participated in semi-structured interviews and the data were analyzed using thematic analysis as described by Morse and Field (1996). The researchers identified four themes: 1) moving from reality to unreality, 2) blackness and color, 3) powerlessness versus purpose, and 4) death. Moving from reality to unreality included subthemes: coming and going, funny things, rationalizing unreality, confusion, not knowing, hanging on to reality, familiar faces, caring nurses and uncaring, trusting, and pain. Blackness and color was the theme that emerged from an experience where everything looked black and white or a rainbow of colors. The theme of powerlessness versus purpose was characterized by feeling out of control, wondering how long the experience would last and having a sense of purpose. The theme of death was associated with participants thinking that they

would not survive, seeing people that were dead or thinking that people were trying to kill them and these were reported to be the most frightening dreams. Participants reported that reassurance from nurses and family during their ICU stay was helpful.

Once again the recall of dreams that occurred while in ICU was the focus of a study by Papathanassogiou and Patriaki (2003). The researchers used a hermeneutic phenomenological perspective to interview eight participants who had been hospitalized in an ICU. The four themes from dreams described were: 1) transformation of lived body, time, and space; 2) aloneness; 3) death-rebirth; and 4) transformations of life. In the first theme participants described experiences of their bodies feeling detached, swollen or heavy. Time was not perceived as passing as it normally would and participants could not recall seeing any walls in the ICU. In the second theme the experience of feeling suspended in space and being alone was described. In the third theme it was common to feel that death was near, but also the experience of rebirth was reported. There was a resulting celebration of being alive. The fourth theme included experiencing a transformation of the self. The researchers described this as a new person emerging after the illness that appreciated life and had come to terms with death. The researchers suggested that the ICU experience may be one of growth and that asking post ICU patients about their recollections may be therapeutic for both the patient and the nurse.

The impact of the experience of ICU has also been found to have negative consequences for patients who had traumatic experiences while in ICU. Researchers considered the possibility that anxiety and traumatic experiences in the ICU may be emotionally devastating enough to cause an increase in PTSD (Schelling, Stoll, Haller, Briegel, Manert, Hummel et al., 1998). In fact, the findings of the study by Schelling et al. demonstrated that occurrence of PTSD increased with the number of traumatic experiences reported by ICU survivors. In this study,

questionnaires were sent to eighty patients more than six months post ICU who had experienced acute respiratory distress syndrome (ARDS) and were in ICU between 1985 and 1995. Self-report of the Post-Traumatic Stress Syndrome ten question inventory (PTSS-10) revealed that 27.5% of the participants had developed PTSD which was much higher than the two control groups. The first control group was very ill surgical patients who did not experience ARDS or ICU and of these 11.9% developed PTSD. The second control group were soldiers who had experienced traumatic war events in active duty and of these, 1.3% developed PTSD.

PTSD caused by critical illness has been examined by a number of other researchers (Cuthbertson, Hull, Strachan, & Scott, 2004; Girard et al., 2007; Jones et al., 2001; Stoll, Kapfhammer, Rothenhausler, Haller, Briegel, Schmidt et al., 1999). Girard et al. used the Post-Traumatic Stress Syndrome ten question inventory (PTSS-10) to screen forty-three mechanically ventilated patients. They found that the incidence of PTSD was 14% at six months following discharge from the ICU, and PTSD symptoms were more likely in females and those receiving higher doses of lorazepam (a sedating medication). Cuthbertson et al. completed a telephone assessment of seventy-eight ICU survivors using the Davidson Trauma Scale. They reported the incidence of PTSD was 14% at three months post ICU and occurred more frequently in younger patients but there was no correlation with the gender of the patient.

In a systematic review of fifteen studies, data on PTSD prevalence, risk factors for post-ICU PTSD and the impact of post-ICU PTSD on quality of life were summarized (Davydow, Gifford, Desai, Needham, & Bienvenu, 2008). The overall prevalence of clinician diagnosed PTSD was 19%. One of the consistent predictors of post-ICU PTSD was post-ICU memories of frightening and/or psychotic experiences that happened in ICU. The authors concluded that the prevalence of PTSD in ICU survivors negatively impacts quality of life. The authors also

suggested that future studies examine how patient factors, ICU management factors and ICU clinical factors relate to one another and to post-ICU PTSD. This knowledge would allow clinicians caring for ICU survivors to be aware of PTSD risk factors and to monitor patients' needs for early intervention.

Delirium is a frequent occurrence in ICU. In a prospective cohort study using CAM-ICU in adult ICUs of a United States medical center, 83.3% of ninety six consecutive patients on mechanical ventilators experienced delirium (Ely et al., 2001a). The literature on the experience of ICU therefore would unavoidably include some experiences of delirium. In much of the literature about the patient's experience of ICU, delirium is not specifically identified. There is discussion about dreams, episodes of confusion, unreal experiences including hallucinations and delusions, traumatic experiences, and ICU syndrome or ICU psychosis but these experiences are not defined as delirium.

The Delirium Experience in ICU

If delirium is not frequently identified in the literature about the ICU experience, what impact does delirium have on that experience? The literature that I reviewed from the late 1990s did not identify the delirium phenomenon and the causes of delirium. In the analysis of interrelating factors of Intensive Care Unit psychosis Dyson (1999) attributes delirium to the environment and the nurse-patient relationship. There was a lack of recognition at that time that delirium was a symptom of medical illness and health professionals believed that it would resolve once the patient was transferred out of the ICU environment to a ward.

Delirium that was called the ICU syndrome was explored by Granberg et al. in 1998. A hermeneutic method was used to describe and give deeper insight to patients' experiences and memory recall both during and after their stay in ICU. In the study by Granberg et al. nineteen

patients who had been mechanically ventilated and had stayed in ICU for at least 36 hours were interviewed at one week and again at 4-8 weeks after discharge from ICU. Study participants described events before being admitted to the ICU, and their ICU stay including details about their feelings, physical experiences, experiences of time, sleep, other patients, and the staff. The authors described themes that identified patients' feelings of chaos, fear, and inner tension that could be positively impacted by a caring relationship providing security, comfort and explanation of events. They concluded that the inner tension and chaotic feelings of the patients were a critical factor in development and progression of the "ICU syndrome."

Approaching the topic of the "ICU syndrome" from a different perspective, researchers developed a questionnaire designed to measure different domains of a patient's experience of intensive care, the intensive care experience (ICE) questionnaire (Rattray, Johnston, & Wildsmith, 2003). The researchers' aim was to design a reliable and valid questionnaire that described and quantified that experience using domains of the ICU experience that are linked to short and long term outcomes. The questionnaire was developed in a two stage process: first patients were interviewed between 6 and 12 months post discharge from ICU in a cross-sectional retrospective study to test and refine questions. In the second stage a prospective longitudinal design was used to test the internal consistency, construct and predictive validity of the questionnaire. Exploratory factor analysis was used to identify the components of the questionnaire and correlational analysis was used to demonstrate predictive validity. The ICE questionnaire included four components: awareness of surroundings, frightening experiences, recall of experiences and satisfaction with care. One interesting finding was that those patients with low scores on the recall of the experiences were more anxious and depressed at six months after the ICU stay. They also had higher scores on avoidance and intrusion. One interpretation

the researchers made was that the association of less clear memories with intrusive thoughts may suggest that these patients had more unpleasant recollections than those who reported clearer recollections. The researchers described an “ICU syndrome” that was not defined as delirium even though the features are comparable.

The term delirium began to appear in studies as one of the experiences that occur as a result of an ICU admission. One example is the prospective study by Pochard, Lanore, Bellvier, Ferrand, Mira, Belghith, et al. (1995) who used a questionnaire to assess pain, comfort, sleep, anxiety, mood and delirium in patients 48 to 96 hours after weaning from mechanical ventilation. Out of the 43 patients who answered the questionnaire, 28 reported dreams and rated the majority of their dreams as unpleasant or nightmares. Diffuse anxiety was experienced by 22 of the 43 patients and 16 described an intense fear of dying. Depression was reported by 38 patients and a decrease in intellectual functioning was identified by 18 patients. Delirium or a confused state was reported by 15 patients, 23 patients could not recall any clear distinction between night and day while on mechanical ventilation, and 9 suffered hallucinations. The authors concluded that these patients who had experienced mechanical ventilation had a poor psychological status. The implications identified in this study were that research concerning the psychological influence of ICU admission and mechanical ventilation on patient morbidity is needed, interventions that may improve psychological status should be implemented, and that a psychiatrist should be consulted early and as often as necessary because of the high prevalence of PTSD.

Other studies have included delirium as one aspect of the psychological status of patients who had been in ICU. One such study is a randomized control trial that looked at the effectiveness of a rehabilitation program following a critical illness (Jones et al., 2003). The

Hospital Anxiety and Depression scale, the Fear Index, the Impact of Events Scale, the Short Form Health Survey and the ICU Memory Tool were administered to 126 ICU patients. The researchers measured levels of depression, anxiety, fear, PTSD symptoms, and level of physical health at eight weeks and six months after ICU treatment. Memory for ICU was assessed at two weeks post ICU discharge. In this study patients in the control and intervention group received ward visits, three telephone calls and clinic appointments at 8 weeks and 6 months following ICU discharge. The intervention group also received a 6 week self-help rehabilitation manual that contained a wide range of advice on physical, psychological, and psychosocial problems following an admission to a critical care unit. Patients in the intervention group had significantly lower scores on the depression scale at eight weeks post ICU admission and improved on the physical function scale at eight weeks and six months post ICU discharge. There was no improvement in anxiety and PTSD symptoms. One-way ANOVA analysis showed that the recall of only delusional memories and no factual memories were associated with increased levels of anxiety and PTSD. Based on their findings the researchers recommended that further psychological care may be needed for patients who recall delusional memories from the ICU to reduce the incidence of anxiety and PTSD symptoms. This is significant when considering the impact of delirium on the experience of ICU as the connection between delirium and PTSD has been made by DiMartini et al. (2007) who used case studies to demonstrate that delirium experiences during a critical illness can provoke PTSD. It has been suggested by other researchers as well that if delirium experiences include frightening delusions and hallucinations, there may be a causative relationship between having delirium and developing PTSD (Kiekkas et al., 2010).

Delirium began to appear more frequently as a main focus of research in the early 2000's.

A study in an 18 bed Australian ICU (Roberts & Chaboyer, 2004) was designed to describe patients' experiences of dreaming post-ICU and to compare the dreams with the behavior observed during their ICU admission (N = 31). The researchers used observation to determine if the patients demonstrated behavior that indicated delirium or not. There was no validated tool used to identify delirium. Seventy-four percent of participants reported having dreams after ICU and more than half of them identified the dreams as scary but there was no correlation between having dreams and agitated behaviors during ICU stay. Therefore there was no correlation between dreams and delirium status.

Two years later, Roberts et al. (2006) conducted a similar study in three Australian ICUs using the Intensive Care Delirium Screening Checklist (ICDS) a validated screening tool for delirium. This prospective cohort study combined qualitative and quantitative methods to compare patient recall of ICU for both persons who had delirium and did not have delirium. Patients who had been identified in a previous study with having had delirium or not having had delirium while in ICU were contacted after discharge from hospital and invited to participate. Participants were 41 persons from 3 Australian ICUs, of which 18 had delirium and 23 did not have delirium. The participant group was compared to a reference group from the previous study to look for bias regarding the group who agreed to participate. Demographics, ventilation status, admission category, severity of illness, length of stay, and delirium status were compared by using univariate analysis and there was no difference in the two groups.

In this study by Roberts et al. (2006) participants consented to a recorded telephone interview and were between 18 and 24 months post discharge from hospital. The structured interview included a combination of open ended and closed ended questions: memories of the ICU experience, if they had discussed the experience with anyone else, and if they usually

experienced dreams outside hospital. Qualitative data about the experiences were analyzed using Colaizzi's (1978) method to identify categories, statements and themes about the participants' dream qualities. The seven themes were: misperception of places, auditory, visual, frightening / persecutory, divine, bodily experiences, or indifferent. Quantitative data was analyzed to compare delirium status during ICU stay with the outcome of recalled dreams and demographics. Univariate analysis was used to compare both delirious and non-delirious patients, and dreamers versus non-dreamers for demographic and clinical variables. There was an increased prevalence of dreaming and of unpleasant or frightening content of dreams in patients with delirium. Within the 41 participants 49% reported only factual memories, 34% reported dreams and memories, 10% reported dreams only and 7% reported no memories. In this study, some of the non-delirious participants recalled good dreams. None of the participants who had experienced delirium recalled good dreams. Using univariate logistic regression, Roberts et al. looked for a predictive relationship between delirium status and recall of dreams but there was no significant association.

Even though the focus of this study by Roberts et al. (2006) could inform my study in that it identifies delirium in ICU with a validated tool and explores the recall of the ICU experience with and without the experience of delirium, there are limitations. The ICDSC tool used to identify delirium is complicated and staff members not trained in psychiatric assessment can, in my experience, have difficulty using this tool. Because there is no information in the study about training for the staff members who did the assessments, the validity of the identification of delirium by the ICU staff could be questioned. As well, it is possible that some patients classified as not experiencing delirium actually did experience it because the nurses in this study only assessed for delirium twice a day. Delirium is a condition that can fluctuate from hour to hour

and if a person is assessed at a moment of mental clarity, they may not be scored as delirious. The focus on dreams limits the experiences described by the participants. The experiences may have seemed like dreams to the participants or they may have been dreaming while still awake as previously described in similar studies about the delirium experience (Dupplis & Wikblad, 2006). The descriptions of the experience of ICU may have been descriptions of thought and perceptual disturbance that were labeled as dreams. Many studies have described a combination of reality and unreal experiences at the same time. What was described as factual memories by participants may not have been factual if compared to the medical records of events. The length of time after discharge from ICU has been shown to impact the recall of experiences in ICU (Lof et al., 2006; Schelling et al., 1998). This study describes the recall at 18 to 24 months post discharge from ICU and the person may have forgotten some of the detail. The use of the telephone for interviewing may have had an impact on the results as in-person interviews may have added data gained in observing body language and with the increased comfort of a personal interview. These limitations were taken into consideration in the design of my study.

Several authors have described experiences that may be delirium in ICU (Crammer, 2002; Misak, 2004; Richman, 2000). For example, Crammer, who is a British psychiatrist, gives a self-report from the point of view of a patient with a confusional state. It is based on notes written of his recollections shortly after recovery and he describes in detail four episodes of confusion during his hospital stay that he identifies as a toxic confusional state or acute brain syndrome. Another author, Misak, is a philosopher from the University of Toronto who discusses her experiences of "ICU psychosis" and coping after her stay in ICU with acute respiratory distress syndrome. She gives recommendations for staff to consider the patient's perspective and also gives suggestions for easing the transition out of ICU. A third example is Richman, a British

sociologist who describes a lengthy hospitalization that included seven weeks in ICU and his recollection of his “dreams” and the experience he calls intensive care syndrome. He offers his illness narrative to nurses to aid in understanding illness. These are narratives that do give an interesting and at times provocative account of their illness experience but there is no documented delirium as identified by a validated tool. In these personal accounts are theories presented by the authors and while they do give insights into the particular lived experiences, we do not know if they describe dreams, memories, or some other phenomenon.

Despite the growing body of knowledge about the psychological impact of the ICU experience including the delirium experience some recent review articles of ICU delirium have little discussion about the patient recall of the experience and the impact of that experience (Arend & Christensen, 2009; Pun & Boehm, 2011). Other recent review articles do focus on memories and psychological outcomes of having had ICU delirium (Belanger & Ducharme, 2011; Kiekkas et al., 2010; Samuelson, 2011). The importance of nurses being able to recognize psychological distress and the need for assessment and follow up for psychological issues during and after ICU admission has been highlighted (Kiekkas et al.). There is still a need to focus on the impact of having a delirium experience in ICU.

The Delirium Experience Outside ICU

Literature found on the topic of delirium experience outside ICU includes the recall of patients who lived the experience, as well as what it was like to observe the delirium from the point of view of families and staff. The focus of this thesis is on the experience of ICU for persons who have experienced delirium, therefore articles were chosen with this in mind. Many of the articles on delirium originate from elderly patients in the general acute care hospital population (Andersson, Hallberg, Norberg, & Edberg, 2002; Breitbart, Gibson, & Tremblay,

2002; Duppils & Wikblad, 2006; McCurren & Cronin, 2003; Schofield, 1997). Following is a discussion of the literature on the experience of delirium outside ICU that includes research articles and literature reviews.

Although most of the research on delirium outside ICU is focused on older persons, a quantitative study by Grover and Shah (2011) included distress after delirium reported by a wider age range of participants from age 18 to 83 years. These researchers found that generally the experience of delirium is remembered as distressing whether the participants remember the details of the delirium experience or not. A qualitative study by McCurren and Cronin (2003) included data from interviews of fourteen patients over sixty years of age who had been identified as delirious during their admission in an acute care hospital. Guidelines by Colaizzi (1978) were used to analyze the transcripts and three themes were identified. Being in the confusion was defined as feelings of fuzziness, misinterpreting reality, and hallucinations. Responding to the confusion included the emotions fear, anxiety, anger and embarrassment that occurred because of the experience. Dealing with the confusion was defined as trying to cope with the strange delirium experiences including the distortion of time and uncertainty about what was real. The authors concluded that enhanced understanding of the reality of a confused patient can help nurses intervene more effectively.

Schofield (1997) conducted a small exploratory retrospective study to examine older peoples' experiences of an episode of delirium. Using a grounded theory nineteen patients aged sixty-six to ninety-one years who had recovered from an episode of delirium were interviewed. Many participants experienced hallucinations and could describe them in detail and also recalled being oriented by nurses, but few knew much about the cause of the experience. There was very little evidence of therapeutic communication used by nursing staff once the delirium had

resolved. Schofield concluded that because participants were willing to discuss their delirium experiences it would be helpful for nurses to provide opportunities for the patients to do so.

In another qualitative study, delirium experiences have been described as like dreaming while still awake and as producing strong emotions of fear, panic and anger (Dupplis & Wikblad, 2006). Fifteen patients aged seventy to ninety-two years who had experienced delirium during an admission to hospital for hip related surgery were interviewed. The method of identifying delirium was not clearly described. Qualitative content analysis was used to identify three main categories: entry into delirium, experiences during delirium and exit from delirium. The majority of patients who had been approached said they could not remember anything about the delirium episode. For the participants who did recall the delirium episode, contradictions were a part of the descriptions of the experience. For example, they described being in hospital and somewhere else at the same time and included things from the present and the past that was both experienced together. The authors questioned if the delirium could have been triggered by unmet physiological basic needs such as being cold or thirsty. They concluded that it is important for nurses to pay more attention to delirious patients and to listen and interact with them during and after the delirium episode.

Fagerberg and Jonhagen (2002) interviewed five outpatients during their follow up visits with physicians. Patients were identified as having had delirium during an admission to acute care during the past twelve months. Delirium was identified using the Confusion Assessment Method (CAM). Data from taped interviews were analyzed by the method developed by Giorgi (2000). The two main phenomena studied were: being temporarily confused, and reasoning about experiences of temporary confusion. Participants described being unable to concentrate and therefore experienced “wide-open senses” and perceived everything that happened around them.

They felt threatened, suspicious, and wanted to escape. They felt shame about their behavior as well as guilt and humiliation about their temporary confusion. They looked for reasons for what had happened and they feared a recurrence. The authors suggest that awareness of the reasoning behind patients' behavior could help healthcare professionals understand why patients become aggressive. Researchers identify an imbalance of power in the relationship between nurse and patient that could contribute to the perception of the situation by the patient. They also point out that increased understanding by the staff about the patients' experiences can decrease the risk of abuse towards patients and suffering by patients. The patients that were interviewed in this study experienced strong emotions during the interviews but none wanted to withdraw from the study and they felt it was important to tell others about their experiences.

As discussed in previous studies many patients do not recall the experience of delirium. To examine patients' recall of the delirium experience, patients with cancer, their spouses/caregivers, and nurses used the Delirium Experience Questionnaire and the patients were rated on the Memorial Delirium Assessment Scale (Breitbart et al., 2002). This study included 154 hospitalized patients with cancer and demonstrated that short term memory impairment, delirium severity, and the presence of perceptual disturbances were significant predictors of delirium recall for the patients who experienced delirium. Less severe delirium, decreased consciousness, increased disorientation and increased perceptual disturbances were associated with decreased recall of delirium. Type of delirium was associated with recall. There were only 43% of those with hypoactive delirium who recalled the experience as opposed to 66% of those with hyperactive delirium. Although disorganized thinking and sleep disturbance did not impact recall, there was decreased recall with older age.

A review of literature on the delirium experience from the point of view of patients,

families and staff was reported by O'Malley et al. (2008). They used a systematic search of articles between 1980 and 2008 including keywords delirium in combination with mental recall, nurse-patient relations, attitude of health personnel, and professional-family relations. The search was carried out using the National Library of Medicine, PubMed and CINAHL databases. Seven qualitative studies and one semi qualitative study were examined.

In this review by O'Malley et al. (2008) patients' experiences were divided into six categories: emotional feelings, perceptual and thought disturbances, subjective perception of delirium, coping styles, sharing the experience, and long term psychological consequences of delirium. Emotional feelings were fear, anxiety, and feeling threatened. Common perceptual disturbances were visual hallucinations of people and animals or misperceptions of real stimuli. One example of misinterpretation was thinking that there was a party on the ward when it was busy and noisy. Feeling trapped in a situation that was hard to comprehend, and feeling out of control in between reality and unreality were also common. Many of the participants in the studies expressed frustration with communication barriers. Coping styles varied: some patients were anxious and fearful while re-experiencing the trauma through perceptual distortion and delusions; other patients were detached and used minimization, denial and repression to cope. Some patients reported a conscious effort to keep a distance from the delirium experience and minimize communication so as not to expose their delirium. Recall of the delirium experience was found to be less common in older patients and those with severe delirium, perceptual disturbances and major cognitive impairment (Breitbart et al., 2002). Factual memories were found to be less frequent in delirious patients than in patients who were not delirious. High levels of (PTSD) were identified in several of the studies in this review. O'Malley et al. identified "...a paucity of systematic empirical research to illuminate our understanding of the experience of

delirium...” (p. 223).

The Impact of Recalling the Delirium Experience

The recall of a delirium experience is frequent and can be quite vivid with powerful associated emotions (Breitbart et al., 2002) but memories of a delirium experience can be affected by cognitive changes in perception, thinking, orientation and memory that are part of this experience (Griffiths & Jones, 2007). An early case report by Mackenzie and Popkin (1980) discussed the stress response after delirium. The authors suggest that delirium is a stressful event that results in a stress response syndrome and a distorted perception of the stressful event impairs the resolution of this syndrome.

The impact of the delirium experience as well as the impact of recalling the experience has been examined. Reflecting on the experience of temporary confusion was the focus of a phenomenological study by Fagerberg and Jonhagen (2002). Five participants described feelings of shame and guilt, humiliation, and fear of recurrence as well as looking for reasons when trying to understand what they had gone through. Breitbart et al. (2002) completed a prospective systematic evaluation of delirium recall using the Delirium Experience Questionnaire in 154 hospitalized patients with cancer. They found that the majority of the participants (53.5%) recalled the delirium experience. However, short term memory impairment, delirium severity, and the presence of perceptual disturbances had a significant impact on recall. The majority of the participants recalled their delirium as highly distressing.

In a hermeneutical phenomenological study, Andersson et al. (2002) described their 50 study participants' experience of delirium as including elements of the past, the present, and the realm of imagination as a present reality. These participants had no past psychiatric history and confronted the idea of having been confused which was a new experience for them. Some

described being pressured by narrating the experience while the majority of patients felt relieved by talking about the event. Roberts et al. (2006) found in a prospective cohort study that delirious patients were less likely to discuss their ICU experiences with others. However, other researchers have suggested that the interview process is therapeutic (Papathanassiou & Patiraki, 2003).

The notion of the need for aftercare following an episode of delirium including therapeutic communication to deal with distress, fear of permanent losses, and education on delirium has come up repeatedly in the literature (Breitbart et al., 2002; Jones et al., 2003; McCurren & Cronin, 2003; Misak, 2004; Pattison, 2005; Roberts et al. 2006; Schofield, 1997). In a Swedish observational study, nurses helped families keep a diary including a description of daily activities and photographs while the patient is in ICU that could be given to the patient afterwards. The purpose was to help the patient understand what happened to them in ICU and help them come to terms with their illness (Backman & Walther, 2001). Out of thirty- nine patients and family members interviewed, twenty-six rated reviewing the diary as a positive or very positive experience because it helped fill in gaps in memory. It has been suggested that this process can decrease the incidence of PTSD (Jones et al., 2006).

Conclusions from Reviewed Literature

From this literature review I have concluded that the long term impact of an ICU admission is an area that has been identified for further exploration by the critical care community. Researchers have begun to recognize that the ICU patients' care extends beyond hospitalization and includes chronic issues of a medical and psychological nature (Jones & Griffiths, 2007). Psychological morbidities such as anxiety, PTSD, and depression are more common in patients with a history of delirium (Volk & Grassi, 2009) and there is a lower quality of life 3 and 6 months post-ICU for patients who have experienced delirium (Van Rompey, Schuurmans,

Shortridge-Baggett, Truijen, Elseviers, & Bossaert, 2009).

The experience of ICU has been associated with physical stress and emotional trauma (Cook et al., 2001; Fredriksen & Ringsberg, 2007; Granberg et al., 1998; Magarey & McCutcheon, 2005). The experiences of the body, the environment and the relationships have been examined. While the stress of certain procedures and situations can be logically seen as unpleasant, uncomfortable and painful it is less clear what the triggers are for ongoing psychological distress that may lead to PTSD. There have been various names for the phenomena that patients in ICU experience such as dreams, ICU psychosis, acute confusional state, and ICU syndrome. Many research studies historically would exclude patients with delirium because they could not communicate, they were uncooperative or there was no tool to assess those who could not speak.

The experience of delirium has been the topic of research for the elderly population especially in acute care environments. Delirium has been investigated in patients with cancer and in terminal illness as well as the experience of observing delirium for families and staff. While there are many similarities in the descriptions of delirium from the acute care population, it is believed that the ICU delirium experience has its own unique characteristics. The severity of illness, additional medications, procedures and situational variables that critical care patients are exposed to may impact the experience. It is known that the frequency of delirium is much higher in ICU than on acute care units. There is inconsistency in research on patients' memories of ICU as they include settings in different countries, different timing of interviews after ICU, and different methodologies (Lof et al., 2006).

We do know that delirium occurs frequently to a large portion of patients in ICU who are ventilated. We do know that fear, anger, suspiciousness, perceptual disturbance, confusion,

shame and guilt are feelings associated with the ICU experience and the delirium experience. We do know that for some patients the experience of ICU and delirium brought positive feelings of transformation peacefulness and enjoyment. What is often discussed in the literature is the importance of communication in coping with the experience while it is happening and afterwards. There are consistent recommendations for the assessment of patients' experiences of delirium and the impact of the memories of those experiences that occur in the ICU.

I have learned in reviewing the literature that considering the reported feelings of distress related to having experienced delirium, it would be important in conducting research to be sensitive in facilitating a discussion of the experience that may evoke these powerful emotions. It would also be important to allow participants enough time to fully explore the impact these feelings have on them. The impact of recalling the experience of delirium is an area that requires further research.

Other weaknesses and gaps are present in the literature. We do not know if many of the research studies were actually including the experience of delirium because they did not use a validated tool to identify delirium (Granberg et al., 1998; Rattray et al., 2003). Further, there has been limited progress in understanding the experience of ICU for persons who have experienced delirium. This literature review included sixty-three articles on ICU and delirium from 1990 to 2011 and only one research article was found that examined the experience of ICU for persons who experienced delirium that was defined and identified using a validated tool (Roberts et al., 2006). As well, there is limited information from a Canadian health care system setting. Not only is there a lack of recognition of delirium itself but one of the barriers to adequate clinical intervention may be the lack of recognition of the distress experienced by patients in ICU with delirium both during and after the ICU admission. This study can contribute to this body of

knowledge by exploring the experience with persons who have had delirium while in ICU.

An important gap in the literature is that there has been research on the experience of ICU and the experience of delirium outside ICU but there is limited research that specifically describes the experience of ICU for a person who has experienced delirium during the ICU stay. My thesis addresses this gap in the literature by examining the lived experience of ICU for persons who have experienced delirium.

CHAPTER 3

METHODOLOGY AND METHODS

Phenomenology as Methodology

Nurses are increasingly using phenomenology to explore patients' lived experience of illness and hermeneutic phenomenology can generate knowledge that is necessary for interpretations and responses in nursing situations (Earle, 2010). Phenomenology is a philosophy and a research method that will help the researcher to describe phenomena as lived experiences and essences of that lived experience. One methodological interpretation of phenomenology is described by van Manen (1997a; 1997b). This interpretation provides a human science approach that brings a hermeneutic phenomenological philosophy to the research. This means that human science aims for interpretive descriptions of a phenomenon that exact fullness and completeness of detail so that through analysis of descriptions, the nature of the phenomenon is revealed and meaning for the subject is understood in the form of essences and hidden meanings (van Manen, 1997b). Hermeneutic phenomenology as defined by van Manen is both descriptive and interpretive. This means that the facts of a lived experience are interpreted in writing them down. Hermeneutics is necessary when there is the possibility of misunderstanding (van Manen, 1997a) and in areas of study, such as delirium, that are different from everyday experiences both a description of the lived experience and an interpretation that helps people comprehend are required. The Heideggerian form of hermeneutics means that the researcher's knowledge and experience will be included in the findings instead of attempting to separate it. The method for this study is Heideggerian hermeneutic phenomenology as interpreted by van Manen. This study describes the experiences in the ICU for ten patients who were identified as delirious at some point during the ICU stay.

Research Methods

Research Design

van Manen is interested in engaged phenomenology conducted by professionals in health science. This means that instead of philosophical and theoretical phenomenology, these professionals provide “reflective understandings of the possible meaning and significance of everyday experiences” (van Manen, 1997b, p. 350). van Manen explains that anything that presents itself to consciousness whether real or imagined, empirically measureable or subjectively felt, is potentially of interest to phenomenology. Suggested approaches by van Manen that produce rich descriptions include the four existentials: lived space, lived body, lived time, and lived human relations. By using van Manen’s approach, a description of the lived experience for a person who has experienced delirium in the ICU can facilitate our understanding of the phenomenon. This knowledge could lead to ICU staff being increasingly aware of the patient’s experience of ICU when they have had delirium and therefore better prepared to act in these situations.

The four steps suggested by van Manen’s include: 1) turn to the nature of the lived experience; 2) engage in existential investigation; 3) engage in phenomenological reflection; and 4) engage in phenomenological writing. The first step involves orienting to the phenomenon. In this first step I recognized that I was approaching this subject from the point of view of a mental health nurse with a certain interest in this topic. I asked myself “What human experience do I feel called upon to make topical for my investigation?” (van Manen, 1997a, p. 41). I then formulated the phenomenological question so that it “teaches the reader to wonder and question deeply the very thing that is being questioned ...” (van Manen, p. 44) and refers us back to our world. Then I examined my presuppositions, assumptions and understandings as well as my

experience and knowledge of the topic of delirium in ICU. van Manen recommends that it is better to examine them and identify their impact than to try to forget them as they may creep back into our reflections.

The second step in van Manen's method involves exploring the phenomenon through using personal experience as a starting point, tracing etymological sources, searching idiomatic phrases, obtaining experiential descriptions from participants, locating experiential descriptions in the literature and artistic representations, as well as consulting phenomenological literature. I was aware of the etymological sources of words used to describe experiences and their meanings in the context of the phenomenon being studied. Idiomatic phrases can be a source to express the richness of human experience. It is important to reflect on verbal manifestations that may have interpretive significance for the actual phenomenological description. For example, while ICU psychosis has been used to describe the phenomenon of delirium in ICU, it is not an accurate description. Another example is that patients have used the term going crazy to describe how the delirium felt. It was important to consider the meanings of such terms in the data. Experiential descriptions from others allow us to become more experienced ourselves. In hermeneutic phenomenological human science the interview serves very specific purposes. The conversation helps to develop a relationship that illuminates the meaning of an experience. By exploring and gathering narrative material a richer understanding can be achieved (van Manen, 1997a). To improve the quality of the interview it is important to adequately prepare the participant and ensure his or her comfort. In interviewing the participant there is gathering of information as well as reflecting on that lived-experience with the participant who is a collaborator in the research process. The description needs to be in the form of the experience itself and not causal explanations, generalizations or abstract interpretations. There is a focus on an experience being

plausible and not on the factual accuracy of the description. It is important to focus on the person's expression of the experience and not their explanations and interpretations about what happened. Narratives about the delirium experience as well as research findings about delirium are available in the literature. Both sources can be useful in this stage of exploring the phenomenon.

The third step in van Manen's approach is engaging in phenomenological reflection. The purpose is to try to grasp the essential meaning of something and to bring about a more direct contact with the experience as lived. This includes conducting thematic analysis, uncovering thematic aspects of life world descriptions, isolating thematic statements, composing linguistic transformations, and gleaning thematic descriptions from artistic sources (van Manen, 1997a). Thematic analysis consists of seeing meaning in the experience. According to van Manen a theme is a reduction of the notion and the means to get at the notion, to give shape to the shapeless, and to describe the content of the notion. Uncovering thematic aspects includes looking at the different aspects of themes that make up an experience and how they are connected. There are three ways to isolate thematic statements: holistic; selective; and detailed. Using these three methods I focused on the text as a whole, the statements and phrases, and every single sentence while attempting to uncover thematic aspects of the phenomenon in the transcript. In order to reflect upon the transcripts of the interviews I immersed myself in the data. I listened to the recorded interviews several times and compared them with the transcripts. Line by line I highlighted interesting words and phrases. Composing linguistic transformations is a creative process by which one writes notes and paragraphs based on reading and research that captures themes and thematic statements. Finding thematic descriptions from artistic sources includes literature, art and poetry. I found drawings on a delirium website and on the wall of an

inpatient acute care unit that had been done by persons who had experienced delirium. These illustrations depicted the experience as distorted, dark, and frightening. I reflected on the images portrayed, the colors used and the titles of the drawings while searching for themes. I also found blogs and poetry on the Internet that used common words in the individual descriptions of delirium which again were usually distressing experiences. I listened to stories of staff that had a relative who experienced delirium. I refined the descriptions of the themes and presented preliminary findings to healthcare professionals at conferences. The transcript themes were shared with my supervisors and we reflected upon them and discussed them. A brief summary of themes was mailed to five of the ten participants who could be contacted to seek their feedback on those themes as part of their experience. Then the participants were telephoned to ask the question "Is this what the experience is really like?" Finally I reviewed each theme and assessed it along with my supervisors to determine its significance in the meaning of the phenomenon by asking "Is this phenomenon still the same if we imaginatively change or delete this theme from the phenomenon?" (van Manen, 1997a, p. 106).

The fourth and final step in van Manen's method is phenomenological writing, which includes attending to the speaking of language, varying the examples, writing and rewriting. The phenomenological method consists of the ability to recognize subtle undertones of language. By varying the examples, a description can bring to life the many parts of an experience that would be limited by only one example of a phenomenon. Because writing creates a reflection of what is written, it causes us to rewrite. This process was one of writing, receiving feedback and rewriting while changing language until the meaning was described as intended.

Participants and Setting

The inclusion criteria for participants were adult patients who had been admitted to ICU and who had been identified as positive for delirium while in ICU using the CAM-ICU tool. Patients with prior dementia, those who were unable to read, those who were unable to speak and those who were unable to speak English were excluded. It became evident after 5 weeks that patients were often transferred out of critical care while they were still delirious. Therefore, I did not ask patients to give consent to the study until they were no longer delirious using the CAM-ICU tool.

Patients were identified for possible inclusion in this study by nurses in critical care as well as on wards and also by the psychiatric consult teams. These patients were approached by the clinical educator for ICU to obtain signed consent to release the name to me. The clinical educator for ICU is not usually involved in direct patient care and therefore was a suitable recruiter for participants to avoid patients feeling they were coerced to participate. I approached each potential participant to explain the study and review the consent form. This was done at the patient's bedside or in another private area. The consent form was signed and a copy of the consent was given to each participant.

Twenty- one patients were identified as having delirium and twenty agreed to meet me to discuss the study. Five patients reported they did not remember anything about ICU. Two patients were too ill to be interviewed. One patient said it was too hard to talk about. One patient had a family crisis and one patient stated he changed his mind. Ten patients from two hospitals were interviewed while inpatients on a medical or surgical unit.

On several occasions there were delays in approaching patients who were not able to speak because of tracheotomies. On a couple of occasions it was necessary to wait for patients to be

medically well enough to tolerate a discussion about the research. It was challenging to procure participants because of the severity of their illness and because of availability of staff to recruit them. Therefore, potential participants may have been missed.

It is always difficult to determine the correct number of participants that will be needed for a phenomenological study. As the research progressed there were several common ideas that were expressed about the experience and in particular several rich descriptions that contained sufficient detail to provide adequate data to describe themes around the experience of ICU for persons who experienced delirium. Part of this experience is the loss of time and lack of recall of the experience and the impact that can have on a person. Therefore, the one interview in which the participant revealed that the experience could not be remembered was included in the data.

The study took place at two acute care hospitals in eastern Canada. For the purposes of this thesis, ICU includes three types of adult critical care units: cardiovascular intensive care, coronary care, and medical/surgical intensive care. The coronary care unit contains private rooms and the other ICUs are open multi-bed units that may have a few private isolation rooms.

Data Collection

Data were collected through interviews that lasted from ten to forty minutes and each one was audio recorded. Each interview was conducted in a private room, usually the patient's room or a classroom on the unit. A semi-structured interview guide was used to conduct the interview (see Appendix E). One participant seemed uncomfortable with being audio recorded and spoke more freely after the recorder was turned off so that data was not recorded but captured in notes taken after the interview. One interview was interrupted by staff accessing the room for treatment purposes. While some participants were emotional during the interview, none of the participants became too upset to finish. Information collected included the recorded interview as

well as the patient's age, gender, telephone number, and mailing address. Two participants requested to have a relative present during the interview for emotional support. During the first interview of this kind the relative was silent. In the second interview that included the presence of a relative, that person gave comments that may have influenced what the participant discussed. However, only the data from the participant was analyzed. None of the other interviews were done with other people present.

Data Analysis

The data were analyzed and written using van Manen's guidelines for phenomenological analysis. In explicating our understandings, beliefs, biases, assumptions, presuppositions, and theories we can identify influences on the analysis of data (van Manen, 1997a). I used my notes along with self-reflection to identify the contribution of my past experiences with persons who had experienced an ICU admission and delirium. In Heideggerian hermeneutic philosophy the researcher's knowledge and experience is not set aside but it is included in the comprehending phase. I have assessed many patients over the past nine years who have experienced ICU and delirium. I do have a baseline understanding of their experiences. I had an expectation of hallucinations, fear of being harmed, participant's doubts about their mental health, the ICU environment, and comments on the quality of nursing care.

Next, in the synthesizing phase descriptions in the literature are found to compliment the transcripts. Using sources from literature, the data were placed in the context of what is already known about the particular experience. A list of themes identified in previous research was compiled and the results were compared to the transcripts to look for similarities and differences.

The step of theorizing occurs in reflecting on the four existentials: lived space, lived body, lived time, and lived human relations. The essences of the experience are uncovered by this

process. Themes were identified by reading the description of an experience as a whole, then highlighting phrases that are meaningful to the phenomenon, and subsequently a detailed line by line approach to isolate thematic statements. After the first interview I identified the need to seek more detail in the interviews about the lived space, lived body, lived time, and lived human relations. I asked questions about the passage of time, feelings in the body, interactions with others and the ICU environment. For example, when discussing the perception of time I would ask if time seemed to go quickly or slowly. I asked if the participants recalled any particular sensations in the body. Also, I asked the participants if they remembered other people around them or what the room was like. Once the interviews were transcribed verbatim, I listened to the tapes while reading transcripts for accuracy. There were brief gaps in the transcripts at times due to noises from equipment, soft voices or heavy accents that prevented the transcriber from identifying some words. I was able to fill in most of those gaps and used the edited transcripts for data analysis.

Finally in recontextualizing there is refinement by writing and rewriting the data while increasing the level of abstraction away from the particular to the more universal sphere. The goal is to come to a description of lived experience with which we can identify. To improve the rigor of the study, accounts were constructed that were “trimmed of all extraneous possibly interesting but irrelevant aspects of stories” (van Manen, 1997a, p. 69). As well, to improve rigor, I composed a thematic summary of all transcripts to mail to each participant for the purpose of validating the overall themes. This is consistent with van Manen’s method in which the participant is a collaborator in the research. A follow up telephone interview allowed for phenomenological reflection and thematic analysis through conversation with the participant as in van Manen’s method. As I am a novice researcher, this process was guided by my thesis

supervisors. I highlighted words and phrases for my supervisors to support themes I had identified and these were discussed during this process. Collaborative analysis also occurred when I discussed the themes with my thesis committee member who has expertise in phenomenology.

Quality of Research

Rigour in phenomenological nursing research is a controversial topic in the literature. Several frameworks have been proposed to facilitate expressions of rigour rather than criteria of rigour for interpretive phenomenology (De Witt & Ploeg, 2006). Some expressions of rigour suggested by van Manen (1997a, 1997b) include orientation and attunement toward the phenomenon of inquiry, concreteness that links the phenomenon to the reader's lifeworld, and resonance that encompasses the felt effect of reading the study findings. The research process suggested by van Manen was followed, however, as a novice researcher I sought a framework that would give me guidance and well defined criteria to apply during the entire research process. The framework I chose for ensuring the quality of research was that of Whittemore, Chase, and Mandle (2001). This framework for achieving rigor includes four primary criteria: credibility, authenticity, criticality, and integrity. It also includes six secondary criteria: explicitness, vividness, creativity, thoroughness, congruence, and sensitivity.

The four primary criteria apply to all qualitative inquiry (Whittemore et al., 2001). Credibility and authenticity are connected and refer to descriptive and interpretive validity. Credibility includes trustworthy interpretations of the meaning of the data that reflect the experiences of the participants in a believable way. Credibility was supported when I sent the thematic summaries to the five participants that I was able to contact and they agreed with the descriptions of the themes as something they could relate to their experience of delirium in the

ICU. Authenticity involves accurately portraying the meanings and experiences of the participants with an awareness of subtle differences in their descriptions and also awareness of the inquirer's influence. Authenticity was achieved in the discussion of the findings of this study as the experiences of every participant were included as a part of the multiple realities of the experience. For example, only two of ten described a life change as a result of the experience. Even though this was not a major theme of the findings it was included in the discussion as a potential area for further research. Criticality and integrity are the approaches that include reflexivity, open inquiry and critical analysis that contribute to validity of qualitative research. Criticality is evidence that critical appraisal of key decisions occurred during the research process and during the presentation of findings. This was achieved by discussing ethical decisions with committee members, reviewing my actions and seeking advice as needed throughout the research process. Integrity allows that the investigator may interpret the data uniquely but those interpretations must be checked to avoid bias and to include consideration of alternate interpretations. Integrity of the research was achieved because these four criteria were a part of the entire research process that was reviewed by my supervisors and committee member.

As this inquiry includes data that is abstract the secondary criteria were also applied as a means of seeking validity of the findings. The questions suggested by Whittemore and colleagues (2001) for self-scrutiny during the study and for post hoc assessments of the study were used to ensure explicitness, vividness, creativity, thoroughness, congruence and sensitivity. Explicitness in presentation of findings allows the reader to follow the researcher's judgments and interpretations and gives insight that provides evidence and support for conclusions. Explicitness was achieved by assessing adequacy of my notes and copies of forms that documented decisions and interpretive processes as well as identifying my biases or

perspectives. A journal was kept noting significant events and decisions during the research process. I identified my assumptions about delirium in ICU before beginning the interviews.

Vividness involves presenting the data so that the essence of the phenomenon is described in enough detail so that the meaning is visible. Vividness was achieved by using the data to provide a rich evocative and compelling description without excessive detail. Creativity uses novel ideas, imagination and flexibility to enhance innovative findings and challenge traditional ways of thinking. Creativity was achieved by using my imagination to bring together depictions of the ICU experience and the delirium experience such as drawings, blogs, and stories in writing about the phenomenon. Thoroughness produces a comprehensive approach and analysis that includes exploring the full scope of the phenomenon and checking data quality. Thoroughness was achieved by ensuring data adequacy, and convincingly answering the research question. The feedback obtained from the participants about their agreement with the thematic summary also supported this criterion. Congruence ensures that study findings fit into contexts outside the study situation and demonstrate logical congruency as well as congruency with the philosophical or methodological approach. Congruence was achieved by ensuring a good fit between questions, methods and participants as well as themes that fit together coherently. There was congruence between the transcripts from the two acute care centers as well. Sensitivity refers to consideration of the multiple voices of the participants and their human, social and cultural contexts so that human dignity and respect are a part of the implementation. Sensitivity was achieved by ensuring that methods and questions reflected an ethical and sensitive respect for participants and their contexts. Even though the describing of experiences has been reported to be therapeutic, the impact of the interview process was considered and supports were available

as needed. The influence of the participants' cultural contexts such as choice of language and dialect were considered during the interviews and in the assessment of the transcripts accuracy.

Ethical Considerations

This study was conducted in compliance with the Tri-Agency Framework: Responsible Conduct of Research (2011). This proposal and an amendment were submitted to the Human Investigation Committee (HIC) of Memorial University of Newfoundland for approval (See Appendix C) as well as to the Research Protocol Approval Committee of Eastern Health (See Appendix D). To avoid coercion, participants were recruited by the clinical educator for ICU who had not provided direct care. Consent process as described in HIC guidelines was followed. Participants were given a written description of the research study that they could share with family and there were several instances when family members were present for the explanation of the study (see Appendix F). There was opportunity to ask questions. Consent was obtained only when the participant was not delirious as assessed by myself using the CAM-ICU features of delirium as a guide. Participants were informed of their right to leave the study at any time. They were offered mental health supports if needed and they were reassured that they would receive the usual care whether or not they participated.

Confidentiality was protected by removing identifying information before interviews were transcribed and by using dates of the interviews to track the transcripts. All research project members involved, including transcribers, signed an oath of confidentiality (see Appendix G). Research supervisors received a copy of the interview transcripts to assist with the analysis. Tapes of interviews were destroyed after the data analysis and the transcripts are stored in a locked drawer of a locked office. Data will be saved for five years after publication of any manuscript from this study and then destroyed by shredding the transcripts. If my job changes

before five years, I will move the transcripts to a locked drawer in my new employment site.

Electronic copies of the transcripts were password protected.

There may have been indirect benefits to participants because the process of collecting data in interviews can be therapeutic. Quality of healthcare can be improved with staff members' increased awareness of delirium as a significant symptom of underlying illness and a distressing experience. Some patients may benefit from recalling their experiences while others prefer to forget their experiences (O'Malley et al., 2008). The well-being of participants was protected by collecting data only as tolerated by the patient. Risks to participants may include fatigue, inconvenience and emotional upset of the interview process. Two participants were visibly upset during the interview and therefore we stopped for a break. Both were offered extra support from the psychiatry team.

The boundaries of the researcher's role were limited to data collection and education on delirium at the end of the encounter. The separation of my role as researcher from my role as mental health nurse was at times a challenge. I often had to remove myself from situations where potential participants were being discussed and I had to remind nurses not to tell me about potential participants. I made it clear to my participants that I did not have access to their charts. The only knowledge I was to have about them was what they had consented to for the study. In fact there were several patients that I assessed in my role as a mental health nurse that would have provided rich data but did not meet the criteria for my study because I had assessed them while they were still delirious. Providing nursing care to a potential participant prior to the recruitment process could lead to coercion because a patient may feel obligated to participate in the study. I clearly described the purpose of research visits and I did not have other contact with research participants to provide mental health assessment or care.

CHAPTER 4

FINDINGS

In the ten interviews I conducted for this study all participants reported not recalling a portion of the time that they were in ICU. For the segments of time that participants could not recall they experienced mixed reactions. Some participants were glad not to remember and some wished they could remember and asked questions about it to family and friends. While some participants were emotional and were intensely affected by the experience, others spoke in a matter of fact manner. Two participants described feeling changed from the experience and that they would no longer take their health or their families for granted. Because this was not a consistent finding in the majority of interviews, it was not identified as a theme but it may be an area for future research. Within the descriptions of the part of the ICU experience that they could recall, many participants expressed similar ideas.

Themes

Four themes were identified from the interview transcripts: *I can't remember, wanting to make a connection, trying to get it straight, and fear and safety concerns*. Following is a discussion of the four main themes identified from the interview transcripts.

Theme One: I Can't Remember

The theme *I can't remember* captures the lack of memory for a period of time during the ICU experience that was noted by all participants. Some participants stated they did not remember much about being in the ICU and others stated they did not remember much about the period of time that they were experiencing delirium. For all the participants in this study, there were periods of time when they were awake in ICU during the delirium. They became aware that they had been awake for these periods of time that they could not recall because they were later

told by family and friends about things they said or did during periods of delirium. They had lost periods of time during the experience. Some participants were very emotional while recalling the experience of losing time and did not want to relive the experience while others were matter of fact about losing time. The meaning and impact of this was different for each participant. While some were glad not to remember, others wanted to know everything. Some described feelings of guilt and shame when they were told how they had behaved and what they said while they were in delirium. Some felt hurt when family members joked about their behavior during this time.

All participants described having to rely on family and friends to tell them what had happened during the time that was lost. Because they had no memory of the events during that time they found it hard to believe what their family members described. When one participant was told what had happened during his lost time he doubted the description because he had no recall of the event and another said he could not believe what others told him about how sick he had been.

They kept telling me oh... you were [very] sick...they kept going back to the bad part or the danger part. So [that] made me more skeptical...and confused as well...how come I don't remember... I can't really remember what you are talking about.

Some participants recalled missing long periods of time being in ICU that they could not remember. These times ranged anywhere from two weeks to two months. For others the loss of time was described as periodic. In describing her experience, one participant felt like she had been gone for a long time and was afraid she would not know her family. However, several participants explained their experience as being “in and out” when recalling that they were aware for periods of time and then periods of time were “lost.” Part of the lost time for some participants was attributed to the effect of their medications as one participant described being “doped up.” In detailing this event one participant explained that:

Time went really fast...it seemed like one minute they were there...the next minute somebody else was around. But then again I was probably in and out on medications and when I'd wake up or become aware of where I was, I might have been after sleeping ten hours....

One participant who had no memories for a long period of time asked her husband to tell her what had happened during this time period. She felt that knowing everything would make it easier for her but her husband did not want to talk about it and just wanted to move on and forget about her experience.

I thought it was the 8th of May and I said to him, oh yes, wish [my sister] a happy birthday and he said that [her birthday is on] the 8th of May. He said it was the 8th of July and I said the 8th of July! Where have I been? Where am I? So they told me, as much as they wanted to ... Gradually I am asking questions but then... I think they hesitate to tell me.

The impact of the lost time was different for each participant. While some felt “happy” that they did not remember everything that they were told had happened, others wished they had remembered details of the part of the experience they were missing. Some study participants were bothered by the fact: “why can’t I remember?” Remembering the whole experience for some would give them “peace of mind” and help them feel “in the loop.” Some participants felt vulnerable because they were not able to recall the whole story of being in the ICU. For one participant the recall of events would help him to feel like part of the family conversation about the events in ICU.

...at least then if the topic comes up with somebody else I won't... feel like a fool, I [won't] feel like I don't know anything... you're part of the conversation instead of being the conversation.

During the interviews some participants were relaying the story of being in the ICU in a matter of fact way and preferred to “let it go” or focus on getting back on track. These participants were not emotional when recalling the experience. They did not appear to be reliving

the experience.

I never got down...I'm lucky that I'm out of it and I feel that I'm going to carry on.

For others, talking about not remembering the experience was very emotional.

The passage of time for me just seemed like I just went to sleep...maybe a day or so and I find out it's six weeks...I was shocked, it brought me to tears, I couldn't believe that...it still bothers me that I could be out that long and not know ...I was hooked up to every kind of machine and hoses and IV drips and everything hanging off me and I was swollen up... stuff that is very unpleasant... to think of myself in that position. So no, I'm glad I don't remember.

Several participants talked about behaving during the delirium experience in ways that they described as being uncharacteristic of them. They could not remember the behavior but they were told by family members that they used swear words, they were agitated, and they talked to staff or visitors in an unkind way.

I can't remember much but my family said that I was saying a lot of stuff to the nurses and to them and I used to get really agitated and I'd use swear words.

Several participants expressed similar concerns that they did or said unpleasant things during the lost time. Some of the participants had feelings of guilt, embarrassment, or shame about their actions while delirious and spoke of their need to apologize and repair relationships after discharge.

I've got to face them...I've got to deal with it [behavior] somehow...I still need to apologize for it because that's not me. It's coming out of my mouth but it wasn't me.

Participants identified that the reactions of family and friends also had an impact on how they felt about what had happened. They felt hurt when others joked about or made light of the experience.

...they still have to make a bit of fun...they're trying to make me feel better I suppose ...it makes me feel bad...it's not funny.

Theme Two: Wanting to Make a Connection

The theme *wanting to make a connection* captures the feeling of being disconnected or separated from others, the challenges of connecting with others due to not being able to talk or move, the efforts participants made to move their mouths or reach out, and the resulting feelings of frustration and fear. All in the study found the experience of having trouble connecting very distressing. Participants expressed the need to make a connection with others to help them feel safe and secure and two participants described experiences when they did feel connected.

Disconnection was described by some as feeling like they were physically separated from everything and everybody in ICU as if being moved to the side of the room. They felt that people were passing by but that they had to fend for themselves because people were doing their work and not interacting with them. Although the staff members were clearly visible to them there was nothing they could do to make the connection.

But it seemed like I was there and every now and then someone would come in to do something and then they would go and pass by and give me a look and then go on again, like you were off in the corner...One would be walking by and one sitting over at the desk, one going that way...At the time it seemed like you were left on your own. Either you get better or you don't... like I had to fend for myself or else I just had to take it.

For others while the feelings of disconnection were vivid and present, they were also surreal. One woman described how the feeling of disconnection could only be compared to being in a bubble.

... it's just like living in a bubble. It felt like I was living in a bubble, I couldn't move my arms or legs. And, ah, people all around me but no one answering me, ...like just calling out to people but... no one hearing or answering... I would be calling out... to people but no one would even look up...

Challenges were present to impede connection. Patients were without a voice because they were intubated or had a tracheotomy. They could not talk about what was real or not real and

they were not able to express their feelings or ask questions. They described instances when people did not look at them. Participants also described difficulties with moving because of weakness, sedation, or restraint that was described as being “tied down.” They could not try to connect by movement.

Several efforts were made by participants to make a connection with others in the ICU environment during the experience of delirium. Despite their efforts to make eye contact, move their mouths, or move their bodies in order to communicate, they were not able to get the attention they wanted. Three participants recalled trying to move their mouths to connect or communicate, thinking others could hear them. They put a lot of effort into trying to talk and thought they were talking. There was a lot of effort put in to trying to communicate.

The feelings that resulted from not being able to successfully connect with others were identified as frustration and fear. The intensity of the experience for these participants was described through words and even demonstrating the movement of their mouths during the interviews. They reported feeling alone or misunderstood and unable to express their concerns or discuss their experiences. One participant spoke about her frustration with not connecting.

But I was frustrated with the nurses and just for example trying to move my mouth; trying to mouth the words and they couldn't understand what I was saying... they weren't getting it. Nobody was getting it.

Even though the majority of study participants described feelings of not being able to connect, this was not the same for all. A couple of participants recalled making a connection during at least a part of the ICU stay even though they were unable to speak. One participant revealed that he had staff members who talked to him and explained everything and this helped him to feel connected. He said he also had some staff members that just sat at the end of the bed which was not helpful. He described an interaction with one particular nurse who spoke as she

did things step by step in providing care. This participant characterized the nurse's behaviors as taking time to connect with him.

There's one nurse had me for three days in a row...she took me one on one and soaked my feet...they thought I was out of it when she was doing it but I can remember...she made me feel so comfortable...talking to me...I was following her commands...more personal involvement...I would focus on what she was saying and I didn't feel so out of it.

One other participant reported that the use of a letter board to communicate helped him connect with family and with staff members. However, most participants felt that as they reached the end of their ICU stay and were able to talk and were feeling better that this enhanced their ability to connect and to communicate with others. Such improvements in feeling connected made their experience of ICU more comfortable and secure.

Theme Three: Trying to Get it Straight

The theme of *trying to get it straight* refers trying to both understand and to make sense of the experience of delirium both during and after being in ICU. During the experience it was difficult to differentiate between what was real and not real and if they were dreaming or awake. Many participants had difficulty understanding what they described as a weird occurrence because they had experienced unusual phenomena such as hallucinations, disorganized thinking, and periods of disorientation. These experiences were compounded by an impaired ability to communicate, which was a barrier to seeking explanations from staff or family. They were searching for cues in the environment to help them and communicating with staff facilitated their understanding of the experience.

Part of the problem of understanding what had happened while being in ICU and having delirium was the difficulty in separating out what was real and what was not real. Some participants thought they were dreaming, while others felt they were awake or dreaming while awake. It was difficult for some participants to tell the difference between what was real and

what was not as events and sleep-wake states were mixed up and the dreams were so vivid that they seemed so real. For one participant the dream was described as a combination of reality and not reality that included the past and present at the same time. He experienced hallucinations about World War II events that he believed were happening to him in the present. As described in this quote from another participant, the combination of reality and things that were not real coupled with the temporary nature of some experiences added to the confusion.

Very confusing...You didn't know what to believe like ...are they [monkeys] really up there in the lights or is that just your mind and then you look at [sister's name] is she really there or is that just my mind...I couldn't get...what's real and what's fake right... it's confusing. And I must have went to sleep or I must've dozed off or something and I woke up and it was gone. The monkeys weren't there.

Perceptual disturbances were very common, for example hallucinations such as hearing music, going through a tunnel with dark colors, a feeling like being on a ship because of feeling the ship move and hearing the ocean waves. These perceptual disturbances only added to the real life quality of what was happening to the person and distorted the sense of reality. One man had experienced everything in the room, including himself, as being tilted.

They were giving me a painkiller and every now and then I'd wake up and it seemed like we were tilted...yeah like you'd have the bed on the wall but so was everything else sort of that way. But I closed my eyes and sometimes it would still be there and other times it wouldn't.

Visual disturbances were common as well, and the vividness of these visions had a similar effect to the other perceptual disturbances just described. The participants described these visual disturbances to include seeing turkeys in a kitchen, car lights on the wall, large black birds, savage monkeys in the lights, fairies, and a lady picking flowers.

The feeling of disorientation was distressing for some and looking for cues to help orientation was difficult for participants. One lady was distressed because she was looking for her mother who was deceased. Some participants found it difficult to tell time as they could see

the time on the clock but did not know if the time was in the morning or in the evening. There were no calendars and no view of the outdoors to look for cues in the environment. One participant spoke of how others kept him informed of the date and what was happening, but he felt confused because he could not determine this on his own.

I was being told anytime I asked ...I was always being kept up to date about what was going on around me but I didn't know on my own...and I'd be kind of confused about it.

Some participants did not realize that they were in ICU and thought they were in a different location such as: a boat, a nightclub, a beauty parlor, a building downtown, a psychiatric facility, or a race track. When they spoke with me they could recall in detail what each place looked like.

The experience for some could be described as being disconnected with “*everything coming at you*” or “*everything was messed up in my head.*” The impaired orientation and thought process caused some participants to misidentify people and misinterpret their actions. One participant recalled trying to figure things out.

I knew I was in a pretty hairy situation, looking around, you know seeing where I was, I knew I was probably in an ICU or something, but I had no concept of time; I didn't realize I was in for so long. ...actually I thought... one of the nurses who gave me a bath...she took the cross and, I saw her put it in her pocket... and I told her that I knew what she had done and I told her to put it back...and anyway two weeks later I found out that the lady I had thought had done it, the nurse...she doesn't work here, she works in the bank so that wasn't even a nurse.

Because of the combination of thinking and orientation difficulties experienced, one participant wondered if he had been in two places even after leaving ICU. He thought one place had real professional staff and the other place was a sham.

I was looking around and up at the ceiling and I said this is like the place I was at yesterday. I see the people walking around and I said I know him, and him. They're not doctors and nurses and they're going around as if they're doctors or nurses. And I go in there and I could see [some] amongst that crowd who would be

legitimately medical people and I'd go back the next day and all the people would be there and I knew every single one of them because I was there when I was supposedly half sensible and they were all legitimate as far as I was concerned.

Participants sought cues in the environment or from staff to help them understand what was happening. The environment of the ICU was referred to as a small area with a lot of people and for some participants it was noisy especially around shift change. Participants recalled that it seemed like everyone was in a hurry and communication was challenging for them because of being intubated and feeling sedated. They talked about some of the actions by staff that helped them become oriented and focused. For example, they said that the nurses who interacted with them and explained things helped them to make them feel more focused. Also, the participants found that when they were able to talk about the strange experiences with staff that this helped them to figure out if an experience was real or not. Staff-patient interaction would help the participant focus and feel less “out of it.” At times, however, participants felt the staff’s assessment of their orientation could be an example of misunderstanding.

... Ah, nurses would come and ask me “do you know where you are?” ... And, ah, I would say [place] and they would say well that’s very good. But I thought [place] was the name of this boat that I was on.

Another participant reported that the staff did not realize that he was aware of what they were doing.

...[the nurse] soaked my feet and a lot of people thought I was out of it when she was doing it but I can remember her doing it.

Several participants described their experience as a puzzle with missing pieces or that it was confusing as they were attempting to associate things that have no real connection. What they were trying to do was to get information about what had happened to them so that they could put the story together after the experience. After transfer out of ICU, some participants had memories of the feelings they had experienced in ICU and many of them tried to make sense of

those experiences. Some reported the memories of these experiences and feelings as coming back in “flashes.” One participant reported having to sit up in bed until she reoriented herself to the present. Those that recalled their unusual experiences were concerned that these may be weird or not normal or that they had a “mental condition.”

Theme Four: Fear and Safety Concerns

The theme of *fear and safety concerns* represents participants feeling that they or their families were in danger or that they were safe because they were being cared for. Participants were very emotional when describing these memories. Even though they could not always say specifically why, some were able to identify the source of their fear. For those participants fear was caused by unexplained experiences including vivid hallucinations, the concern of re-experiencing delirium, and feeling helpless and weak from medication effects, illness and restraints. The experience of disorientation reported by one participant created a feeling that he was in World War II and had been picked up by Japanese soldiers on another ship. This participant said he believed that the ICU staff members were these soldiers. He also felt that staff members were trying to harm him when they were trying to give him a bath. He did not understand what was happening or why. The result of feeling afraid was that participants occasionally fought against staff.

These feelings of fear were compounded by the unusual experiences such as hallucinations. Participants could not explain or understand these strange experiences. Some of the visual hallucinations were described as vivid and very frightening. Several participants recalled fearing that they were going crazy. They described that the main unusual experiences they had while awake were the visual hallucinations and experiencing reality and non-reality at the same time. An example of a visual hallucination was described as large “man sized” black birds flying

overhead that would try to attack. One participant recalled vivid details of an experience that included visual and auditory hallucinations of monkeys in overhead lights. This experience had a lasting effect because she spoke of feeling afraid from these hallucinations even after she had been out of the ICU for weeks.

... the one that was most upsetting was the monkeys ...up in the lights...you could hear them jumping up and down and they were balling like they were trying to get at me... I didn't know if they wanted to get at me or what but they were up in my lights in the ceiling...I could see them jumping up and down. They were on all the lights not just at the one that was at my bed but all around the room... and they were like, they were savages. They were gone savage and I didn't know what they wanted if they wanted to get out or if they wanted to get at me...To this day I'm still afraid to look up at the lights... And I always think, when I talk about it I whisper because I'm afraid they'll hear me. That's what it was like when they were up there.

The delirium experiences were so disturbing that participants feared re-experiencing them. One participant remembered being very distressed and was emotional when recalling her experience. She recounted that while in the ICU she was afraid of returning to the state of having the delirium experience and therefore would refuse a sleeping pill. These events caused her to fear future surgery that would send her back to the ICU because she may re-experience delirium again.

... 'dear God in heaven, if you can't make me better just take me home with you because I can't live like this.' I was just sort of at my wits end you know... I was scared, I was everything. I was scared I was going to go back in that bubble... I couldn't sleep in the night time and they were saying, [name] you should have a sleeping pill. Why won't you have a sleeping pill? I said, no my dear I can't have a sleeping pill because I'm too afraid I'm going to experience what I saw before.

Another participant described feelings of helplessness, weakness and fear because she was unable to move. She described herself as like an “invalid.”

Being sedated was unpleasant and contributed to feeling “like you're not in the same world.” Therefore, one participant reported that he would not take the sedating medication and

when he started to resist it he “got put in the straps.” By this he meant physical restraints.

Another participant recalled that because he was afraid he had been physically resisting the restraints to the point where he injured himself. Others also recalled fighting back against staff members when they thought that the staff members might harm them.

Participants did experience feeling safe at times. One participant reported holding a cross that his wife gave him helped him feel safe. Nurses did contribute to the feelings of safety as well by actions such as rubbing a participant’s head or saying kind words.

... I can remember the nurse you know... rubbing her hand over my head I can remember that... and she was smoothing my hair down, her words were so kind you know...even when I was in that state I could feel someone taking care of me.

When participants were aware and able to talk they found that talking about their experiences was helpful. For example, one participant felt reassured that her experiences were not real and appreciated that a nurse was available to help her if she experienced a hallucination.

... I remember one nurse was telling me that if I had seen or heard anything just let her know and she come over and talk to me because she told me the things that I’m seeing were not real... I knew the nurse was there.

CHAPTER 5

DISCUSSION

The experience of being a patient in ICU and having a delirium is not well understood. While this is not an experience common to most people, it is important that ICU staff understand the experience from the patient's point of view. The four existentials including lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relations (relationality) were proposed by van Manen (1997a) as a way to illuminate aspects of our lifeworld and to describe findings from a phenomenological study. This description of the four existentials is the essence of the experience according to van Manen (1997a). For the participants in this study the experiences of space, time, their bodies, and human relations were affected by both being in the ICU and having delirium. In the following sections I will discuss how the findings relate to van Manen's four existentials.

Spatiality

The ICU environment was described by participants as small, crowded and noisy. Their perception of the space was influenced by hallucinations and disorientation. In fact, for some participants the experience of the space was inconsistent as it changed depending on their current state of mind. For most of the participants, space was seen as real, unreal and changing locations, all at the same time. Within this space people would come and go. Participants stated that at times the space seemed familiar and at other times it was difficult to get clues from the surroundings to help with orientation.

Corporeality

Corporeality refers to how we are physically present in the world as in the experience of our bodies (van Manen, 1997a). Difficulty moving and difficulty speaking were bodily

experiences described by participants. For example, some recounted feeling like they were physically removed from others in the ICU as if they were on a side of the room alone. Others reported being tied down by physical restraints. For at least part of the time in ICU the participants could not speak because of having breathing tubes in their throats.

Temporality

Temporality is our subjective experience of time including past, present and future (van Manen, 1997a). The study theme *I can't remember* is specifically related to temporality as it describes lost time. The loss of time due to not remembering and the impact it had on participants was significant because all participants reported lost periods of time from minutes to months. During the delirium experience the past, present and future was experienced at the same time while participants were trying to connect things that have no connection. For these participants, the experience of time was interrupted and therefore impacted the recall of their experiences of ICU.

Relationality

Relationality refers to how we relate to other human beings in our lives (van Manen, 1997a). The theme *not making a connection* describes the difficulties that participants had in relating to others, including staff and family. It was this lack of connection that caused much frustration and distress for participants. Not making a connection contributed to the participants feeling "out of it." Communication impairment, disordered thinking and sedation were barriers to connecting with others.

Themes

The themes identified in this study, *I can't remember*, *wanting to make a connection*, *trying to get it straight*, and *fear and safety concerns*, are comparable to findings that are

reported by other researchers in the literature. In addition to discussing the four themes from this current research and how they compare to the literature, the following discussion presents new insights into the experience of ICU for patients who have delirium.

I Can't Remember

The first theme identified in this study, *I can't remember*, is part of the ICU experience as described by Capuzzo, Pinamonti, Cingolani, Grassi, Bianconi and Contu, 2001; Granberg et al., 1998; Jones et al., 2001; and Lof et al., 2006. In my review of this literature I found that it is not clear if the participants in these studies experienced delirium. Even though at least some of the participants in each of these studies may have had delirium it was not always identified.

An example of a study about recall of ICU that did not identify delirium is a hermeneutic phenomenological study by Granberg et al. (1998) who interviewed 19 ICU patients who had been ventilated and stayed in ICU for at least 36 hours. Participants were asked about what they recalled about ICU. The authors described an "emptiness in the mind" that occurred for participants when they became awake. They also described fragmentary memories like a jigsaw puzzle with missing pieces as well as altered time awareness. However, participants could remember in detail and described their feelings of confusion and unreal experiences. These findings are generally consistent with and supported by my findings in this current research study, however there are two exceptions. First, the participants in the study by Granberg et al. recalled events that had happened to other patients in ICU, whereas none of the participants in the current study reported this. Second, Granberg et al. implied that patients may feel ashamed or frightened of difficulties with memory or thinking and will respond by claiming to not remember anything. The potential participants that were approached for my study were not distressed in appearance when they stated they did not remember anything and some said they were glad they

did not remember.

Sigmund Freud (1915) described defense mechanisms that help people cope with unpleasant events. One example is repression in which a repressed idea is one that has been pushed aside or driven from conscious awareness (Billig, 1999). Perhaps some part of not remembering the ICU experience is a defense mechanism. Does this then mean that it is protective to recall nothing at all as some of the participants in my study suggested?

In a prospective study by Capuzzo et al. (2001) the relationship between analgesia, sedation and recall of ICU were compared from data gathered by a telephone survey, a chart review, and a quality of health questionnaire. The authors question the value of amnesia as some patients suffer psychological problems after ICU stay, especially if they have no factual memory of events. They suggest that memories of some unpleasant factual events in ICU may give some protection against psychological problems compared with having no memories at all. In the findings of the current study there were participants who reported that they had no recall of ICU. While some were distressed by not recalling, there were others that did not want to recall and they did not express distress about amnesia. Participants who were distressed about what they did recall reported both real and unreal events. Therefore, the suggestion posed by Capuzzo et al. is not fully supported.

The findings of the current study highlight the fact that loss of memory about the ICU experience is a frequent occurrence and that those patients can have mixed reactions to the loss of memory. This loss of memory may be related to medication effects, delirium or other factors. While some survivors of ICU want to fill in the gaps of memory, others report that they do not want to remember. Researchers have proposed that a prospective diary containing factual events that occurred during a person's ICU stay may fill in the gaps of memory. In a randomized control

trial by Knowles and Tarrier (2009) reading such a diary was shown to have a significant impact on lowering anxiety and depression scores 2 months after discharge from ICU. It is not known from the findings of the current study if the participants would have benefited from someone keeping a diary of their ICU stay.

Wanting to Make a Connection

Several participants in the current study reported feeling disconnected by a lack of communication or feeling physically away from others. This experience has been explored in other research studies. Lof et al. (2006) described participants coping with feeling alone in their struggle to survive in ICU and that they tried to establish contact with staff or family in response. Granberg et al. (1998) reported participants feeling isolated from the rest of the world and feeling safer with certain nurses or afraid of others who looked angry or were mean. McCurren and Cronin (2003) told the stories of elders with delirium and they defined the confusion as a haziness that caused a feeling of dissociation and a disconnection from reality. Russell (1999) found that nurses only spent an average of 5 per cent of their time engaged in verbal communication with unconscious patients. Perhaps the practice of nurses not engaging with patients contributes to patients feeling disconnected during their ICU stay.

In this current study, the participants described the positive impact of interaction with staff. Explanations of the illness and what was happening, and feeling that staff were present to care for them helped them feel a sense of connection. This was echoed in a study that combined both qualitative interviews and quantitative surveys by Hofhuis et al. (2008). They concluded that increased attention by nurses only to technical equipment instead of to patients, decreases patient trust level. However, providing emotional support is found to be helpful and reassuring by patients. The key theme of support in the findings of the study by Hofhuis et al. was divided into

three categories: providing the seriously ill patient with information and explanation, placing the patient in a central position (communication and being taken seriously), and personal approach by the nurse. Connection with staff has been identified as an important positive experience in past studies and in this current study.

Trying to get it straight

Detailed descriptions of hallucinations, misinterpretations, disorientation, and general feelings of confusion were evident in the interviews of the participants of this study. These findings have been reported in many other studies about the experience of delirium both outside ICU (Andersson et al., 2002; Fagerberg & Jonhaggen, 2002; McCurren & Cronin, 2003) and in ICU (Granberg et al., 1998; Lof et al., 2008; Magarey & McCutcheon, 2005).

The data collected outside ICU is similar to the experience as described within the ICU and supports the theory that delirium is not an ICU psychosis as it has been previously named and is not an experience caused by the ICU specific environment. In a hermeneutic phenomenological study with 50 elderly patients who had not been in the ICU, Andersson et al. (2002) focused on the meaning of having a delirium episode that the authors called an acute confusional state. The participants were asked what they recalled about the experience and their interpretation of what had happened. The interpretation was that they had been “trapped in incomprehensible experiences and a turmoil of past and present and here and there.” The authors suggest that one approach for nurses to use to help patients cope is to confirm and support them in narrating their experience both during and after the acute confusional state (delirium). This is supported by the current study as participants also described the positive impact of being able to discuss the experiences with staff and determine what was factual.

In order to heighten awareness about delirium in elders and to encourage all health care

providers to assess all hospitalized older adults for delirium, McCurren and Cronin (2003) interviewed fourteen elders about what they recalled and what helped during this time. They used a phenomenological approach and analyzed the data according to the method suggested by Colaizzi. The authors produced three clusters of themes: being in the confusion, responding to the confusion, and dealing with the confusion. McCurren and Cronin reported that being in the confusion was described by participants as dreaming and being awake at the same time, misinterpretation of real events, and disorientation. Participants described groping, trying to get it all together, and internalizing the event. In this thesis I focused on the experience of ICU delirium as opposed to delirium in general. However, the findings of my study are similar in that participants described these same experiences and were trying to get it straight or understand what had happened.

Another finding from this study is the difficulty for patients in differentiating real from unreal and misinterpreting some events. This has been described by Fagerberg and Jonhagen (2002) who interviewed five elders about their temporary confusion and their reasoning about the experience. The participants described having wide open senses such that they perceived everything around them and they were unable to concentrate on one specific thing. They misinterpreted things around them and were not sure what was real.

The research on delirium within the ICU includes experiences about trying to get it straight as described in the research by Granberg et al. (1998), Lof et al. (2006) and Magarey and McCutcheon (2005). Participants who have difficulties comprehending the situation of delirium and having memories of unreal experiences that are very detailed have been previously reported by Granberg et al. and Lof et al. Magarey and McCutcheon also reported experiences of reality and unreality occurring at the same time and participants trying to rationalize the hallucinations.

These findings are also comparable to findings from the current study.

An important finding from this current study is that participants reported feeling that staff did not realize how confused they were or on the other hand how much they were aware of in their surroundings. This suggests the need for staff to complete a thorough mental status assessment as a component of neurological assessment to fully understand the ongoing needs of the patient.

Participants also described feeling sedated or medicated to the point of losing consciousness for periods of time and being disoriented upon waking. This finding supports recommendations that daily interruption of sedation could improve neurological assessments of wakefulness and content of consciousness (Truman & Ely, 2003). Participants clearly stated that medication sometimes could make things worse regarding mental status and that the interaction with staff is very important to help them feel oriented.

Fear and safety concerns

The participants in this study described feelings of being afraid due to hallucinations, disorientation, helplessness and fears of being in danger. The feeling of fear related to delirium is commonly reported in the literature (Adamson et al., 2004; Fredriksen & Ringsberg, 2007; Lof et al., 2006; Magarey & McCutcheon, 2005; Wang, Zhang, Li, & Wang, 2008). Adamson et al. found that fear was a common theme of dreams and nightmares in ICU. In the current study, fear was described as not only part of dreams but also part of being awake in response to real and unreal experiences. Fear of delirium returning has been noted by Fagerberg et al. (2002) and Granberg et al. (1998) and was also reported by two of the participants in the current study.

From the narrative interviews of fifty elderly patients who had experienced delirium, Andersson et al. (2002) interpreted that part of the experience of the acute confusional state was

the feeling of being trapped in an incomprehensible state. The authors defined the things that come to mind during the experience as frightening, neutral, or pleasant. In the current study the participants did indeed describe neutral and pleasant experiences but the experiences described in most detail were the frightening experiences. Participants were often very emotional when recalling frightening experiences.

Granberg et al. (1998) proposed loss of control and emotional or psychological issues as the major causes of the ICU syndrome and describe delirium as a psychological reaction that includes withdrawal into a psychotic state. However, the current study is consistent with other research findings that emotional and psychological reactions came during and after the unusual experiences that occurred during a state of delirium and were not causes of delirium (Lof et al., 2008; Magarey & McCutcheon, 2005; McCurren & Cronin, 2003).

Two participants in the current study felt they had been positively changed by the experience. They felt that after being so sick they would no longer take their health for granted and they were impressed by how much their families cared about them. This theme of feeling changed from the experience has been present in previous research findings (Lof et al., 2008; Papathanassiogiou et al., 2003). Because only two of the ten participants described this it was not identified as a major theme for this study, however, it is an area for future exploration.

Summary

This study illuminates experiences of ICU for patients who also experienced delirium that can be very distressing. The experience includes the impression of the ICU environment, the staff members and the physical sensations as well as the emotional responses. The patient's impression of the experience is influenced by perceptual disturbance, sedating medications and memory impairment. Many of the findings of this study support those of various studies in the

literature that have been conducted within the ICU and outside the ICU. While the experiences of being in ICU may provide unique content to the details of the experience such as being unable to talk due to intubation, aspects of the themes that have been identified in the current study have been reported by patients who experienced delirium outside ICU as well. This evidence supports the belief that delirium is not a product of environment alone. Past research about the experience of ICU has not always included the identification of delirium as part of that experience. The impact of not remembering the ICU experience with delirium is different for each patient and the protective role of not remembering is not clear.

In an intensive care unit the initial focus is often on the ABC's (airway, breathing & circulation) of care and basic survival. Once a person is stabilized medically, staff members are able to consider other patient needs including the mental status and how the patient is coping with the intensive care experience. The impact of the experience on patients is clearly the focus of this study. The importance of assessing and intervening with the impact of the experiences that patients have in ICU has been emphasized by the participants in this study. Nurses and other health care professionals can influence the experience and create a connection that can assist the patient to comprehend what is happening to them during their ICU stay especially when they also experience delirium.

CHAPTER 6

NURSING IMPLICATIONS, LIMITATIONS, AND CONCLUSION

Nursing Implications

The participants in this study said they wanted to tell their stories because it may help someone else. They wanted the information to be passed on to staff members and they hoped that it would help to improve the care of patients in ICU. The experience of delirium is not an event that is common to the majority of the general population and therefore it is more challenging to describe in a way so that persons who have not experienced delirium can understand. As one participant stated “it is only a person who goes through it who can really understand.” In phenomenology the lived experience is described in such a way that it is brought to life for the reader. Through this method rich descriptions of our lifeworld are developed to make an experience comprehensible (van Manen, 1997a).

This research study explored the experience of ICU for patients who had experienced delirium while they were in ICU. The findings are similar to existing literature and new insights have been identified. This chapter contains a description of some implications for the nursing profession that may also be implemented by other healthcare professionals who care for patients who have an episode of delirium in the ICU and are recovering from an admission to the ICU.

Practice

Several points were made by participants that were important messages for critical care nurses giving direct patient care. Some of the study participants said they were assisted to feel connected to reality when nurses interacted with them and explained treatments and activities. Participants were able to differentiate between the help they received from a nurse who just sits at the end of the bed as opposed to a nurse who talks and explains things as they are happening.

The lack of ability for a patient to communicate because of being intubated or having a tracheotomy causes distress and increased fear when the patient is unable to explain the experiences they have during delirium. This inability to verbalize can make it difficult for nurses to assess a patient's mental status. Participants in the current study had difficulty differentiating reality and hallucinations as well as trouble focusing their thoughts and telling the time of day. Resistance to care was often based on fear. Participants later became embarrassed and ashamed by the behaviors they exhibited during delirium. Participants reported that medication effects could contribute to feeling sedated and having a worsened cognitive state with increased confusion.

In light of these findings it is important for all critical care staff to recognize the needs of the patient in ICU with delirium. Education about assessment, behavioral manifestations, and appropriate interventions is essential. Nurses are in a key position to ensure early recognition and treatment of delirium in ICU and can positively influence patient outcomes.

In the literature interventions by staff that have been reported as helpful in coping with ICU and delirium include communication, providing information, being present, and providing support (Granberg et al., 1998; Magarey & McCutcheon, 2005; Ozer & Akyll, 2008; Pattison, 2005; Rattray et al., 2003; Russell, 1999). Also, Granberg et al. reported that when participants "anchored" themselves to a significant other it helped them to maintain a sense of self and reality. Ozer and Akyll (2008) found that well planned information related to ICU pre-op teaching reduces rate of disturbance caused by the ICU environment. Russell (1999) argued that the provision of information from nurses not only diminishes anxiety, but allowed patients to become involved in decisions about their care. The findings of this study support the need for all these interventions as well as those recommended by Pochard et al. (1995) that early diagnosis of

psychological concerns, presence of family, facilitating movement, decreasing noise, providing periods of uninterrupted sleep can improve psychological status of ICU patients. The participants in my study clearly stated that interaction with staff that provided information and orientation was very important. Staff helped them to feel connected to reality and feel cared for. They also highlighted the benefits of having family with them to help them feel safe. Noise in the environment was reported as a factor that added to the confusion and the ability to move or not move was a significant factor in feeling disconnected and vulnerable.

Nurses can incorporate practices into the routine care of a patient in ICU that can facilitate orientation and comfort. Accurate assessment of mental status at the beginning of every shift and as needed including screening for delirium is essential as the first step in identifying patient needs. Communication using basic techniques that demonstrate nonverbal behaviors consistent with caring and a relaxed approach can provide a sense of safety and security. Eye contact, and simple explanations of equipment, interventions and surroundings can be helpful to maintain orientation. Repeating simple directions and explanations are required when the patient has impaired memory, orientation and disorganized thinking. Minimizing restraints and sedating medications and focusing on comfort measures may decrease patient agitation caused by fear and confusion. Providing cues in the environment to facilitate orientation including: windows, clocks and calendars that are visible from a lying position; day and night routines with lights on in the day and off at night; and reduced noise to minimize confusing stimuli are all interventions that can be implemented in ICU.

The findings from this study demonstrate a gap in the care of patients who have been admitted to ICU. Even though there is data that shows the risk of PTSD, anxiety and depression after an ICU admission, the patients in the ICU settings included in this study do not receive

routine follow up assessment of their psychological and emotional health. Literature exists on the use of inpatient follow up, outpatient clinics and patient diaries to assist with psychological recoveries but strong evidence on the benefits of each is needed (Adamson et al., 2004).

Participants in a recent international web based study (Deacon, 2012) have identified the need for information, education, assessment, therapy and personal support to cope with psychological and emotional challenges post-ICU.

It can be very challenging emotionally and physically to care for a person who is experiencing delirium. Having an understanding of the possible underlying physiological and cognitive processes and realizing that the behaviors exhibited are often not under the patient's control may enable staff members to intervene effectively. Learning how to provide a sense of security for patients in the ICU can provide staff members with a tool to manage symptoms of delirium including the agitation.

Education

Educators in clinical areas need to include the topic of patients' experience of the ICU including delirium when they teach nurses to care for ICU patients. The skills to assess for delirium each shift should be taught as a routine part of orientation for all staff. A nursing school's curriculum should include this content as well. Patients in this study have said that nurses were not always aware that they were confused or disoriented; therefore the skills to do a thorough mental status assessment should be part of a basic nursing education program. The knowledge of the experience of ICU for persons experiencing delirium brings a comprehensive view of these persons to health care professionals and provides a way to understand what may motivate behaviors that are observed. For example patients who are delirious may have fear and safety concerns as described in the current findings and this can explain patient behaviors such as

fighting against nursing care. Patients who have delirium may have trouble telling what is real and may have impaired thinking and therefore require simple explanations, and supportive direction. Communication techniques and therapeutic interventions can improve nursing care.

Administration

Delirious patients may require one on one nursing care. The presence of staff to provide reality orientation, and a sense of safety from interaction with nursing staff members has been described as very helpful by participants in this study. In ICU a nurse may be assigned more than one patient. In this era of limited healthcare resources, ICU staff members may not be able to be continually with a patient who is delirious so it may be necessary to justify the use of constant observation for patients with delirium by using a sitter such as a licensed practical nurse. The prevalence of delirium is likely to increase as aggressive treatment of older people increases (Truman & Ely, 2003, p. 26). Administrators need to consider the impact of patients' suffering if left alone while experiencing delirium in the ICU. That way as the patient population grows their needs can be met.

Research

From the findings of this study there are questions that arise for further research about memory, the impact of staff interventions, the impact of medications, and the general psychological recovery after experiencing a delirium in ICU. Future studies could also compare the experience of delirium for those in ICU with a hyperactive delirium and those with a hypoactive delirium.

There is no clear understanding of the reason for memory loss from an ICU experience and if there is a psychological cause involved. Is it medication related? Is amnesia protective for a survivor of delirium in the ICU? Is there a link between PTSD and memories of ICU with or

without delirium? There are recent studies about a nursing intervention using diaries that contain facts of a patient's ICU stay to help fill in the gaps in memory of factual events (Backman & Walther, 2001; Jones, Backman, Capuzzo, Egerod, Flaatten, Granja, Rylander, & Griffiths, 2010; Knowles & Tarrier, 2009). There is some evidence that diaries can have a significant impact on improving psychological outcomes after ICU such as decreased depression and anxiety symptoms including PTSD. More research is needed on the implications of using these diaries as it is hard to determine if it was the diary that made the difference, or the interaction with the staff member who presented the diary (Deacon, 2012).

Staff can intervene to help patients in ICU to become oriented, to feel connected and aware of events around them and to feel less afraid. The qualities of such interventions and the best method for intervening are another area for future inquiry. Many nursing interventions have been suggested for years to help decrease the impact of the ICU experience and the delirium experience. If recommendations have been published at least since 1995 (Pochard et al.) are they being carried out and how effective are they? Most nonpharmacological interventions have been based on data from non- ICU settings. Are they effective or appropriate in the ICU setting?

The impact of medications on mental status in delirium is an area that has been studied in regards to managing agitation but limited in the area of the impact on the experience for the patient. For example, do antipsychotics help a patient feel more oriented, think more clearly and feel less afraid? Do periods of being off sedation improve the patient's ability to be aware of factual events in ICU and improve psychological outcome?

Psychological outcome after experiencing delirium in ICU is another area that requires research. Effective screening and intervention for anxiety, mood and cognitive disorders post ICU is limited.

Limitations

The purpose of this study did not include distinguishing between the experiences of different types of delirium. Further, there are many patients who experience hypoactive delirium who are not identified (Peterson et al., 2006). This type of delirium is not associated with obvious agitation and it is often misidentified as depressed mood or as the person's usual presentation. Therefore, the majority of the participants in this study probably had the most obvious type which is a hyperactive delirium. It is possible that hyperactive delirium is associated with different experiences than other types of delirium. A limitation of this study is that a specific type of delirium could have been targeted.

The reliability of delirium identification for each of the ICU staff members who recognized the participants as delirious was not tested. The participants were felt to meet the criteria of being delirious following the confusion assessment method for ICU (CAM-ICU) but it is possible, though unlikely, that there may have been an error in diagnosing delirium.

Another limitation to the findings in this research is the limitation of language. Perhaps another type of depiction such as a video with narration could more thoroughly simulate a delirium experience. As van Manen (1997a) discussed there is also an "epistemological silence" that can happen when something is unspeakable because it is beyond our ability to express (p. 112).

The quality of the data may be limited because of the challenges in procuring participants. Participants were missed because of the severity of their illness, their reluctance to talk about the experience because it was too difficult, because staff did not identify them or because staff members were not available to approach them.

Conclusion

The experience of ICU for persons who have had delirium has a great impact on the person experiencing it and affects emotional as well as physical health. This phenomenological study has described the lived experience of ten patients who were admitted to ICU and were delirious during that admission. The method of van Manen (1997a) was utilized. From the interview data four themes were identified; *I can't remember*, *wanting to make a connection*, *trying to get it straight*, and *fear and safety concerns*. The essence of the experience described in terms of the four existentials includes the impact of the environment, the staff members, family presence, physical sensations, perceptual disturbances, aspects of the past, present and future on the patient. The ability to connect and communicate that is impacted by sedation, disordered thinking and impaired memory as well as the inability to verbalize is also a significant part of the essence.

The effects of an experience in the ICU that includes delirium can be longstanding and continue after transfer out of ICU. While the environment of ICU can influence the experience of the patient it is not the cause of a delirium experience. Interventions that provide comfort and safety have been reported to be effective. Nursing staff can significantly influence the well-being and quality of life of a patient in ICU who experiences delirium.

As more patients are treated in ICU and survive critical illness, there are more people who will require support to recover and rehabilitate. Healthcare personnel will have to consider the impact of the ICU experience and the delirium experience on these survivors of ICU. Considering the patient perspective is an essential part of planning care. The findings from this study contribute to the body of knowledge about the impact of the ICU and the delirium experience and can facilitate development of treatment plans for survivors.

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APPENDIX A

CAM-ICU Worksheet

**Used with permission from the ICU Delirium and Cognitive Impairment Study
Group**

CAM-ICU Worksheet

Feature 1: Acute Onset or Fluctuating Course	Score	Check here if Present
<p>Is the pt different than his/her baseline mental status? OR Has the patient had any fluctuation in mental status in the past 24 hours as evidenced by fluctuation on a sedation scale (i.e., RASS), GCS, or previous delirium assessment?</p>	Either question Yes →	<input type="checkbox"/>
Feature 2: Inattention		
Letters Attention Test (See training manual for alternate Pictures)		
<p><u>Directions:</u> Say to the patient, "I am going to read you a series of 10 letters. Whenever you hear the letter 'A,' indicate by squeezing my hand." Read letters from the following letter list in a normal tone 3 seconds apart.</p> <p style="text-align: center;">S A V E A H A A R T</p> <p>Errors are counted when patient fails to squeeze on the letter "A" and when the patient squeezes on any letter other than "A."</p>	Number of Errors >2 →	<input type="checkbox"/>
Feature 3: Altered Level of Consciousness		
Present if the Actual RASS score is anything other than alert and calm (zero)	RASS anything other than zero →	<input type="checkbox"/>
Feature 4: Disorganized Thinking		
Yes/No Questions (See training manual for alternate set of questions)		
<ol style="list-style-type: none"> 1. Will a stone float on water? 2. Are there fish in the sea? 3. Does one pound weigh more than two pounds? 4. Can you use a hammer to pound a nail? <p>Errors are counted when the patient incorrectly answers a question.</p> <p>Command Say to patient: "Hold up this many fingers" (Hold 2 fingers in front of patient) "Now do the same thing with the other hand" (Do not repeat number of fingers) *If pt is unable to move both arms, for 2nd part of command ask patient to "Add one more finger"</p> <p>An error is counted if patient is unable to complete the entire command.</p>	Combined number of errors >1 →	<input type="checkbox"/>
Overall CAM-ICU		
Feature 1 plus 2 and either 3 or 4 present = CAM-ICU positive	Criteria Met →	<input type="checkbox"/> CAM-ICU Positive (Delirium Present)
	Criteria Not Met →	<input type="checkbox"/> CAM-ICU Negative (No Delirium)

APPENDIX B**PERMISSION TO USE RESOURCES FROM ICU DELIRIUM AND
COGNITIVE IMPAIRMENT STUDY GROUP**

Permission granted

- Brenda

Brenda T Pun, RN, MSN, ACNP
Project Clinical Manager
Vanderbilt University Medical Center
Phone: 919-484-3964
www.ICUDelirium.org
brenda.pun@vanderbilt.edu

NOTICE OF CONFIDENTIALITY - This material is intended for the use of the individual or entity to which it is addressed, and may contain information that is privileged, confidential and exempt from disclosure under applicable laws. If the reader of this material is not the intended recipient, you are hereby notified that any dissemination, distribution or copying of this communication is strictly prohibited. Please notify the sender of the error and destroy the Email you received.

From: Karen Whitehome [mailto:Karen.Whitehome@easternhealth.ca]

Sent: Wednesday, September 02, 2009 10:06 AM

To: Pun, Brenda

Subject: RE:

Hi Brenda;

I have put a couple of items from your website in my research proposal so I have to ask you permission to use:

- 1) CAM-ICU worksheet
- 2) Photo of a patient in ICU from your website home page
- 3) Your patient information sheet for Going Home

Thanks,

Karen

APPENDIX C
LETTER OF APPROVAL AND AMMENDMENT FROM
HUMAN INVESTIGATION COMMITTEE



Faculty of Medicine

Human Investigation Committee
Suite 200, 2nd Floor, Borden-Whitmore Plaza
90 Armbrose Drive
St. John's, NL, Canada, A1B 2X2
Tel: 709 777 6274 Fax: 709 777 6276
hics@mun.ca www.mun.ca/hic

November 9, 2009

Reference #09.202

Ms. Karen Whitehorne
C/o Dr. A. Gaudine
Psychiatry
Room 1153
General Hospital Site

Dear Ms. Whitehorne

RE: **"The Lived Experience of ICU for People Who Have Experienced Delirium: A Phenomenological Study"**

This will acknowledge receipt of your correspondence.

This correspondence has been reviewed by the Co-Chair under the direction of the Committee **full approval** of this research study is granted for one year effective **November 9, 2009**.

This is to confirm that the Human Investigation Committee reviewed and approved or acknowledged the following document (as indicated):

- Revised consent form, approved

This approval will lapse on **November 9, 2010**. It is your responsibility to ensure that the Ethics Renewal form is forwarded to the HIC office prior to the renewal date. *The information provided in this form must be **current to the time of submission** and submitted to HIC **not less than 30 nor more than 45 days** of the anniversary of your approval date.* The Ethics Renewal form can be downloaded from the HIC website
<http://www.med.mun.ca/hic/downloads/Annual%20Update%20Form.doc>

*The Human Investigation Committee advises **THAT IF YOU DO NOT** return the completed Ethics Renewal form prior to date of renewal:*

- *Your ethics approval will lapse*
- *You will be required to stop research activity immediately*

- *You may not be permitted to restart the study until you reapply for and receive approval to undertake the study again*

Lapse in ethics approval may result in interruption or termination of funding

For a hospital-based study, it is **your responsibility to seek the necessary approval from Eastern Health and/or other hospital boards as appropriate.**

Modifications of the protocol/consent are not permitted without prior approval from the Human Investigation Committee. Implementing changes in the protocol/consent without HIC approval may result in the approval of your research study being revoked, necessitating cessation of all related research activity. Request for modification to the protocol/consent must be outlined on an amendment form (available on the HIC website) and submitted to the HIC for review.

This research ethics board (the HIC) has reviewed and approved the research protocol and documentation as noted above for the study which is to be conducted by you as the qualified investigator named above at the specified site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Human Investigation Committee currently operates according to *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; ICH Guidance E6: Good Clinical Practice* and applicable laws and regulations. The membership of this research ethics board is constituted in compliance with the membership requirements for research ethics boards as defined by *Health Canada Food and Drug Regulations Division 5; Part C.*

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

We wish you every success with your study.

Sincerely,



Fern Brunger, PhD
John D. Harnett, MD, FRCPC
Co-Chairs
Human Investigation Committee

C C VP Research c/o Office of Research, MUN
VP Research c/o Patient Research Centre, Eastern Health
HIC meeting date: November 26, 2009



Office of Medicine

1000 University Avenue
10th Floor, 10th Street, Suite 1000
Oshawa, Ontario, Canada
L1G 4G1
Tel: (905) 707-5572 Fax: (905) 707-6776
Email: medinfo@westernhealth.on.ca

February 22, 2010

Ms. Karen Whitehorne
C/o Dr. A. Gaudine
Psychiatry Room 1153
General Hospital Site

Dear Ms. Whitehorne

Reference #09.202

Re: The Lived Experience of ICU for People Who Have Experienced Delirium: A Phenomenological Study

This will acknowledge receipt of the correspondence dated February 22, 2010, wherein you request an amendment to the above noted research study.

The co-chair of the Human Investigation Committee has reviewed your correspondence and has approved the amendment dated February 22, 2010.

It is your responsibility to seek the necessary approval from Eastern Health, other hospital boards and/or organizations as appropriate.

This Research Ethics Board (the HIC) has reviewed the amendment for the study which is to be conducted by you as the qualified investigator named above at the specified study site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Human Investigation Committee currently operates according to the Tri-Council Policy Statement and applicable laws and regulations.

Sincerely,

Fern Brunger, PhD
John D. Hamett, MD, FRCPC
Co-Chairs
Human Investigation Committee

C C VP Research c/o Office of Research, MUN
VP Research c/o Patient Research Centre, Eastern Health
For office use only: March 4, 2010

APPENDIX D
APPROVAL OF EASTERN HEALTH RESEARCH PROPOSAL
APPROVAL COMMITTEE



Eastern Health

**Department of Research
Charles R. Bell Building, 81 Kenmount Rd.
P.O. Box 13122
St. John's, NL A1B 4A5
Tel: (709) 752-4636
Fax: (709) 752-4733**

November 25, 2009

Ms. Karen Whitehorne
Dept. of Psychiatry – Room 1153
Health Sciences Centre, 300 Prince Philip Drive
St. John's, Newfoundland & Labrador
A1B 3V6

Dear Ms. Whitehorne:

Your research proposal HIC # 09.202 – “*The lived experience of ICU for people who have experienced delirium: A phenomenological study*”, was reviewed by the Research Proposals Approval Committee (RPAC) of Eastern Health at its meeting on November 24th, 2009, and we are pleased to inform you that the proposal has been approved.

The approval of this project is subject to the following conditions:

- The project is conducted as outlined in the HIC approved protocol;
- Adequate funding is secured to support the project;
- In the case of Health Records, efforts will be made to accommodate requests based upon available resources. If you require access to records that cannot be accommodated, then additional fees may be levied to cover the cost;
- A progress report being provided upon request.

If you have any questions or comments, please contact Donna Bruce, Manager of the Patient Research Centre at 777-7283.

Sincerely,

Mike Doyle, PhD
Director of Research
Chair, RPAC

cc: Ms. Donna Bruce, Manager Patient Research Centre
Dr. A. Gaudine, Psychiatry, Room 1153, HSC

MD/jmps

APPENDIX E
INTERVIEW QUESTIONS

1. What is your age?
 - a) 20 or less
 - b) 21-30
 - c) 31-40
 - d) 41-50
 - e) 51-60
 - f) 61-70
 - g) 71-80
 - h) 81-90
 - i) 91-100
2. Tell me what you remember about being in the intensive care unit.
3. What was that experience like for you?
4. You had delirium while in ICU. Do you recall anything unusual?
5. Is there anything else you would like to tell me?
6. Are there any other questions that you think I should have asked you?

APPENDIX F

CONSENT TO PARTICIPATE IN NURSING RESEARCH

TITLE: The Lived Experience of ICU for People Who Have Experienced Delirium: A Phenomenological Study

INVESTIGATOR(S): Karen Whitehorne, BN, RN

You have been invited to take part in a research study. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

The researchers will:

- discuss the study with you
- answer your questions
- keep confidential any information which could identify you personally
- be available during the study to deal with problems and answer questions

If you decide not to take part or to leave the study this will not affect your usual health care.

1. Introduction/Background:

Delirium is a state of confusion that comes and goes and is a symptom of medical illness. It is not well known what it is like for the person who has confusion or delirium while he or she is in the ICU. Nurses want to understand what it is like for the person who has delirium so they can help these people feel more comfortable.

2. Purpose of study:

This study will ask people to talk about what they remember about being in ICU. This study will help nurses gain a better understanding of what it is like for patients who have experienced delirium while in ICU. Nurses may be able to use this information to improve patient care.

3. Description of the study procedures and tests:

In a private room, you will be asked to talk about what you remember about being in ICU. This interview will be audio taped. The interview will be transcribed and reviewed to find the main ideas expressed. A summary of the interview will be mailed to you to make sure the information is correct. A second interview will take place over the telephone to ask about the interview summary.

4. Length of time:

You will have one interview for about one hour. Later after a summary of themes from that interview is written and mailed to you there will be a phone call for about fifteen minutes to ask you if what was written is what you intended.

5. Possible risks and discomforts:

While talking about your experience you may have upsetting feelings or become tired. You can stop at any time. If you wish to have support or someone to talk to about your feelings, the nurse researcher can make arrangements for you to meet with a health care professional.

6. Benefits:

It is not known whether this study will benefit you.

7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. What about my privacy and confidentiality?

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However it cannot be guaranteed. For example we may be required by law to allow access to research records.

When you sign this consent form you give us permission to

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

Access to records

The nurse researcher, Karen Whitehorne will keep a list of persons who were interviewed for this study. Your name will not be typed on the transcript of your interview. You will not be identified.

Other people may need to look at the list of study participants or typed interview transcripts. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when Karen Whitehorne is present.

Use of records

The research team will collect and use only the information they need for this research study.

This information will include:

Your phone number so you may be contacted for a 15 minute interview.

Your mailing address so you can be sent the theme summary from your interview.

Your age.

Your gender.

Information from study interviews.

Your name and contact information will be kept secure by Karen Whitehorne in Newfoundland and Labrador. It will not be shared with others without your permission.

Your name will not appear in any report or article published as a result of this study.

Information collected for this study will be kept for 5 years after publication of a manuscript.

Information collected and used by the research team will be stored by the researcher Karen Whitehorne, who is the person responsible for keeping it secure.

Your access to records

You may ask the researcher to see the information that has been collected about you.

9. Questions:

If you have any questions about taking part in this study, you can meet with the researcher who is in charge of the study at this institution. That person is:

Karen Whitehorne

777-6104

You can also speak with her supervisors:

Dr. Alice Gaudine

777-7258 agaudine@mun.ca

Dr. Robert Meadus

777-6716 meadusr@mun.ca

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Office of the Human Investigation Committee (HIC) at 709-777-6974 or

Email: hic@mun.ca

After signing this consent you will be given a copy.

Signature Page

Study title: The Lived Experience of ICU for People Who Have Experienced Delirium: A Phenomenological Study

Name of principal investigator: **Karen Whitehorne**

To be filled out and signed by the participant:

	Please check as appropriate:
I have read the consent.	Yes { } No { }
I have had the opportunity to ask questions/to discuss this study.	Yes { } No { }
I have received satisfactory answers to all of my questions.	Yes { } No { }
I have received enough information about the study.	Yes { } No { }
I have spoken to Karen Whitehorne and he/she has answered my questions	Yes { } No { }
I understand that I am free to withdraw from the study	Yes { } No { }
<ul style="list-style-type: none"> • at any time • without having to give a reason • without affecting my health care 	
I understand that it is my choice to be in the study and that I may not benefit.	Yes { } No { }
I agree to be audio taped	Yes { } No { }
I agree to take part in this study.	Yes { } No { }

Signature of participant

Date

Signature of witness (if applicable)

Date

To be signed by the investigator or person obtaining consent

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of investigator/person obtaining consent

Date

Telephone number: _____

APPENDIX G
OATH OF CONFIDENTIALITY

Human Investigation Committee
Undertaking of Confidentiality

I understand that as an investigator or member of a research team, I must maintain strict confidentiality of information obtained from participants in research studies and/or their health and study records.

I understand that not all members of a research team will require confidential information about research participants and that the principal investigator will limit the number of persons on the team who require such information to as few as possible.

As an investigator I agree not to disclose or discuss any confidential information to which I have access except with the appropriate members of the research team.

As a staff member of the research team I agree not to disclose or discuss such information unless specifically authorized to do so by the investigator to whom I am responsible.

I understand that a failure to abide by this requirement could cause individual participants embarrassment. Breach of confidentiality could have serious personal, social and legal consequences for the participant and for the participant's family, friends and associates. I appreciate that an unauthorized disclosure could have consequences for the participant in his or her employment.

I also acknowledge that as part of my employment relationships, if I should make an unauthorized disclosure of information about a participant in a research study, I may be dismissed from my position or suffer formal reprimand. I appreciate that I shall be legally responsible for my actions and, in the event of litigation for my unauthorized disclosure of information; I agree to indemnify my employer for any damages incurred by him.

Printed name of research team member:

Position on the research study:

- Investigator
 Staff member

Signature of research team member:

Witness name:

Witness signature:

Date:



