

DELIRIUM: THE LIVED EXPERIENCE

CECILY POLLARD RN CMHN

Graduate Diploma of Business (Professional Management)

Submitted in fulfilment of the requirements for degree of Master of Nursing

(Nursing & Midwifery H8A)

University of Tasmania

March 2014

STATEMENTS AND DECLARATIONS

Declaration of Originality

“This thesis contains no material which has been accepted for a degree or diploma by the University or any other institution, except by way of background information and duly acknowledged in the thesis, and to the best of my knowledge and belief no material previously published or written by another person except where due acknowledgement is made in the text of thesis, nor does the thesis contain any material that infringes copyright”

Statement of Ethical Conduct

“The research associated with this thesis abides by the international and Australian codes on human and animal experimentation, the guidelines by the Australian Government’s Office of Gene Technology and the rulings of the Safety, Ethics and Institutional Biosafety Committees of the University”

Authority of Access

This thesis may be made available for loan and limited copying and communication in accordance with the Copyright Act 1968.



Cecily Pollard

March 2014

CONTENTS

STATEMENTS AND DECLARATIONS	ii
LIST OF TABLES	vi
LIST OF FIGURES	vi
ACKNOWLEDGEMENT.....	vii
ABSTRACT	viii
CHAPTER ONE: INTRODUCTION and LITERATURE REVIEW	1
1.1 Background to the Study	1
1.2 Literature Review.....	9
1.2.1 An historical perspective of delirium	13
1.2.2 Identification and pattern	17
1.2.2.1 <i>Risk factors</i>	20
1.2.2.2 <i>Causes</i>	21
1.2.2.3 <i>Delirium, dementia and depression</i>	22
1.2.2.4 <i>Poor outcomes</i>	25
1.2.3 Professional skills	26
1.2.4 Qualitative research.....	28
1.2.4.1 <i>The nursing perspective</i>	28
1.2.4.2 <i>The patient experience</i>	30
1.3 Conclusion	33
CHAPTER TWO: METHODOLOGY	35
2.1 Descriptive Qualitative Approaches	36
2.2 Grounded Theory	41
2.3 Methods.....	47
2.3.1 Recruitment of participants	47
2.3.2 Inclusion and exclusion criteria.....	50
2.4 Ethics.....	51
2.5 Data Collection	52
2.5.1 Data analysis	53
2.5.2 Strategies used to ensure rigour in the study	58

CHAPTER THREE: THE TERRIFYING EXPERIENCE OF LIVING THE DELIRIUM:	60
3.1 Living the Delirium and Living after the Delirium	60
CAMEOS	62
Daisy	62
Lance	62
Charlie	62
Gilbert	63
Gavin	63
Dorothy	63
Mabel	64
Ted	64
George	64
Alfred	64
Henry	65
3.2 Living the Delirium	65
3.2.1 The suffering	65
3.2.1.1 <i>The feeling</i>	66
3.2.1.2 <i>The suspicion and mistrust</i>	67
3.2.2 The predicament	70
3.2.2.1 <i>Being trapped</i>	70
3.2.2.2 <i>To be abandoned</i>	72
3.2.2.3 <i>The dismissal</i>	74
3.2.2.4 <i>The disconnection</i>	76
3.3 Living After the Delirium	80
3.3.1 How I was before	81
3.3.1.1 <i>Their strength</i>	81
3.3.1.2 <i>Why was this happening to me?</i>	83
3.3.2. How am I now?	85
3.3.3 How have I been left?	87
3.3.3.1 <i>The remaining scars</i>	87
3.3.3.2 <i>The strength of healing</i>	90
CHAPTER FOUR: DISCUSSION, IMPLICATIONS, RECOMMENDATIONS AND CONCLUSION	94
4.1. Discussion of the Main Findings	96
4.1.1 Living the delirium	96
4.1.2 Living after the delirium	101
4.2 Implications and Recommendations for Clinical Practice	105

4.2.1	Living the delirium.....	105
	<i>Recommendation One</i>	106
	<i>Recommendation Two</i>	107
	<i>Recommendation Three</i>	109
4.2.2	Living after the delirium	109
	<i>Recommendation Four</i>	109
	<i>Recommendation Five</i>	113
4.3	Limitations of this study	113
4.4	CONCLUSION	114
REFERENCES		118
Appendix 1: Information Sheet		125
Appendix 2: Consent Form.....		127
Appendix 3: Interview Guide		128
Appendix 4: The Confusion Assessment Method Instrument.....		129
Appendix 5: The Mini-Mental State Exam		131

LIST OF TABLES

Table 1	Summary of interventions to prevent delirium	7
Table 2	Summary of literature review	10
Table 3	Diagnostic Criteria DSM-IV-TR.....	15
Table 4	Summary of the types of delirium and presentation	20
Table 5	Comparison of the features of delirium, dementia and depression	24
Table 6	Summary of design features proposed by Sandelowski (2000)	39
Table 7	Six strategies for data analysis	40
Table 8	Criteria for assessing quality of research	41
Table 9	Summary of the stages of coding	46
Table 10	Inclusion and exclusion criteria.....	50
Table 11	Participant and interview details	51
Table 12	Living the delirium	56
Table 13	Living after the delirium	57

LIST OF FIGURES

Figure 1	Mapping method identifying the major and subthemes.....	12
Figure 2	Recruitment process.....	49
Figure 3	Open coding process.....	55
Figure 4	Example of coding process	61

ACKNOWLEDGEMENT

I would like to extend my sincerest gratitude to the eleven people who shared their time and experiences with me. You provided open and honest insight from a unique perspective. I am indebted to you for allowing me to discuss your experiences of being delirious.

I wish to thank my supervisors, Professor Mary Fitzgerald and Dr. Karen Ford for their guidance and patience through my academic journey.

Jill and Tina, thank you for your editorial expertise and encouragement.

Thank you, Rob and Trish, for your belief and support in the project from the beginning to the end.

My friends and you know who you are, thank you for your encouragement and assistance throughout this journey.

Finally, I always knew the spirit of my late partner and my late parents followed me in my journey.

ABSTRACT

Delirium: The Lived Experience

Delirium is one of the most serious and prevalent cognitive disorders occurring in the older person post-surgery. Delirium is a potentially preventable and reversible cause of post-operative functional disability, morbidity and mortality. As well as the significant impact for the person, delirium also results in increased health care costs and poses a substantial challenge for clinicians.

Medical and nursing textbooks concentrate on diagnosis, reduction of the modifiable risk factors and treatments. Nursing research has examined documentation, nursing skills and lack of education on how to nurse the delirious patient. However, little research has focused on the patient's experience of incomprehension and various feelings of discomfort during an acute episode of delirium. The importance of researching the patient's experience of delirium provides health care staff insight into the experience, enables understanding and acknowledgement, and supports improving evidence-based care to meet the needs expressed by the delirious patient.

The aim of this study was to explore the lived experience of delirium in the acute inpatient orthopaedic population with the anticipation that increased understanding and knowledge of this lived experience will support the development of evidence-based nursing care management of the delirious patient.

This study examines the experiences of eleven patients who described their experiences of delirium in semi-structured interviews. The interviews were transcribed verbatim, and analysed using the techniques of qualitative description (Sandelowski 2000) and the grounded theory coding process described by Glaser and Strauss (1967).

The findings of this study provide an insight into the incomprehensible emotional pain suffered by patients while they were delirious and the disparate feelings of remorse, guilt and shame they experienced after the episode of delirium. It is hoped that the findings of this study will contribute to the care of the delirious patient post-surgery. Following this study, it is apparent that more research is required into the long-term impact of the experience of delirium.

CHAPTER ONE: INTRODUCTION AND LITERATURE REVIEW

1.1 Background to the Study

Hospitalisation holds many risks for the elderly inpatient, and these risks often result in complications unrelated to the primary reasons for being admitted to hospital. Delirium is one of those complications that are seen frequently in the elderly acute hospital population. Delirium is a medical emergency that may have very serious outcomes for patients, health care staff and hospital systems if left untreated.

Older people with hip fracture, dementia or a serious illness are at a greater risk of an episode of delirium when admitted to hospital (Harding 2004; Segatore & Adams 2001; Ski & O'Connell 2006). Delirium is a serious common clinical syndrome, with an acute onset and a fluctuating course over a short period (American Psychiatric Association [APA] 1994; Inaba-Roland & Maricle 1992; Meagher 2001; Rapp 2001). Symptoms include disturbances to consciousness, cognitive function, and perception and the condition is associated with poor clinical outcome (Bruce et al. 2007; McAvay et al. 2006; Robertson & Robertson 2006).

Medical literature describes how to prevent, recognise, assess and treat delirium. Yet there is minimal description of how a delirious episode impacts on the patient. The purpose of this study is to clarify and record the experience of an acute episode of delirium from a patient's perspective.

This study of orthopaedic patients and their lived experience of a delirious episode post-surgery will be presented in four chapters. Chapter One includes a brief description of delirium and the literature review regarding delirium and the lived experience of delirium. Chapter Two presents the research question, rationale for the design chosen for the study, tools and process used for participant recruitment, ethical considerations and data analysis. Chapter Three provides the results of the study. Finally, Chapter Four provides a discussion of the study results and implication for nursing care.

Delirium is an acute condition with poor outcomes for patients and family carers. The numbers of older patients with delirium is likely to increase relative to population increase over time, as age is a strong risk factor for the development of delirium. The research consistently suggests that older people who enter hospital are at risk of developing delirium (Adamis et al. 2007; Harding 2004; Inaba-Roland & Maricle 1992; Segatore & Adams 2001). The Australian Orthopaedic Association National Joint Replacement Registrar Annual Report 2011/12 reported that 85,000 joint replacements had been undertaken in the previous year and the ages of people undergoing this surgery ranged from 68 to 73 years of age (Australian Orthopaedic Association 2012). Additionally, the Ski and O'Connell (2006) study identified Australia's fastest growing population group as the older adult aged 85 and over and this age predisposes them to developing delirium when admitted to hospital. The experience of delirium in an increasingly aged population may have devastating long-term effects on health outcomes and quality of life for this older population (Flinn et al. 2009; Milisen et al. 2002; Robertson & Robertson 2006).

In this chapter I will discuss the importance of researching delirium, with emphasis on the small body of research into the lived experience of delirium. One group in which delirium is particularly prevalent is the older population that has undergone orthopaedic surgery. This study was conducted on an orthopaedic ward of a tertiary general hospital. The importance of exploring the experiences of this hospital population and the aims of the study will be stated.

Within the history of medical psychiatry, the term delirium is one of the first psychiatric syndromes to be described. In the nineteenth century, the French psychiatrist Chaslin, writing in 1895, introduced 'acute confusion without a cause' as an acute brain disorder (cited in Camus 2002). Patients with this acute brain disorder presented with what we know today as delusions, hallucinations, agitation and hyperactive delirium. Similarly, Lasegue in 1881 described delirium tremens as perceptual disturbances as a dream-like experience, and Regis in 1911 referred to toxic or infective causes for a post dream-like confusional experience (cited in Lloyd & Guthrie 2007 pp 270-289). The word delirium means 'to deviate from a straight line, to be crazy, deranged, out of one's wits, to be silly, to dote, to rave' (Adamis et al. 2007, p. 461). Delirium was introduced by Celso in the first century AD (1AD) who used the term to define alterations in consciousness, fever and behaviour (Adamis et al. 2007; Kyziridis 2006).

In her 1920 textbook *Nursing mental disorders*, Harriett Bailey, RN, identified delirium and it was not until 1980 that delirium was identified as an organic brain syndrome by the American Psychiatric Association (American

Psychiatric Association [APA] 1994). The *Diagnostic and Statistical Manual of Mental Disorders* (DSM) published by APA provides a common language and standard criteria for the classification of mental disorders. The DSM-IV-TR (2000, 293.0) criteria for diagnosing delirium are considered 'the gold standard' (Breitbart, Gibson & Tremblay 2002; Bruce et al. 2007; Day, Higgins & Koch 2009; Duppils & Wikblad 2004a; Duppils & Wikblad 2007; Franco et al. 2001; Kyziridis 2006; Milisen et al. 2002; Robertson & Robertson 2006; Ski & O'Connell 2006; Voyer et al. 2008).

The population is ageing and as a consequence there are more people over the age of 65. In 2011 14% of the Australian population was 65 years and over (Australian Bureau of Statistics [ABS] 2012). The rate of delirium in elders admitted to hospital dramatically increases to 14–56% of new admissions to general wards; 70–87% in Intensive Care Units and 78% within the orthopaedic inpatient population (Bickel et al. 2004; Inouye 2006). Many patients with delirium are discharged before their symptoms are fully resolved (Meagher 2001). The incidence of delirium in hip surgery patients 60 years and over (elective and non-elective) was 40.5–55.9% (Delirium Clinical Guidelines Expert Working Group 2006).

Delirium in the elderly has been linked to morbidity, mortality, longer hospital stays, increased nursing workloads, higher rates of admissions to nursing homes post discharge (Duppils & Wikblad 2004a; Inouye & Charpentier 1996; Maldonado 2008) and increased health costs (Franco et al. 2001). In addition, delirium can be a frightening and extremely stressful experience for patients and caregivers. Despite being regarded as a medical emergency

delirium is often unrecognised and as a result of this is often mismanaged by health care staff (Inouye 2006; McAvay et al. 2006; Neitzel, Sendelbach & Larson 2007; Robinson & Eiseman 2008; Ski & O'Connell 2006).

There appears to be no one cause for delirium, rather the aetiology of delirium is multifactorial. Severe illness of any kind, infections; drug intoxication; metabolic disturbances; nutritional deficiencies; surgical procedures, especially joint surgery; are all important precipitating factors (Adamis et al. 2007; Day, Higgins & Koch 2009; Foreman et al. 2001; Inouye & Charpentier 1996; Inouye, et al. 2001; McAvay et al. 2006; Neitzel, Sendelbach & Larson 2007; Robertson & Robertson 2006; Segatore & Adams 2001).

Delirium is a common life-threatening and potentially preventable clinical syndrome developing quickly over hours or days and tending to fluctuate during any twenty-four hour period. It is characterised by disturbance of consciousness and attention and acute change in cognition (APA 1994). The key features of delirium are fluctuating awareness and impairment of attention. Additional symptoms include, among others, impairment of memory, orientation and language, the presence of hallucinations, disorganised thinking and disturbances to the sleep–wake cycle (Inaba-Roland & Maricle 1992; Meagher 2001; Rapp 2001). The diagnosis of delirium depends on the clinical history, behavioural observations and the bedside assessment of cognitive function. As delirium may be the only indicator of this serious illness, any patient whose mental state suddenly deteriorates is best presumed to be delirious until proven otherwise (Meagher 2001).

Conditions that may mimic delirium such as dementia, psychotic disorders and depression should be excluded. The irritability, apathy and decreased concentration associated with depression can be very similar to hypoactive delirium, while the delusions and the combative behaviours of hyperactive delirium can look very similar to the picture of dementia and schizophrenia (Flinn et al. 2009; Holmes 1996; Maldonado 2008; Robertson & Robertson 2006; Speed et al. 2007). This misdiagnosis of delirium can have dire consequences for the patient, which may lead on to longer hospital stays (McCurren & Cronin 2003), and morbidity and mortality outcomes (Inouye 2006).

Although prevention is the best way to reduce the onset of delirium, the knowledge of risk factors creates a potential for the prevention or minimisation of delirium. Nursing interventions (see Table 1) implemented for patients at risk and based on reducing the effects of delirium could lead to identifying those who are at risk of becoming delirious from those who are not at risk with the potential to minimise poor patient outcomes from an episode of delirium.

The literature identifies best practice for assessing and treating delirium, and strategies to educate nurses to recognise and manage delirium. The treatment interventions that were recommended in antiquity through the nineteenth century are still valid today. However, the interventions of antiquity and modern day infrequently allude to the lived experience of being delirious and the intervention is in the context of discharge planning provision of psychological support for the patients.

Table 1 Summary of interventions to prevent delirium

Assess for clinical risk factors	Address pain
Address cognitive impairment	Review medication
Address dehydration/constipation	Address poor nutrition
Assess hypoxia	Promote sleep hygiene
Address infections	Prevent sensory impairment
Address immobility/limited mobility	

Adapted from National Institute for Health and Care Excellence (NICE) *Clinical Guideline 103*, 2010, pp. 11–14.

Delirium is an interesting and important area to research. It is a medical emergency and identifying causes, effective treatment and management processes is complex and challenging. There is much evidence of high prevalence rates and subsequent poor outcomes for those who experience delirium. A small body of research, which includes the orthopaedic hospital population, has focused on the lived experience of delirium by exploring the way patients have made sense of their experiences and reporting a variety of emotional responses to their experience of being delirious (Andersson et al. 2002; Bowker 1995; Breitbart Gibson & Tremblay 2002; Crammer 2002; Duppils & Wikblad 2007; Fagerberg & Jonhagen 2002; Fleminger 2002; Harding Martin & Holmes 2008; McCurren & Cronin 2003; Schofield 1997). The Fagerberg and Jonhagen (2002) study of the lived experience of delirium reported the patients were unable to find any connections between the delirium experience and non-delirium experience to help them make sense of their delirium experiences.

One of the significant aspects of delirium is the impact on the person. Understanding this impact of an experience of delirium may enable a raised

awareness, knowledge and acknowledgement among health care professionals, especially nurses, of being delirious. In my clinical role as Clinical Nurse Consultant, Consultation–Liaison Psychiatry, delirium was one of the top five reasons general nurses referred patients to the service. From my practice with these patients, assessing them and trying to engage nursing staff to understand the impact of an experience of delirium, I had concerns over a long period of time that my general nurse colleagues did not have a clinical appreciation of the lived experience of delirium.

A qualitative study has the strength to uncover more about people, that is, why they may be the way they are. In contrast, the weakness of a qualitative study is that assumptions cannot be made beyond the data collected from the specific group of people studied (Elliott & Lazenbatt 2005). In order to improve the understanding of being delirious and how best to support those who are delirious, it is essential to first understand the experience of being delirious. However, a literature search of what the experience of being delirious is like revealed a very small body of suitable works. This study will examine the lived experience of delirium from a patient's perspective using a qualitative research approach. This factor will be discussed in detail in Chapter Two.

The research question in the context of this study relates to the lived experience of delirium with the aim to clarify and record the patient's experience. It is anticipated that greater knowledge of these patients' experiences will contribute to improving the understanding nurses have of the state of being delirious and how best to support and nurse this vulnerable

post-operative patient population admitted to an orthopaedic ward of a tertiary general hospital.

The elderly are a large group of the inpatient hospital population and, if admitted for surgery, are at risk of experiencing delirium as a serious complication post-surgery. Delirium has been linked to poor outcomes for the patient, increased health costs and a challenge for health care staff to recognise and manage appropriately. In addition, delirium can be a very frightening experience for patients and caregivers. Understanding the lived experience is an important step in improving care.

1.2 Literature Review

In this section of the chapter, literature concerning the lived experience of delirium will be discussed and summarised. The review of the literature will be presented under key themes of *history, identification and pattern, professional skills, and qualitative research*.

The purpose of this review is to provide a background to the study based on contemporary literature and to determine if a gap exists in the research regarding the lived experience of delirium in the acute care facility from the perspective of patients. To clarify why this study is needed it was first necessary to review the current literature. A comprehensive search was performed using databases to access all level of evidence (research and expert opinion). Searches of CINAHL, Medline, PsycINFO, EPOCH, PubMed, Proquest platform and Google Scholar search engine were accessed for the period 1992–2010 using the key words delirium, orthopaedic, lived experience, post-operative delirium, nursing documentation, delirium

psychiatry, delirium causes, delirium hallucinations, delirium assessment management. In total, 50 papers were located and cited in this review (see Table 2 Summary of literature review). The majority of literature was based on studies conducted in Canada, United States of America, United Kingdom and Sweden. There were few Australian research papers on this subject.

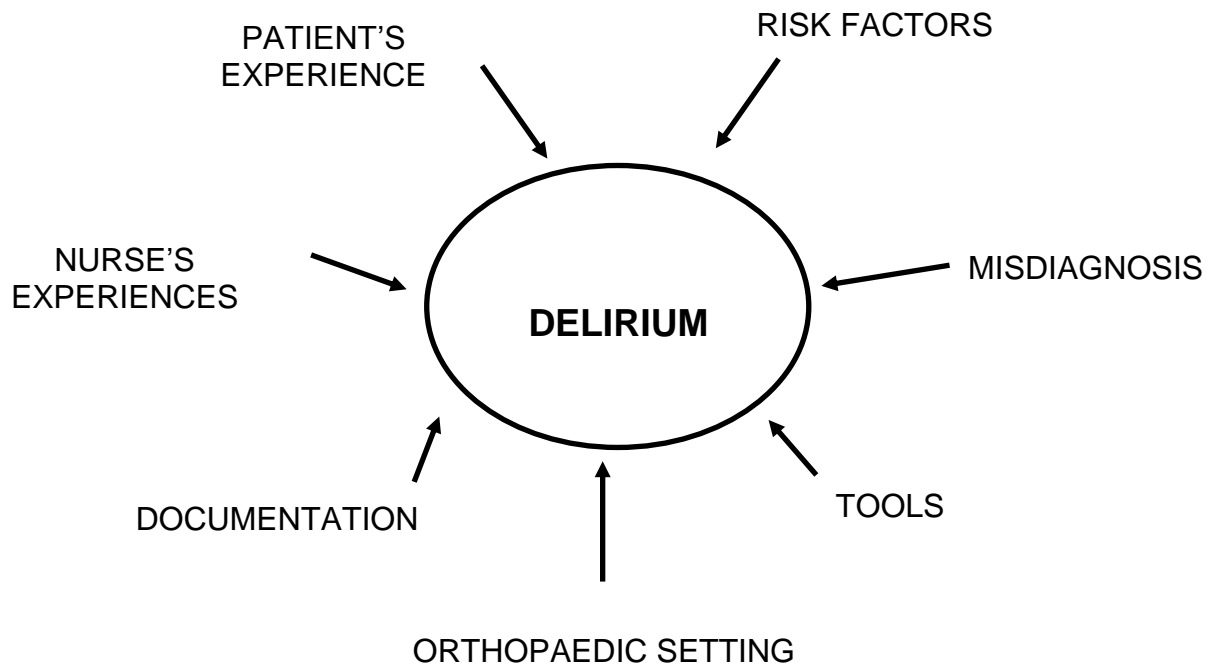
Table 2 Summary of literature review

Themes	Subthemes
History (an historical perspective of delirium)	Definitions Early medical diagnosis DSM
Identification and pattern	Assessment tools Incidence Risks, pre-hospital and hospitalisation Orthopaedic settings Mortality and morbidity
Professional skills	Misdiagnosis Documentation Education
Qualitative Research	Nursing staff experience Patient's experience

Of the 50 research papers identified, 19 were quantitative research, 11 were qualitative research, 4 were expert opinion and 11 were letters or editorials, the majority therefore considered to be expert opinion or Level IV evidence. (NHNRC Guidelines 1999). This process identified that the majority of the studies within the selected period were quantitative and medical research.

The literature review of the above studies into delirium were analysed according to themes and subthemes using a mind-mapping method as an aid to organise the information required on the topic of delirium. Key themes were identified and linked to this topic and then subthemes were connected to the appropriate key themes. The following demonstrates the major themes and indicates the subthemes that were identified (see Figure 1).

Figure 1 *Mapping method identifying the major and subthemes*



Subthemes

Risk Factors: age, mobility, consent, how common, history,

Misdiagnosis: surgery, 3D's[#], hyperactive, hypoactive, delusions, hallucinations, psychiatric, poor outcomes, nursing homes, morbidity, mortality, hospital costs

Tools: Diagnostic Statistical Manual, Confusion Assessment Method, Mini Mental Status Examination, laboratory testing

Orthopaedic setting: age, surgery, common

Documentation, nurses, medical, poor, terminology

Nurse's experience: workload, fear, and poor skills

Patient experience: adult, children, intensive care, medical, orthopaedic,

3Ds = delirium, dementia and depression

1.2.1 An historical perspective of delirium

Delirium is referred to within classical literature, for example, Shakespeare's death of Falstaff, Lady Macbeth's sleep walking, the famous King Lear, the post-partum delirium of Tolstoy's *Anna Karenina* and Dickens' *Pickwick Papers*, Chapter Three, 'The Strollers Tales' (Kyziridis 2006). From a historical perspective the concept of delirium dates back to the age of Hippocrates and has survived repeated attempts at definition and redefinition over the past 2000 years.

Delirium is one of the earliest mental disorders identified in medical history and has been the topic of countless research studies through the ages. Celsus in the first century AD coined the term delirium for acute mental disturbance although the two subtypes were described as separate conditions, *phrenitis* referring to the agitated presentation of hyperactive delirium and *lethargus*, referring to the lethargy presentation of hypoactive delirium (Adamis et al. 2007). An important contribution in the sixteenth century was the work of the French surgeon Ambroise Paré (1510–1590), who wrote about delirium as a complication of surgical procedures (Adamis et al. 2007). He described delirium as a transient condition that commonly followed fever and pain due to wounds, gangrene and operations involving severe bleeding of the patient. In 1904 Picket proposed a distinction between delirium and confusion, believing that delirium had an organic cause while confusion could be caused by non-organic factors (Adamis et al. 2007).

In the nursing education textbook *Nursing Mental Disorders* (Bailey 1920) Harriett Bailey described delirium as:

A temporary general disturbance of consciousness, a perversion of the intellectual and perceptive faculties, which is characterised by confusion, by more or less transitory delusions and fleeting hallucinations, accompanied by disordered, senseless speech and muttering, and motor unrest. Delirium may vary in degree of severity from a mild wandering type in which the patient is incessantly engaged in disjointed conversation with imaginary persons or muttering to himself, with comparatively little motor activity, to an excited form characterised by extreme restlessness and violence, shouting and attempting to escape from bed or room and from the tormentors created by his imagination who annoy and harass him, or struggling with the imaginary enemies and those who try to limit his activity and prevent his escape. The mood is variable and may be happy, sad, anxious apprehensive or fearful. Delirium may develop as a symptom in the infectious diseases and toxic conditions arising from disordered physical function, in alcoholic and drug poisoning, in conditions of exhaustion and senility and following accidental injuries trauma and surgical operations. (1920, p. 60)

Bailey also identified delirium under the following headings:

- Traumatic psychosis
 - delirium frequently follows operations on the brain
- The alcoholic psychosis *delirium tremens*
- Hypothyroidism
 - in severe cases restlessness is marked and delirium may develop
- The infective psychosis
 - sensations may be rendered more acute in the beginning of the delirium
- The exhaustive psychosis
 - the mental symptoms are those of delirium, the severity of the delirium diminishes and the patient recovers
- Hysteria
 - the disorders of conduct may range from stupor to delirium.

(Bailey 1920, pp. 107, 109, 117, 119, 120, 144)

Today's literature identifies how common delirium is within the elderly hospitalised patient, the range of risk factors especially infection, symptoms of delirium and poor outcomes for the patient who has experienced delirium during hospitalisation.

In contemporary nursing and medical practice the *Diagnostic and Statistical Manual* (DSM) published by the APA is used for classification of mental health disturbances. This manual is applicable for both children and adults and lists known causes of these disorders, statistics in terms of gender, age at onset and prognosis as well as some research concerning the optimal treatment approaches. First published in 1952, this manual is used by all mental health professionals for the standard classification of mental disorder. The *Diagnostic and Statistical Manual Fourth Edition, Text Revision*, describes delirium as:

A neuropsychiatric syndrome of an acute onset and fluctuates characterised by disturbances in consciousness, attention, orientation, memory, thought, perception and behaviour and the five sets of diagnostic criteria are due to a general medical condition, due to substance intoxication, due to substance withdrawal, due to multiple aetiologies and not otherwise specified. (APA 2000, pp. 136–137)

Over recent decades there has been an increase in the quantity and quality of delirium research associated with diagnostic criteria (Bruce et al. 2007).

Delirium has more than 25 synonyms including acute confusion, ICU psychosis, acute organic syndrome and post-operative psychosis, and these synonyms may mislead clinicians about the characteristics and features of delirium (Meagher 2001). Delirium is a common complication among the elderly inpatient orthopaedic population irrespective of the primary diagnosis and by definition delirium has an underlying cause. In this study the diagnosis of delirium was according to the *Diagnostic and Statistical Manual of Mental Disorders Fourth Edition Text Revision* [DSM-IV-TR], Chapter 2, 293.0 (APA 2000) see Table 3.

Table 3 Diagnostic Criteria DSM-IV-TR

A. Disturbance of consciousness (i.e. reduced clarity of awareness of the environment)

with reduced ability to focus, sustain, or shift attention.

- B. A change in cognition (such as memory deficit, disorientation, language disturbance) or the development of a perceptual disturbance that is not better accounted for by a pre-existing, established, or evolving dementia.
 - C. The disturbance develops over a short period of time (usually hours to days) and tends to fluctuate during the course of the day.
 - D. There is evidence from the history, physical examination, or laboratory findings that:
 - (i) the disturbance is caused by the direct physiological consequences of a general medical condition or
 - (ii) the symptoms of criteria A and B developed during substance intoxication or
 - (iii) medication use is aetiologically related to the disturbance or
 - (iv) the symptoms of criteria A and B developed during, or shortly after, a withdrawal syndrome or
 - (v) the delirium has more than one aetiology (e.g. more than one aetiological general medical condition, a general medical condition plus medication side effect) or
 - (vi) a clinical presentation of delirium that is suspected to be due to a general medical condition or substance use but for which there is insufficient evidence to establish a specific aetiology or
 - (vii) delirium due to causes not listed in this section (e.g. sensory deprivation).
-

Inaba-Roland and Maricle (1992) identified that delirium frequently mimics psychiatric disorders such as paranoia, delusions, disorganised thinking, depression, anxiety, and memory impairment. Although the existence of delirium has long been recognised as a serious complication of physical illness, there is no common accepted terminology for delirium (Kyziridis 2006). Yet delirium is commonly identified throughout research papers and texts as a common life-threatening and potentially preventable clinical syndrome developing quickly over hours or days and tending to fluctuate during a twenty-four-hour period. It is characterised by disturbance of consciousness, impaired attention, behavioural changes and an acute change in cognition (APA 1994; Inaba-Roland & Maricle 1992; Meagher 2001; Rapp 2001). The most defining feature is the reduction of awareness of the environment

because of a medical or surgical condition, especially within the older age group. The symptoms are alarming and, if not promptly treated, or prevented there is the potential for serious consequences for the patient and the patient's family unit (Inouye 2006; Kyziridis 2006; McAvay et al. 2006; Meagher 2001; Neitzel Sendelbach & Larson 2007; Robertson & Robertson 2006; Robinson & Eiseman 2008; Ski & O'Connell 2006).

1.2.2 Identification and pattern

Delirium is the most frequent complication in older persons, especially post-operatively and its incidence is increasing with the progressive ageing of western populations. In most studies this varies between 15 and 53% for surgery that includes hip fracture repair. Of this percentage, 15–25% are elective surgery and 25–65% are emergency admissions with hip fracture (Marcantonio et al 2000) being the most common reason for an emergency admission and these statistics are generally supported in the literature (Breitbart et al. 2002; Bruce et al. 2007; Day et al. 2009; Duppils & Wikblad 2004a; Franco et al. 2001; Inaba-Roland & Maricle 1992; Inouye 2006; Inouye & Charpentier 1996; Inouye et al. 2001; Lueng et al. 2005; Lundblad & Hovstadius 2006; McAvay et al. 2006; McCaffery et al 2004; McCarthy 2003; Meagher 2001; Milisen et al. 2002; Rogers & Gibson 2002; Pretto et al. 2009; Robertson & Robertson 2006; Robinson & Eiseman 2008; Smith et al. 2008; Speed et al. 2007; Voyer et al. 2008; Waszynski 2007). The incidence of delirium in the Australian population is comparable to the identified ageing population of these studies (Ski 2006).

The frequent and dangerous complication of delirium within the population of elderly hospital patients with hip fracture received little attention in both nursing and medical orthopaedic literature (Robertson & Robertson 2006). The orthopaedic patient over the age of 75 years is mostly admitted for hip and knee surgery and of this group 44–66% develop delirium (Bruce et al. 2007; Day, Higgins & Koch 2009).

Poor assessment of delirium is one of the precipitators associated with increased risk of nursing home admissions, increased health costs (Franco et al. (2001), mortality and morbidity rates, and functional decline for a patient who experiences a delirium episode. Therefore, patients should be assessed frequently using a standardised assessment tool at the bedside to facilitate prompt identification and management (Inaba-Roland & Maricle 1992; Waszynski 2007; Wiltlox et al. 2010). These tools are used to assess the cognitive functioning of patients and the most common and validated tools are the Confusion Assessment Method (CAM) (Appendix 4) and the Mini Mental Status Examination (MMSE) (Appendix 5). The CAM created by Inouye et al. (1990) and based on the DSM-IV criteria from the APA (1994) is the most widely used tool by non-mental health medical and nursing staff for assessing delirium and several studies have been done to validate clinical usefulness (Waszynski 2007). The MMSE, developed by Folstein, Folstein and McHugh (1975), has been validated and extensively used in clinical practice and research. It is a screening tool for cognitive impairment with older patients and relies on verbal response, reading and writing (Kurlowicz & Wallace 1999). Both tools are practical to use repeatedly and routinely and training to administer and score the tools is necessary to obtain valid results (Kurlowicz

& Wallace 1999; Waszynski 2007). However, no one tool has been shown to incorporate the full assessment of delirium (Rapp 2001).

There may be disturbance of psychomotor behaviour and it is the level of this psychomotor activity that precipitates recognition by health care staff. This psychomotor activity is the basis of the classifications of the three types of delirium. There are three types of delirium: hyperactive, hypoactive and mixed and an understanding of these types helps clinicians to recognise the syndrome. (Duppils & Wikblad 2007; Harding 2004; Inaba-Roland & Maricle 1992; Inouye et al. 2001; Neitzel, Sendelbach & Larson 2007; Rapp 2001; Segatore & Adams 2001; Ski & O'Connell 2006; Steis, Shaughnessy & Gordon 2012). With hyperactive delirium the patient's agitation is prominent and may include hallucinations and or delusions. The patient may attempt to leave and become threatening, or dislodge critical monitoring equipment. These patients may be restrained and medicated. Hypoactive delirium, the most common type, may be diagnosed as depression because of the observed withdrawn behaviour, slow speech and drowsiness or it may even be left undetected because of poorer functional ability due to age. With mixed delirium the patient presents with fluctuating signs associated with both hyperactive and hypoactive types of delirium. The characteristics of both hyperactive and hypoactive types of delirium may place the delirious patient at risk of injury to themselves and or others and there is little acknowledgement of the unexpected strength the older patient displays when they feel a strong compulsion to flee the environment (see Table 3). Risk management in the service of clinical governance brings a strong care imperative for nurses to

find ways of constantly watching and containing delirious patients alongside their workload of caring for other patients (Schofield 2008).

Table 4 Summary of the types of delirium and presentation

Hyperactive Delirium	Agitation, mood lability, psychotic symptoms, disruptive behaviours
Hypoactive Delirium	Lethargy, apathy
Mixed Delirium	Features of both increased and decreased psychomotor activity

1.2.2.1 Risk factors

There are significant predisposing risk factors within the older inpatient population. The Inouye and Charpentier (1996) study identified old age and dementia as significant risk factors and this has been supported by other studies (Bruce et al 2007; Leung et al 2005; McCarthy 2003; Meagher 2007; Smith et al 2009) which identified depression, age and dementia as significant predisposing risk factor as well as age, inpatient populations and dementia. Similarly, the Meagher (2001) study found even if the exposure to the causes of delirium were minimal these significant pre-hospital risk factors of old age and dementia establish a high vulnerability for the likelihood of delirium. Furthermore, the Inouye (2006) study highlighted being delirious in some people may help to identify mild cognitive impairment that otherwise would remain unidentified. The study and also proposed the vulnerability of the brain in patients with dementia may predispose them to delirium and as a consequence, worsening of functional status, loss of independence and poorer outcomes for this patient group may occur. Supporting this vulnerability is the Stenwall et al. (2008) study of the family's experience of encountering

older persons with acute confusional state. They noted that the families reported the confused person never returned to their cognitive baseline after a delirious episode. A helpful factor for the assessment of delirium is the assessment of cognitive function and preoperative evaluation should include a formal cognitive assessment in older patients that are at risk of developing delirium post-operatively (Agnoletti et al. 2005; Smith et al. 2009).

1.2.2.2 Causes

As previously noted, delirium is a common life-threatening and potentially preventable clinical syndrome that has many causes and that may affect people of any age admitted to hospital. In many cases, no acute cause of delirium can be ascertained, but a number of physiological, psychological, sociological and environmental factors may instigate an episode of delirium (Bickel et al. 2004; Day, Higgins & Koch 2009; Flinn et al. 2009; Foreman et al. 2001; Harding 2004; Inaba-Roland & Maricle 1992; Inouye & Charpentier 1996; Inouye et al. 1990; Kyziridis 2006; Mantz, Hemmings & Boddeart 2010; Meagher 2001; Neitzel, Sendelbach & Larson 2007; Paulsen et al. 2011; Pretto et al. 2009; Rapp 2001; Rogers & Gibson 2002; Segatore & Adams 2001; Speed et al. 2007; Steis, Shaughnessy & Gordon 2012). The underlying physiological causes have been identified in the literature using the acronym VINDICATE, which stands for Vascular, Infections, Nutrition, Drugs, Injury, Cardiac, Autoimmune, Tumours, Endocrine (Agnoletti et al. 2005).

Delirium is rarely caused by a single factor and Inouye and Charpentier's 1996 study identified the inter-relationship between the patient's baseline vulnerability on admission and the risk factors that occur during

hospitalisation. Their cohort study of patients in general medical wards of a university teaching hospital of 196 patients over 70 years of age with no delirium and 312 patients with delirium, found that patients with cognitive impairment or co morbidities were vulnerable to any risk factor for developing delirium (Inouye & Charpentier 1996). Examples of the hospital-related risk factors identified in this study were physical restraints, indwelling catheters inducing involuntary immobilisation and urinary tract infections with associated systematic physiological imbalances and more than three medications given 48 to 24 hours before onset of delirium. Patients undergoing orthopaedic procedures are identified as an at risk group for delirium post-operatively because of the factors in relation to anaesthesia, hypotension, hypoxia and hypothermia (Rogers & Gibson 2002). The study of Milisen et al. (2002) highlighted a better understanding and knowledge of delirium among health care professionals working in orthopaedic units will lead to early detection and reduction of the modifiable risk factors, and provide better symptom and person management of the condition in the acute phase of a delirious episode.

1.2.2.3 Delirium, dementia and depression

The fact that the symptoms of delirium, dementia and depression (known as the 3Ds) within the elderly population overlap and have the ability to co-exist are important factors that are often not recognised (Ski & O'Connell 2006). Depression is most commonly a missed diagnosis in the elderly. If the symptoms of delirium are missed it can prove to be fatal and the symptoms of dementia are often confused with depression and delirium. Although the symptoms of each can overlap considerably, a number of clues to differentiate

are listed and, in particular, one should investigate the time of events, the patient's functional status and co-morbid conditions (see Table 5). Harding (2004) suggests that health professionals tend not to recognise delirium and dismiss it as senility and a normal part of ageing.

Table 5 Comparison of the features of delirium, dementia and depression

Feature	Delirium	Dementia	Depression
Onset	Acute (hours to days)	Insidious (weeks to months)	Acute (days to weeks)
Course	Fluctuating, lucid periods in a day	Relatively stable	Relatively stable
Duration	Days to weeks	Months to years	Weeks to months
Consciousness	Reduced	Clear	Clear
Attention	Impaired	Normal, except severe cases	May be disordered
Hallucinations	Usually visual or visual and auditory	Often absent	Predominately auditory
Delusions	Fleeting, poorly systemised	Often absent	Sustained systemised
Orientation	Usually impaired at least for a time	Often impaired	May be impaired
Memory	Immediate and recent memory impaired, remote memory intact	Immediate memory intact, recent memory more impaired than remote	May be selectively impaired
Psychomotor	Increased, reduced or shifting unpredictably	Often normal	Varies from retardation to hyperactivity (in agitated depression)
Speech	Often incoherent slow or rapid	May have word finding difficulties, preservation	Normal slow or rapid
Thinking	Disorganised or incoherent	Impoverished and vague	Impoverished retarded
Physical illness or drug toxicity	One or both present	Often absent in Alzheimer's disease	Usually absent, but debatable

Adapted from: Evans & Williams (2000, p. 494).

Leung et al. (2005) suggest the evaluation of a patient's psychological status preoperatively is overshadowed by the focus on multiple co-morbid medical conditions. The severity of the symptoms of depression is associated with an increase of incidence of post-operative delirium among the surgical patient group; screening for depression in this elderly group is useful prognostic information for the possible development of delirium (Greene et al. 2009; Leung et al. 2005; Smith et al. 2009).

1.2.2.4 *Poor outcomes*

The elderly orthopaedic patient group who have experienced a delirious episode post-surgery are identified within the literature in morbidity and mortality statistics and poor outcomes post discharge (Day, Higgins & Koch 2009; Marcantonio et al. 2000; McCurren & Cronin 2003). Delirium is a poor prognostic sign with a high mortality and the consequences of delirium for the older patient are diverse, can be persistent and may result in negative outcomes for the patient (Voyer et al. 2008). The studies of Marcantonio et al. (2000), McAvay et al. (2006), McCarthy (2003), Meagher (2001), Robertson and Robertson (2006), Robinson and Eiseman (2008) demonstrate that an occurrence of delirium increases the length of the rehabilitation process, prolongs hospital stay, worsens the functional and cognitive status, increases admission to nursing homes and increases the mortality rate for patients who experience a delirious episode. Inouye (1996) identified that 11.5% of people who experience delirium die within the first month of discharge from hospital and one year after discharge the mortality rate associated with delirium is 35-40%.

1.2.3 Professional skills

In the prodromal phase of days or hours of delirium, early symptoms occur before all the criteria for delirium are met. This phase involves alterations in behaviour, emotional state and sleeping patterns of the patients. The Duppils, and Wikblad (2004a) study identified that patients' disorientation and urgent calling for attention were frequent behaviours displayed in this prodromal phase of delirium. The study also noted that paying attention to the behaviours during this prodromal stage may assist in preventing missed or misdiagnosis of delirium.

The complexity of the reasons for misdiagnosis of delirium may be attributable to transient changes in cognition and are often missed by staff caring for the patient. Delirium is of short duration with an abrupt onset, characterised by fluctuating symptoms during the day that worsen at night. Lucid intervals, the lack of formal cognitive assessment and an under-appreciation of its clinical consequences all contribute to misdiagnosis of delirium (Duppils & Wikblad 2007; Inouye 2006; Inouye et al. 2001; McCarthy 2003; Milisen et al. 2002; Neitzel, Sendelback & Larson 2007; Robertson & Robertson 2006; Robinson & Eiseman 2008; Rogers & Gibson 2002; Segatore & Adams 2001; Speed et al. 2007; Steis, Shaughnessy & Gordon 2012; Voyer et al. 2008). These facts are reinforced in the study conducted by Ski and O'Connell (2006) that indicated delirium is misdiagnosed and mistreated in up to 94% of older patients in hospitals.

Besides the clinical and legal importance of documentation, the use of documentation to identify a behaviour pattern can assist greatly in

recognising, diagnosing and monitoring treatment. However, there are limited studies on the documentation of delirium. In the Voyer et al. (2008) audit of 226 nursing notes, 64.2% of the reviewed notes revealed hyperactivity and disorientation were the most reliable symptoms of delirium documented. These findings were supported by Milisen et al. (2002), who found that both medical and nursing staff were poor at documenting delirium; in fact, no cognitive functions were documented by medical staff regardless of their daily visits. This study also identified that nursing notes were inconsistent and scanty in recording the description of delirium and the term delirium was never used. The patients were described as “confused” or “acutely confused”. A study by Milisen et al. (2002) noted that documentation of the cognitive status is poor in the medical and nursing records of elderly patients with hip fractures. This leads to under-diagnosis of delirium and failure to diagnosis delirium arrests any attempts at prevention or early intervention which compounds the poor prognosis and outcomes.

Nurses have frequent and continuous 24-hour contact with patients, which means nurses play a crucial role in the early recognition of delirium; however, nurses identify their lack of skill of cognitive assessment in identifying delirium (Inouye et al. 2001; Voyer et al. 2008). This lack of ability is of great concern and improvements to the process of recognising delirium are essential to address the problem. It is important to recognise that an acute cognitive decline in the older patient is an abnormal event that is suggestive of a health problem and not a normal part of ageing. Education and training for detection of delirium and its key features are recommended for nurses during routine clinical care. Instruction in how to administer brief cognitive assessment

assists in detecting the key features of delirium. Such education programs ideally should be included in training school curriculums, continuing education programs for the nursing profession and mental health professionals involved in providing education and support for the staff (McCarthy 2003; Schofield 2008; Inouye et al. 2001).

Delirium is associated with poor outcomes for the patient and one way to prevent the poor outcome is to prevent the development of delirium by developing and managing different models of care. The literature identifies these models can include establishment of a Delirium Room as an integral part of an acute care for the elderly unit and supported by a geriatric consultation service (Flaherty et al. 2003); orthopaedic units being supported by geriatric consultation service (Marcantonio et al. 2001); a nurse-led delirium prevention and management program (Pretto et al. 2009); psychiatric clinical advice action plan for nurses (Lundblad & Hovstadius 2006); and support from psychiatric teams (Breitbart, Gibson & Tremblay 2002; Holmes 1996; Tsai et al. 2012).

1.2.4 Qualitative research

1.2.4.1 The nursing perspective

In the literature review thus far it is apparent that much of the literature is primarily based on medical research focusing on prevalence, causes, diagnosis and management of the elderly medical patient suffering from delirium. One area that attracted investigation is the need for research into nurse's experiences of caring for the delirious patient (Andersson, Hallberg &

Edberg 2003; Breitbart, Gibson & Tremblay 2002; Rogers & Gibson 2002; Schofield, Tolsan & Fleming 2011). Knowledge about the nurses' experience can provide understanding and information about effective and successful measures in the encounter (Andersson et al. 2003).

Andersson et al.'s 2003 study of 48 nurses within an orthopaedic setting found that a major task for nurses in providing care to patients in a confusional state is to interpret and understand the patients' experience. That is, what is going on in their minds, taking time, being close and listening to the patient express his or her anxiety or physiological discomforts. The nurses had difficulties in establishing and maintaining reciprocity with the acutely confused patient. The nurses used their capacity to sense the patient's feelings and experiences and they acted as a companion and surrogate to protect their delirious patient.

With the increasing number of the elderly being admitted to general hospitals, especially those over the age of 75 years, a vital role of nursing is to provide close observation over a 24-hour period and to accurately assess the cognitive function of patients to enable relevant planned care to be provided to the patient. The Rogers and Gibson (2002) study was conducted in an orthopaedic unit and interviews from 10 registered nurses supported current knowledge relating to prevalence, onset, duration and course of acute confusion. The study identified significant implications for nursing practice and education. The typical escalation of behaviour by patients with delirium in the evening and night requires assessment of appropriate staffing levels to ensure staff and patient safety. Attention to the needs of the patient with

hypoactive type delirium, and to patients' recollections of their experiences of being delirious need to be taken into account when designing effective nursing interventions and education programs.

Breitbart, Gibson and Tremblay's (2002) study of 154 hospital cancer patients who were referred to a psychiatric service identified the distress of anxiety, frustration, helplessness and fear experienced by nurses when caring for the delirious patient who was hallucinating and deluded.

1.2.4.2 *The patient experience*

The terms acute confusional state and delirium are used interchangeably by most health care professionals, with nurses tending to use acute confusional state and medical staff using the term delirium. Both terms refer to the same phenomena characterised by the APA (1994).

Duppils and Wikblad's study (2007) of 15 patients who had undergone hip related surgery found their experiences were like dramatic scenes that gave rise to strong emotional feelings of fear, panic and anger. The patients described the experience as dream-like and when the delirium had resolved they felt desperate feelings of remorse.

Fagerberg and Jonhagen (2002) interviewed five older patients after a delirious episode to better understand the experience of being delirious. The findings from the study were presented under the headings of 'being temporarily confused' and 'reasoning about experiences of temporary confusion'. The patients' experiences of being temporarily confused were of threat, suspicion, wide-open spaces and the need to flee. In their reasoning

about the experience, the patients focused on their feelings of shame and guilt, the humiliation they felt, they looked for reasons and they expressed fear of a recurrence. This study also identified the importance of the voice of the elderly and of showing trust in the experiences they describe.

The Andersson et al. (2002) qualitative study involved interviews of 50 elderly patients hospitalised for orthopaedic care who had developed an acute confusional state during their hospitalisation and their reflections on returning to lucidity. The majority of the participants of the study spontaneously remembered their experience and described being trapped in an incomprehensible experience and a turmoil of 'past and present' and 'here and there'. The striking finding of this study was that the patients' experiences were emotionally difficult and frightening for them. The study indicated that what takes place during an acute confusional state can be understood at some level.

A way to provide an understanding of the impact a delirious experience has on a person is by allowing the people who had the delirious experience tell their story. This was the aim of the study of McCurren and Cronin (2003) and the findings revealed a frightening world of misinterpretations, hallucinations, paranoia and loss of control with the emotional responses to the delirious episodes being fear, anxiety, frustration and anger.

Harding, Martin and Holmes (2008) recruited from two orthopaedic trauma wards nine patients who had become delirious after reparative hip surgery. The aim of this study was to better understand the experience of delirium in this group of patients. The findings of the study identified the participants'

struggle to make sense of their experience and their anxiety about their own mental state. The study also recommended information be provided to the patient and their family about delirium, training for health care staff and supervision to help the health care staff understand and manage their own anxieties about caring for delirious patients.

Schofield's 1997 study involved a sample of 19 patients who had experienced and recovered from an episode of delirium. Medical and nursing notes were consulted as an additional check for the diagnosis of delirium. The participants in this study viewed their experience with bewilderment, surprise and some curiosity. This study also highlighted that the fact that the participants were so willing to talk about their experience suggests the need for patients to be given the opportunity to talk over the delirious episode.

Within the small body of literature reviewed, two self-reports were identified and I regarded them as a useful addition to reviewed qualitative studies, even though self-reporting may be considered by some to be flawed by bias. These reports were authored by psychiatrists admitted to a surgical ward and intensive care unit. Bowker's account (1995) of his delirious episode concluded by identifying the strong emotion of embarrassment he felt for being delirious. He found that delirium was as distressing as severe pain and needed to be identified and treated with the same degree of diligence as severe pain as soon as delirium develops. Bowker stated he was not surprised at the published evidence for significant psychological trauma arising from some experiences of delirium with later psychiatric morbidity. Crammer (2002) identified four episodes of being delirious during his hospital

admission. Crammer stated when he was delirious he was disorientated, misidentified others and developed false beliefs. The resolution of his delirium was like waking from sleep. He stated that delirious patients require full assessment by psychiatrists and psychologists. Crammer also commented that the quiet patient could easily be overlooked.

1.3 Conclusion

Studies that adopt a qualitative approach raise the issue of the role of a literature review. The qualitative researchers Corbin and Strauss (2008) note that a literature review can be useful in order to decide a research topic, to formulate a research plan and to enhance the researchers' awareness to subtleties uncovered in previous research. This literature review provided me with the opportunity to identify the gaps that exist in the body of literature and the rationale for this study. The experiences of patients may be very different because of the reasons for their hospitalisations and their age may affect the impact of the episode of delirium. To research the experience of delirium in a particular group of patients may be a valuable path to the best way to care and support patients. The group for this study includes the patient following orthopaedic surgery. The following chapter will discuss the methodology used for this study.

The literature review process has determined what has already been studied on the topic of delirium and how this information is related to the topic of this study. Delirium is commonly unrecognised and or misdiagnosed by nurses and physicians, and this lack of recognition may be because of the lack of knowledge related to delirium. Medical and nursing textbooks concentrate on

diagnosis, reduction of modifiable risk factors and treatments. Nursing research has examined documentation, skills and lack of education. Also demonstrated in the literature review is that the experience of delirium from the patient's perspective has been largely ignored except by a limited number of qualitative researchers. Increased knowledge and understanding of the lived experience of delirium in the elderly hospitalised patient on the orthopaedic ward can hopefully reduce the suffering for elderly patients in the future and encourage nursing staff to listen and interact with patients when they are delirious.

Therefore, in the light of this literature review, it has become apparent that limited research has been undertaken into the patient's experience of delirium. The very lack of research has increased the worth of its study by providing a better understanding of the experience and hence enhancing the nurse's knowledge and skills to manage the patient who has had orthopaedic surgery and becomes delirious during the post-operative phase. Corbin and Strauss (2008) also noted a review of literature may bias the researcher towards 'what others say instead of 'what I think'.

The literature studied for this review is what I knew when I did this review in 2010. To prevent any bias and to maintain currency of my professional knowledge, I continuously updated the literature review as relevant publications were evident and these papers are used in later chapters.

CHAPTER TWO: METHODOLOGY

Methodology is, in simple terms, the study of method and method relates to the precise process of finding knowledge or understandings. Chapter Two reports on the methodology and methods used for the data collection and analysis in this descriptive qualitative study. The methodology section will situate this qualitative research within the interpretive paradigm as an inductive process intended to generate understanding of the social world rather than truth that is generalizable. The work of Sandelowski (2000) will be referred to and discussed before a justification for the selection of grounded theory techniques for inductively deriving understandings of the experience of delirium post orthopaedic surgery. In the methods section of the chapter each step in the data collection and analysis process will be detailed.

As identified in the preceding literature review, much of the literature has suggested best practices for preventing, assessing and managing delirium, but little of the literature has described the lived experience of delirium as described by patients post orthopaedic surgery.

There are many different techniques for analysing data, this was overwhelming to me when deciding which method to choose for this qualitative study. The most important understanding gained was there are many ways for the analysis and the process included becoming familiar with the data by immersion, then looking for patterns, themes and relationships within the data so that an understanding was gained of the emerging results. I worked with the thought that analysis was a process of making sense of the participants interviews while at the same time being mindful there are various

approaches in qualitative research methodology, for example, in ethnography, phenomenology, grounded theory and narrative study. The hallmark of the qualitative approach is the personal meaning of individual experiences and actions of individuals in the context of their social environment. That is, qualitative studies offer the participants the opportunity to describe the rich complexity of their experiences as they live through the situation.

The aim of this study was to gain first-hand knowledge of the experience of patients with delirium post-operatively. The supports for this small independent research project were: the dearth of literature available on delirium, the very limited work of other researchers on the topic of the patient's experience of being delirious, and my clinical expertise in the area of delirium. When there is little research already done, qualitative description is appropriate as a beginning for the research endeavour (Milne & Oberle 2005; Neergaard et al. 2009; Sandelowski, 2000; Sandelowski, 2010).

I will describe descriptive the qualitative approach and grounded theory, then discuss why the combination of these approaches has been chosen as the methodology for this study.

2.1 Descriptive Qualitative Approaches

The growth in qualitative health science research has led to the introduction of an array of qualitative methodologies, resulting in what Sandelowski (2000) has called 'methodological acrobatics'. Those words used by Sandelowski describe and highlight how researchers sometimes feel obliged to designate their work as phenomenology, grounded theory, ethnography or a narrative

study methodology, when in fact it does not make any methodological contribution and may neglect the benefits of an alternative approach, namely qualitative description. Qualitative researchers in health sciences have diverse backgrounds, most are inspired by phenomenological and hermeneutical traditions and their approaches are mostly theory driven (Neergaard et al. 2009).

Qualitative research methods are methods of inquiry, that is, the aim is to gather an in-depth understanding of human behaviour by investigating not only the 'what, where and when' but also the 'why and how' of reasons that govern human behaviour. It is the research method that produces findings or interpretations and refers to research about a person's life, a person's lived experience, people's emotions and behaviours, a cultural phenomenon and social movements. Whereas other qualitative approaches often aim to develop concepts and analyse data in a reflective or interpretive interplay with existing theories, the final product of qualitative description is a description of the informant's experience in a language similar to the informant's own language (Neergaard et al. 2009).

A qualitative descriptive study follows the tradition of qualitative research, that is, a method of investigation that aims at describing the person's perception and experience of the world and its phenomena. It is particularly amenable to obtaining answers to questions of specific relevance that have minimal recognition in research literature. Examples of such questions are 'what are people responses to a certain event?', and 'what factors hinder recovery from an event'? Sandelowski (2000) stated that qualitative descriptive studies offer

a comprehensive summary of an event in the everyday terms of those events, that is, the facts of the event are presented in the vehicle of communication known as everyday language. It is not theory driven, it is founded in the existing knowledge, and there are thoughtful linkages to the work already undertaken by others in the field and the clinical experience of the research group.

According to Neergard et al. (2009, p.3) qualitative description differs from other qualitative methods in several ways:

- It is neither a dense description (ethnography), or a theory development (grounded theory) nor an interpretative meaning of an experience (phenomenology); it is a rich direct description of an experience or an event. The data analysis of qualitative description is a description of the participant's experiences in a language similar to the participant's own language.
- The interview guide in qualitative description is typically based on expert knowledge and focuses on poorly understood areas in health care that have the potential to be amenable to intervention.
- Qualitative description is probably the least theoretical qualitative approach because of being founded in existing knowledge, the linkages to the work of others in the field and the researcher's clinical expertise in the field.

Qualitative description has generally been viewed as the 'poor cousin' to more developed qualitative methods, for example grounded theory (Milne & Oberle 2005). Qualitative descriptive designs are reasonable and a well-considered

combination of sampling and data collection analysis and Table 6 summarises the design features proposed by Sandelowski (2000).

Table 6 Summary of design features proposed by Sandelowski (2000)

Design issue	Design specifics
Philosophy	Pragmatic approach Overtones of other qualitative approaches (phenomenology, grounded theory, ethnography or a narrative study)
Sample	Purposeful sampling Maximum variation sampling is especially pertinent
Data collection	Minimally-moderately structured open-ended interviews with individuals or focus groups Researchers are interested in Who, What, Where and Why of the experience Observation of specific occurrences Review of documents or other pertinent materials
Analysis	Qualitative content analysis using modifiable coding systems that correspond to the data collected When appropriate 'Quasi-statistical' analysis methods are added using numbers to summarise data with descriptive statistics Stay close to the data-low level interpretation (if using qualitative software such as NVivo, the use of "in vivo coding" procedures works well here) Goal of the analysis strategy is to understand the latent variable (useful for concept clarification and instrument development)
Outcomes	Straight description of the data organised in a way that "fits" the data (chronologically by topic by relevance)

Sandelowski's proposed design features are supported by six strategies for data analysis that demonstrate commonness to many qualitative methods including qualitative description (Neergaard et al. 2009) (see Table 7 below).

Table 7 Six strategies for data analysis

1. Coding of data from notes, observations or interviews
2. Recording insights and reflections on the data
3. Sorting through the data to identify similar phrases, themes, sequences and important features
4. Looking for commonalities and differences among the data and extracting them for further consideration and analysis
5. Gradually deciding on a small group or generalizations that hold true for the data
6. Examining these generalizations in the light of existing knowledge

(Neergaard et al. 2009).

Although many critics are reluctant to accept the trustworthiness of qualitative research, frameworks for ensuring rigour have been in existence for many years. When researchers present and examine standards of rigour they create an important opportunity for those in nursing research, management, practice and education to foresee and specify the boundaries of the chosen methodology (Chiovitti & Piran 2003). An approach to assessing the quality of research studies involves criteria that are the accepted standards for best research practice by which studies may be judged. However, there are several sets of criteria for assessing the quality of a research study and this raises the question of which should be used when evaluating a study (Elliott & Lazenbatt 2005). An example is detailed in Table 8.

Table 8 Criteria for assessing quality of research

Qualitative research	Qualitative research	Original grounded theory criteria	Strauss & Corbin's grounded theory criteria
Credibility	Credibility	Fit	Two sets of criteria: Research process Empirical grounding of findings
Transferability	Auditability	Work	
Dependability	Fittingness	Relevance	
Confirmability		Modifiability	
(Lincoln & Guba 1985)	(Beck 1993)	(Glaser & Strauss 1967)	(Strauss & Corbin 1998)

Adapted from Elliott & Lazenblatt (2005, p. 49)

The next section will examine grounded theory as it pertains to this descriptive qualitative study.

2.2 Grounded Theory

Grounded theory is a qualitative research method that was developed by two sociologists, Anselm Strauss and Barney Glaser in the 1960s while they were working collaboratively in the faculty of nursing doctoral program at the University of California, San Francisco. Their studies on the dying patient and the nurses' lived experience in hospital led to their publication of *The discovery of grounded theory* (Glaser & Strauss 1967). In the 1990s a critical debate concerning the approach to grounded theory occurred between the two founders. The debate resulted in Glaser's viewpoint being referred to as the classic model, and implies that the relationship between the researcher and those under investigation should be detached. Strauss and Corbin's

reformulation of grounded theory was described as the evolutionary model, which states the researcher interacts in the research process and the researcher's interpretations are incorporated into every element of the inquiry (Strauss & Corbin 1998).

Another major difference between the two grounded theory approaches is that Glaser claimed that the researcher starts doing grounded theory with a research interest, but does not start with a research question. He wrote that 'There is no need to waste time on the debate as to whether or not the research question should dictate the method or the method the research question' (Glaser 1992, p. 24). However, Strauss and Corbin believed that 'the research question in a grounded theory study is a statement that identifies the phenomenon to be studied' (Strauss & Corbin 1998, p. 40). In undertaking a grounded theory approach, the researcher needs a research question or questions that will help them deeply explore the phenomenon with flexibility and freedom.

The area of verification was also another difference between these researchers. Glaser believed the hypothesis did not need to be verified or validated, in contrast to Strauss and Corbin who emphasised that it was mandatory that the verification be done throughout the course of the research project rather than assuming that verification is only possible through follow up quantitative research. The classic and evolutionary models share the concept of theoretic sampling, constant comparison analysis, theoretical sensitivity, theoretical coding, memo writing, identification of core category and theoretical saturation (Glaser 1992; Strauss & Corbin 1998).

The last major area of difference between Glaser, and Strauss and Corbin, was the issue of inductive or deductive analysis. Inductive analysis is the theory developed from the data and deductive analysis is the data developed from an identified theory. Strauss and Corbin (1998) presented grounded theory as a combination of both analyses including verification, whereas Glaser's (1992) view was one of inductive analysis for grounded theory. Strauss and Corbin (1998) believed using both analysis approaches gave the researcher much more flexibility to look at the data for potential situations of change.

Originally, grounded theory was philosophically based on symbolic interactionism attributed to Herbert Blumer (Heath & Cowley 2004), which explores how people define reality and how their beliefs are related to actions. It is argued that people create their reality by attaching meanings to social constructs. Symbolic interactionism stresses that the meanings of an event to an individual are only obtained through interpretation. 'Grounded' means that the theory is developed from the questions that are repeatedly asked by the researcher: Who? When? Why? Where? What? How? How much? With what results?—it is grounded or has its roots in the data collected. The key feature of grounded theory methodology includes the grounding of theory within the data, the making of constant comparisons, the asking of theory-orientated questions, theoretical coding and the development of a theory (Strauss & Corbin 1998).

It is the seminal work of Glaser and Strauss (1967) where the grounded theory approach of constant comparison method is identified as the process

of constant comparison of incident to incident, incident to codes, codes to codes, codes to categories and categories to categories and continues until a grounded theory is fully integrated (Birks & Mills 2011, p.11). Strauss and Corbin (1998) used both inductive and deductive reasoning, making the constant comparative method of data analysis most appropriate for theory building. This study was not building a theory, but a grounded theory approach was used for the data analysis because such an approach provided a structured process for analysis.

Strauss and Corbin's meaning of the term grounded theory is theory that is derived from data, systematically gathered and analysed through the research process. In this method, data collection, analysis and eventual theory stand in close relationship to one another with an emphasis on the analytical steps of open, axial and selective coding for developing the theory (1998, p.12).

The following describes the open, axial and selective coding as provided by Strauss and Corbin (1998):

- Open coding is the process by which concepts are identified and developed in terms of their properties and dimensions. This includes asking questions about the data, making comparisons for similarities and differences between incidents and events. Similar ones are grouped to form categories. Open coding is used to fracture the data (Glaser & Strauss 1967).
- The next stage is axial coding which is a set of procedures used to put the data back together in new ways. The authors describe this process as relating subcategories to a category, which is developed

by using a coding paradigm. The aim of the coding paradigm is to make explicit connections between categories and subcategories. This process is often described as the “paradigm model”, and involves explaining and understanding relationships between categories in order to understand the phenomenon to which they relate.

- Selective coding is the process of selecting the core category and systematically relating it to the other categories and validating those relationships, filling in and refining and developing those categories. Categories are integrated together and the grounded theory is determined. The core category is the central phenomenon around which all the other categories are integrated. Once this is done, validation occurs by generating hypothetical relationships between the categories and the data, enabling the researcher to be able to say ‘under these conditions this happens’, ‘whereas under these conditions this is what occurs’. The validation of the theory against the data completes its grounding.
- Validation is done by generating hypothetical relationships between categories and using the data from the interviews to test the hypothesis.

Table 9 summarises the stages of coding.

Table 9 Summary of the stages of coding

Open coding	Identification, naming, categorizing and describing phenomena found in the text
Axial Coding	The process of relating subcategories to categories that leads to the occurrence of the development of the phenomenon
Selective coding	The process of relating subcategories to categories that leads to the occurrence of the development of the phenomenon

In this study I have employed the techniques of qualitative description as described by Sandelowski (2000) and the coding process of Strauss and Corbin (1998) because:

- the study was small
- the six strategies of Sandelowski's design feature are similar to grounded theory
- the systematic method of the coding process detailed by Strauss and Corbin provided instructions that proved to be a good guide.

This study adapted the process of constant comparison analysis. The adaptation was that the participants were only interviewed once; however, constant comparison was through the continual comparison across the data sets as described in grounded theory (Chiovitti & Piran 2003; Corbin & Strauss 2008; Eaves 2001; Elliott & Lazenbatt 2005; Heath & Cowley 2004; Strauss & Corbin 1998). The categories developed from the adapted process were rich in meaning.

2.3 Methods

As previously stated, the rationale for this study is that many elderly patients requiring orthopaedic surgery will suffer from post-operative complications, such as delirium. The need for orthopaedic surgery is common and will become even more so because of the longevity of the aged population. Delirium is a frightening experience and causes the patient severe suffering; it is of great importance that knowledge is increased regarding the severity of the suffering so that these insights motivate professional staff to make improvements in prevention, treatment and management strategies to alleviate the patient's suffering.

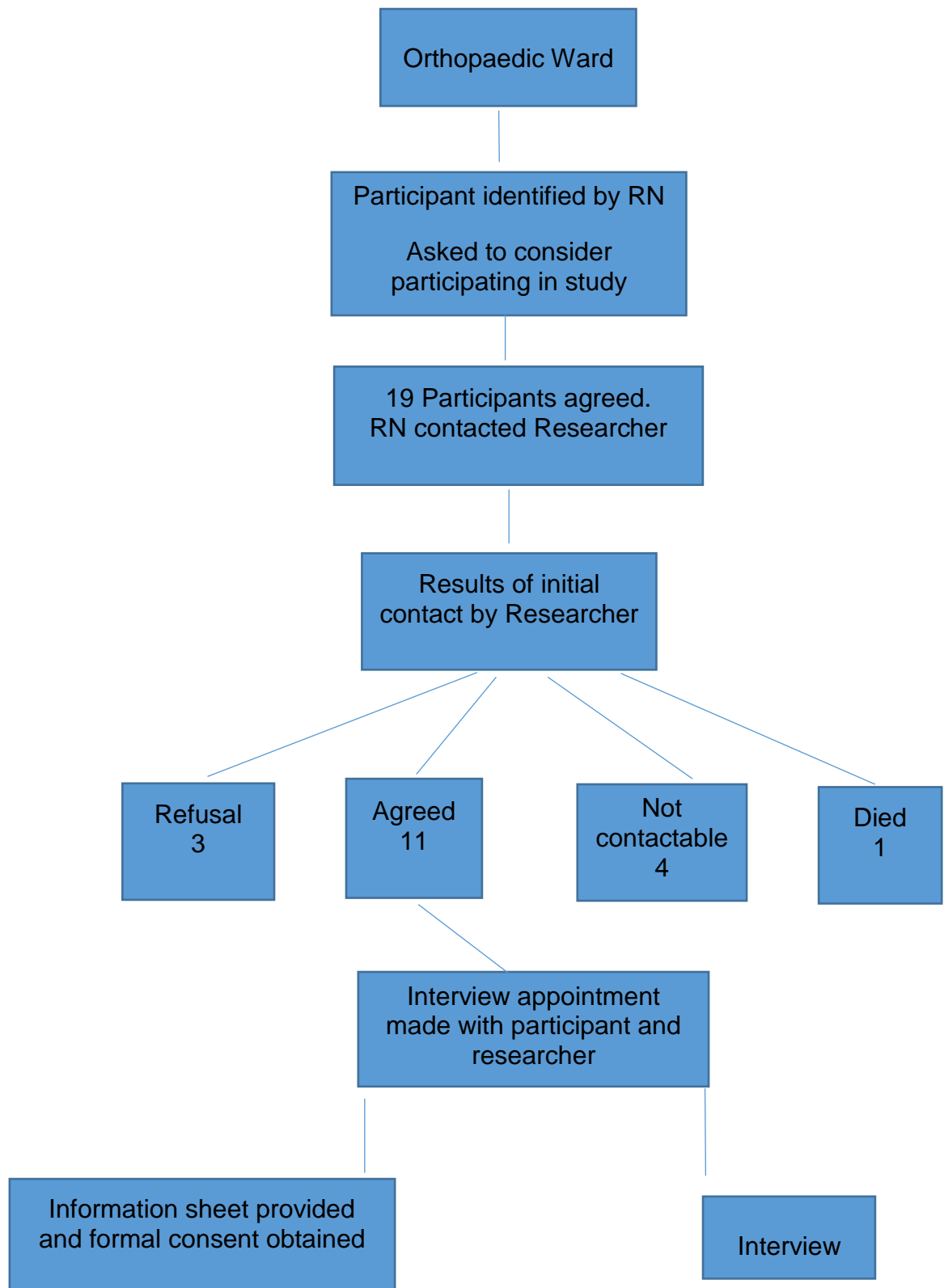
The site of the study was the orthopaedic ward of the acute tertiary hospital in the capital city of a state of Australia and discussions were held and support gained with the nursing and medical staff to conduct the study on the ward.

2.3.1 Recruitment of participants

The participants, whose ages ranged from 54 years to 87 years old, with the majority aged in their 70s had been admitted to the ward for planned knee and hip replacement surgery and shoulder repair surgery. To gain access and consent a registered nurse of the orthopaedic ward identified suitable patients from the individual medical file where documentation of delirium was entered and confirmed by the medical diagnosis. This registered nurse asked the patients if they were interested in taking part in the study, they were given an information sheet (Appendix 1) to read and discuss with the nurse. When the patient indicated their willingness to participate in the study, they agreed to

make their telephone number available to enable me to contact them and arrange an appointment at a time and place of their choice. At the time of the interview participants were given another opportunity to ask questions and then were asked to read and sign the consent form (Appendix 2). The participants were also given information that the interview would be audiotaped and their identifier would be deleted. Figure 2 summarises the recruitment process.

Figure 2 **Recruitment process**



2.3.2 Inclusion and exclusion criteria

A person is considered to lack capacity if they are unable to make a decision because of an impairment or disturbance in the functions of the brain whether the impairment is temporary or permanent. Capacity can be regained, for example, the mentally ill have capacity at certain times but are not able to make some or all decisions at other times (Department of Health and Human Services [DHHS] 2009, pp. 15–24). Delirium is characterised by disturbed attention and cognition which develops over a short period of time and tends to fluctuate during the course of a day. The disturbed cognition and the fluctuation may impact on a delirious patient's capacity to make decisions for themselves raising an ethically sensitive area when considering the exclusion and inclusion criteria for the study as detailed in the following Table 10.

Table 10 Inclusion and exclusion criteria

Exclusion Criteria	Inclusion Criteria
Patients during an acute phase of delirium	Patient will be literate and have a command of the English language
Patients with a pre-existing admission diagnosis of dementia	Patients will be admitted to the orthopaedic inpatient ward for joint replacement surgery
Patients with a pre-existing psychiatric diagnosis	Patients will have a co morbidity of delirium
	Patients who meet the selection criteria and reside in Southern Tasmania

As described in Table 10, nineteen patients met the inclusion criteria, three refused to participate when contacted by myself, four were unable to be contacted and one died prior to contact being made. Eleven participants were interviewed either in their own homes, my office, rehabilitation and orthopaedic ward. Except for Gavin, Gilbert, Daisy and Dorothy (pseudonyms), the other participants' spouses/partners were present at the interviews.

Table 11 Participant and interview details

Name	Age	Date of interview	Place of interview
Daisy	87	13/5/08	Rehabilitation Ward
Charlie	54	16/6/08	Researcher's office
Lance	71	22/6/08	Participant's home
Gilbert	70	23/6/08	Participant's home
Gavin	76	24/8/08	Participant's home
Dorothy	72	9/9/08	Orthopaedic Ward
Henry	67	22/10/08	Researcher's office
Alfred	72	4/11/08	Participant's home
George	82	4/12/08	Researcher's office
Ted	78	13/1/09	Participant's office
Mabel	84	25/5/09	Researcher's office

2.4 Ethics

As this research involved human participants the *National Statement on Ethical Conduct in Human Research (2007)* (National Statement [2007]) and its series of guidelines made in accordance with the *National Health and Medical Research Council Act 1992* were used to guide the ethical considerations in the study. Approval was obtained from the Social Science Human Research Ethics Committee, Department of Health and Human

Services and the University of Tasmania, approved the study (H0009761) on 19 December 2007. Informed consent was obtained from the participants prior to the interviews. To ensure confidentiality and anonymity for the participants, the data that were collected during the interviews were kept in a locked cupboard in my home office. Fictitious names were used and participant identifiers were also removed from the reported data to preserve anonymity. In addition, participants were not obliged to participate in the study and could withdraw at any time without any penalty. The study was not funded.

2.5 Data Collection

There is no definitive answer to the issue of sample size in qualitative research, it is the richness and saturation of data that guides how many interviews will be conducted and a variety of techniques are used to produce data about the area of a study. The main techniques used are focus groups, structured interviews and semi-structured interviews.

A structured interview is an approach to ensure that each interview is presented with exactly the same questions in the same order. This ensures that answers can be reliably collected and that comparisons can be made with confidence between sample subgroups or between different survey periods.

A semi-structured interview is a method where the interviewer develops questions which are only guidelines for the interview allowing the participants to be flexible with their responses and allowing the interviewee to explore interesting topics that may emerge.

After considering these methods, I chose a semi-structured interview method to allow the participants maximum flexibility in discussing their experiences of delirium. Each participant was interviewed for approximately one hour at their location of choice, which included my office, their private home, the rehabilitation ward of the hospital and one interview was held pre-discharge because of an extended inpatient stay (refer to Table 11 for demographics of the participants). All interviews were audiotaped and transcribed with the deletion of any participant identifier.

The participants were encouraged to talk without interruption in response to the semi-structured interview questions. I was sensitive to the person's emotions and their sometimes difficult experience of talking about their delirium. While listening to the participants' stories and with my clinical expertise I was able to ask additional questions to tease out details while describing some of their experiences. Questions that guided the interview were: Why were you recently admitted to the orthopaedic ward? What was your experience as a patient like? How did you feel during that time of being confused? (refer to Appendix 3 for further research questions).

2.5.1 Data analysis

To analyse the data an adaptation of constant comparison as described by Corbin and Strauss (2008); Strauss and Corbin (1998) was used. Coding of the data enabled me to try to understand what the participants were telling me about being delirious, the feelings they experienced, what they believed happened to them, how they felt about the experience and what was the most important feeling or feelings they used to describe their experience. This

compelled me to listen very carefully to what the participants were saying and how they were saying it. This gave me the encouragement to understand what they were saying and not jump to conclusions based on my own theoretical knowledge and clinical expertise.

In the first stage of open coding, I analysed the transcribed data line by line by asking the questions 'what does this mean' and 'what does this seem to mean'? This process identified words that were the most prevalent and had the same meaning or importance and as a result the emergence of preliminary concepts began (see below).

Staff, ambivalence, medication, trust, suspicion, previous experience, left with, time of experience, brain, mind, health, thoughts of validation, trapped, the experience, no understanding, no sympathy, intense feelings, family experienced, security, loss of mind, abandonment, trauma, recall of experience, during the experience, loss of security, family experience, staff assistance, how left, grief, ashamed, guilty, remorseful, distress, embarrassment, am an idiot, disbelief, silly, I was evil, I am to blame, my age, my health, my medications, need to apologise to everyone, terrible terror inside me, strong willed, self-resilient,, always of sound mind, level headed, strong in mind, dreadful, scary, daunting, horrendous, terrible maze, scared stiff, horrified, off the planet, really went off, devastated , felt shocking about it, but it was me, left its mark, did not want to be alone, doing ungodly things, haven't got over it, it was me, never had it before, unbelievable, the disgust, one of the worst, still feels it could have been true, harmful, remember the worst, muddled mind, a dream, puzzling, really a terrible thing, unbelievable, I was dying, people killing me, being killed, poisoning me, still concerned, still have thoughts.

As Figure 3 illustrates, there were many initial codes that included a group of codes. I continued to compare codes against codes and data against data (axial coding), giving an understanding of the relationship between them. By using constant comparison, the subcategories produced were *the suffering*, *the predicament*, *how I was before*, *how am I now*, *how have I been left*. The core categories identified were living the delirium and living after the delirium (refer to Tables 12 and 13).

Figure 3 Open coding process

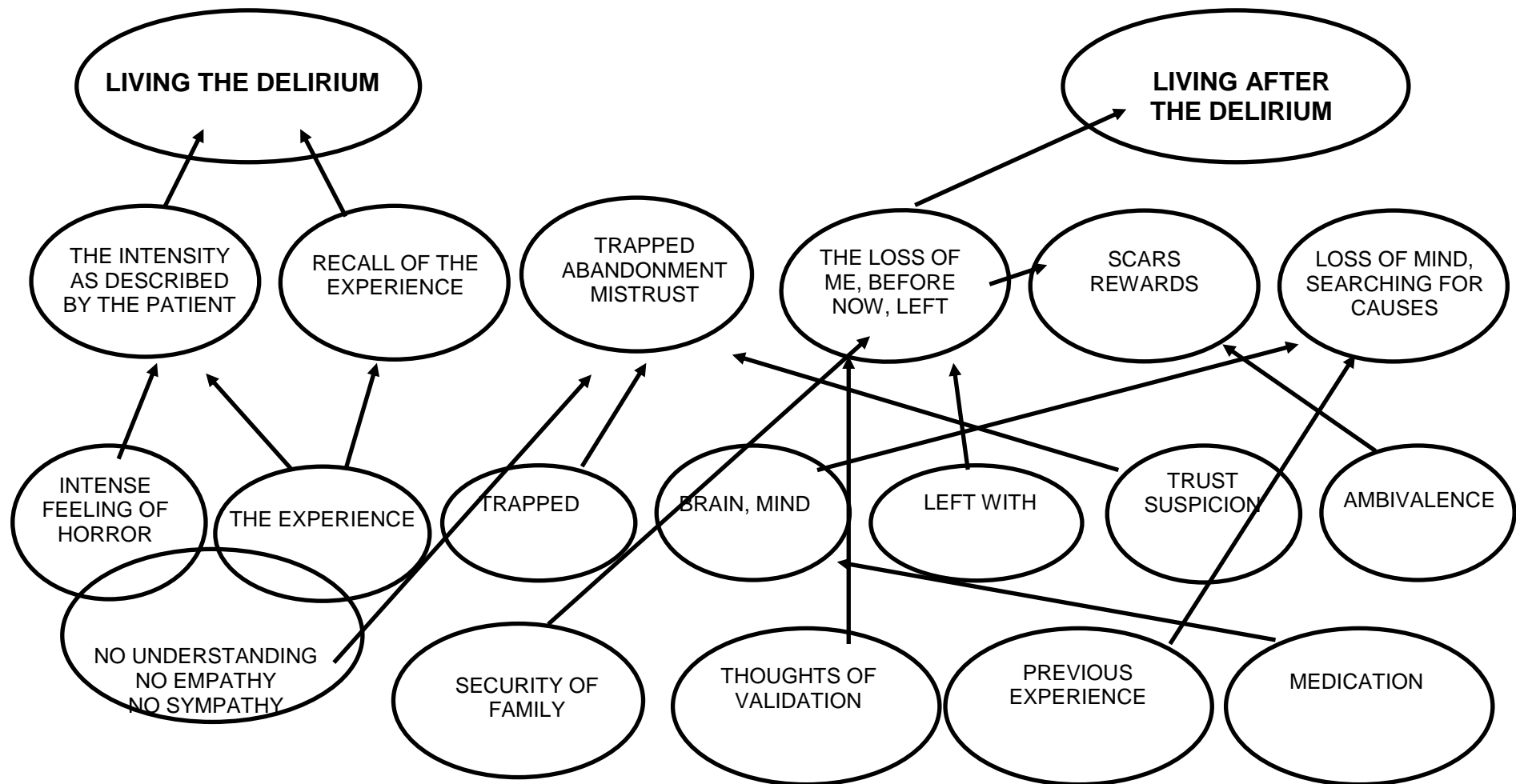


Table 12 Living the delirium

THE SUFFERING		THE PREDICAMENT			
THE FEELING	THE SUSPICION AND MISTRUST	BEING TRAPPED	TO BE ABANDONED	THE DISMISSAL	THE DISCONNECTION
<ul style="list-style-type: none"> • HORROR • TERROR • FEAR • TERRIFYING • HORRENDOUS • SHOCKING • DREADFUL • DAUNTING 	<ul style="list-style-type: none"> • SUSPICIOUS • DID NOT SEEM TO TRUST ANYONE • EVERYONE AGAINST ME • BEING KILLED • POISONING ME • SECURITY • WHO WAS GOOD WHO WAS BAD 	<ul style="list-style-type: none"> • TRAPPED • COULD NOT GET OUT • BEING SHUT IN • UNDERNEATH • LOCKED IN THE BATHROOM • BEING PUT OUT OF THE WAY • NEVER GET OUT OF HOSPITAL • THOUGHT OF DYING 	<ul style="list-style-type: none"> • NO UNDERSTANDING • NO SYMPATHY • LOSS OF SECURITY • NO ANSWERS TO MY QUESTIONS • NEED THE FAMILY • SORT OF LOST • BEING ALONE 	<ul style="list-style-type: none"> • TREATED AS A JOKE • IT'S NOTHING • IT'S COMMON • NO UNDERSTANDING • NO EMPATHY • NO SYMPATHY • HORRIFIED 	<ul style="list-style-type: none"> • IMAGINED HEARD VOICES • CONFUSED • TAKING ME AWAY • TV WAS A CAMERA • BUILDING ON FIRE • PLATES WERE BOMBS • CO-PATIENT WAS A SPY • TISSUE BOX BECAME A DOG • BLACK KNOBS IN EVERY CORNER • THEY MADE A BOAT • EVERYONE WAS THERE • PUTTING SPIDERS IN THE ROOM • ALL THE ROOTS IN THE CEILING • ON A RIVER'S EDGE • GRANDDAUGHTER IN THE NEXT ROOM • FLOATING AROUND THE ROOM ON BITS OF TIMBER • ROOM MOVED

Table 13 Living after the delirium

HOW I WAS BEFORE		HOW I AM NOW	HOW HAVE I BEEN LEFT	
THEIR STRENGTH	WHY WAS THIS HAPPENING TO ME	THEIR SHAME AND GUILT	THEIR REMAINING SCARS	THEIR STRENGTH OF HEALING
<ul style="list-style-type: none"> • STRONG WILLED • RESILIENT • SOUND MIND • LEVEL HEADED • STRONG IN MIND • NEVER LIKE THAT • WOULDN'T DO IT • NEVER BEEN IN HOSPITAL 	<ul style="list-style-type: none"> • WHY • COULDN'T THINK STRAIGHT • ALL THE MEDICATION • WHAT CAUSES IT • LOSS OF MIND • MUDDLED MIND • MY OTHER CONDITIONS • I THOUGHT I WAS GOING SILLY • SOMETHING THAT JUST HAPPENED 	<ul style="list-style-type: none"> • IT WAS ME • I WAS EVIL • NEED TO KEEP APOLOGISING • I AM TO BLAME • ASHAMED • REMORSEFUL • GUILTY • IDIOT • EMBARRASSED • REALLY HORRIFIED TO THINK THAT WAS ME 	<ul style="list-style-type: none"> • NEVER AGAIN • STILL PERSISTING • STILL CONCERNED • ONE OF THE WORST • REMAINS UNSURE • ONGOING FEAR • NEEDS TO CONTINUE TO CLARIFY • AFFECTED PHYSICALLY AND MENTALLY • NEVER WANT IT AGAIN 	<ul style="list-style-type: none"> • CONQUERED IT • NOT AFRAID OF FURTHER SURGERY • DON'T WORRY ABOUT IT • REGAINED CONFIDENCE • CAN'T DO ANYTHING ABOUT IT • KNOWLEDGE OF OTHERS HAVING IT • IMPORTANT TO TELL ABOUT EXPERIENCE

2.5.2 Strategies used to ensure rigour in the study

An important last step for me was the interpretation and consideration of the implications of my study findings and the comparison of them with other studies of the lived experience of delirium. This step revealed that this study's findings were likely common experiences for patients who become delirious after joint replacement surgery. As such, the findings may be transferable to other hospital settings.

The following points describe what was crucial for this study to achieve quality:

- The eleven interviews were digitally recorded, professionally transcribed in detail and I checked the transcripts against the recordings of the interviews.
- The detailed drafts of the analysis records were kept.
- Regular meetings took place with my supervisors to discuss and validate my interpretation of the data.
- The meetings with my supervisors and the suggested subsequent steps were journalled.
- The trustworthiness of the interpretations were supported by using verbatim quotes of the participants which confirmed the categories/themes and connecting the quotes to the individual participants.
- My reflection of personal bias and maintaining neutrality within the study.

- As mentioned in the previous paragraph the findings of this study can inform other practice settings, be replicated in other similar settings.

This chapter outlines the underpinning methodological approach to clarify and record the patient experience of delirium post orthopaedic surgery. The research question and design have been specified to examine the lived experience of these patients. The specified inclusion and exclusion criteria have been explicitly delineated regarding the characteristic of the study sample with DSM-IV-TR was provided to describe the diagnostic criteria of the study. The research protocol details how the participants were recruited from patients of the orthopaedic unit and outlined the methods used consistent with the methodological approach. Finally, the data analysis procedure used to clarify the lived experience was provided.

The next chapter will outline the findings of this study.

CHAPTER THREE: THE TERRIFYING EXPERIENCE OF LIVING THE DELIRIUM

3.1 Living the Delirium and Living after the Delirium

The aim of this chapter is to present the findings from the data analysis of the interviews of the eleven participants who participated in this study.

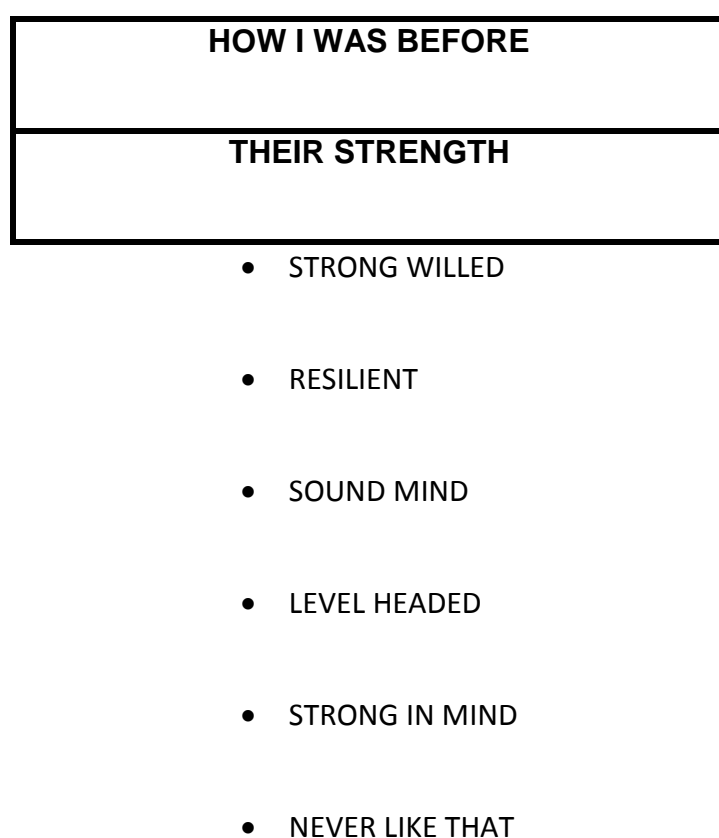
An analysis of the transcribed taped interviews was carried out by a process of coding, noting similarities and differences and constant comparison between the transcripts that led to the development of the categories. Finally, the two core categories were identified: Living the Delirium and Living After the Delirium.

The aim of this study was to clarify and record the experience of delirium following orthopaedic surgery from a patient's perspective. It is anticipated that the increased knowledge nursing staff have about a patient's experience of suffering delirium will assist them to have a better understanding of the management and the support required to care for this group of patients.

The qualitative analysis yielded two main categories, Living the Delirium and Living After the Delirium. These and the sub categories are presented in Tables 12 and 13. The figure provides an illustration of the interplay of the data collected and the phases for the systematic analysis of this data using the method as described by Glaser and Strauss (1967) and Strauss and Corbin (1998). The section below illustrates the findings from the open coding, which is a collection of the descriptive words used by the participants. The

middle section, illustrates findings from the axial coding and demonstrates the minute examination and interpretation of those descriptive words to formulate the subcategories namely the suffering, the predicament, how was I before, how am I now and how have I been left. Finally the core categories were developed from the subcategories and these are Living the Delirium and Living after the Delirium and these are the drivers of the story of living a delirious episode while an in-patient of a hospital. The figure below illustrates an example of the coding process.

Figure 4 **Example of coding process**



CAMEOS

The data resulting from the personalised experiences of suffering delirium is rich with personal feelings and I will show respect to those who told their story to me by writing a cameo about each of them using anonymous first names.

Daisy

Daisy is an elderly widow who lives in a rural area with her granddaughter and her son. Her other 4 children live locally and interstate. Daisy had cared for her granddaughter since she was 10 years of age and highlighted how important and proud she was of her granddaughter. She was admitted to hospital for knee surgery. Daisy sobbed during the interview when speaking of the fear for her future as a result of her very frightening experience of delirium.

Lance

Lance was interviewed in his home with his wife present. He and his wife regularly take winter breaks in Queensland. His orthopaedic surgery for a knee replacement was the reason for Lance to be admitted to hospital and he vividly discussed his previous experiences and his most recent experience of delirium. Lance was still not able to comprehend that his experiences of the delirium were not real. Lance was very definite that he did not want to experience delirium again.

Charlie

Charlie is a retired farmer and still lives in a rural town in the south of the state with his wife. Charlie required surgery for a fractured humerus and he had not

been admitted to hospital before this admission. For Charlie this admission was very distressing because of suffering a delirium episode after his surgery.

Gilbert

Gilbert, a retired professional, is married with children. Gilbert enjoys the game of golf but does not enjoy the loss of independence since handing in his driver's licence. Gilbert was interviewed in his own home following his surgery for a total hip placement. Gilbert was very concerned about becoming a problem to others because of the loss of independence, but he was not concerned if he ever needed surgery in the future, regardless of his risk of suffering delirium after future surgeries.

Gavin

Gavin is a widower who lives independently in his own home. He moved back to Tasmania following the death of his wife to be near his four children. Gavin was admitted for surgery for his third total knee replacement. Gavin's main concern was the lack of rehabilitation/convalescence after surgery especially for those who live alone, as he does. Gavin also identified his choice of an epidural anaesthetic for his surgery as the cause of his confusion.

Dorothy

Dorothy is a very contained elderly lady who has had many surgeries during her life span. Dorothy was very eager to be part of the study in the hope that her story of the suffering of being delirious would influence staff's understanding of the syndrome. Dorothy lives alone and her very supportive children live in Tasmania and interstate.

Mabel

Mabel now lives with a carer, in a small country town in the south-west of the state and had always been responsible for her-self. Mabel's experiences of delirium were pre and post the surgery for bilateral knee replacements and her hospital stay was extended due to complications of pre-existing co morbidities.

Ted

Ted and his wife of 59 years recently moved to the capital city after living in rural Tasmania. Ted had been on the waiting list for many years for his knee surgery. Ted was a very proud owner and restorer of old cars and showed the researcher many photographs of the cars he had owned including the current one in the garage. Ted is also grieving the recent loss of his driver's licence.

George

George lives in a south-west coastal town with his wife. George worked on farms and drove heavy farm machinery for all his working life and he was a man of few words! This was his first admission to hospital and the reason why he was in hospital was the need of orthopaedic surgery for a hip replacement.

Alfred

Alfred required orthopaedic surgery to replace his knee that had been injured 46 years ago in a motorbike accident. He had been on the waiting list for his knee surgery for two and half years. Alfred was interviewed in his own home and his wife was present at the interview.

Henry

Henry lives in south-east Tasmania, having recently moved from Queensland with his wife. He required a total hip replacement. Henry had experienced delirium before this episode.

3.2 Living the Delirium

Living the delirium was identified as a core category. Participants described the experience of living the delirium as dramatic with terrifying sights that gave rise to intense feelings and there was no minimising of their experience. The delirium was an emotional wound for them. The analogy of wound will be used because wounds leave scars and the participants were left with a scar from having experienced the delirium.

The terrifying feelings participants experienced were related to a number of reasons. These included: the high degree of the mistrust and suspicion they had for the health care staff, family and friends and the environment; their sense of powerlessness and the inability to escape; of being alone and abandoned; the dismissal by staff and others and the strength of the disconnection of their thoughts from reality.

The core category, Living the Delirium, was made up of the sub categories, 'the suffering' and 'the predicament'.

3.2.1 The suffering

Suffering is a profound and disturbing experience for a human being. In this study, the people's suffering was the experience of delirium following their

orthopaedic surgery and while reliving this experience during their individual interviews, they spoke of the profoundness and the reality of their experience of delirium as a very deep emotional wound.

The subcategory of 'the suffering' was made up of 'feelings' and 'mistrust and suspicion'.

3.2.1.1 The feeling

The feeling came from the axial coding made up of the words used by the participants to express their feelings. The words were *horror, terror, fear, terrifying, horrendous, frightening shocking, dreadful, daunting, felt like dying*.

There was no doubting the intensity of disturbance experienced by the participants. The vividness of their experience was still in their minds, they started talking about the experience straight away and they did not have to pause to select the words to describe their feelings of being delirious.

Participants described their feelings of the experience. These feelings were of a similar level of intensity for them: For Lance it was '*very frightening*'; Dorothy said '*it was the most terrifying thing*'; '*one of the worst experiences I have ever had*' was the feeling described by Charlie; Daisy said '*it was very frightening*'; and '*daunting*' was the feeling felt by Gavin when he was not able to recognise some of his visitors. Alfred said '*it was frightening*'. For George being a patient in a hospital for the first time, the experience was '*terrifying*'. Mabel described her experience as '*horrible*'.

For Lance his previous episodes, eight and three years prior, were as vivid as the most recent experience of delirium. In this recent experience of delirium

Lance was feeling very fearful of *'being harmed'*. Charlie described one night as *'very horrendous'* when he felt very fearful of being harmed. An image of distress is described by Lance and Charlie.

Dorothy said *'it was terrifying because I felt like someone was going to kill me'* and Ted was so frightened *'that one bloke, the nurse, I thought he was killing me'*. Both Dorothy and Ted describe the terrifying and frightening feelings of the thought of being killed that they experienced while delirious.

Dorothy said *'I was all in this terrible maze, it was awful'*. Dorothy was describing the feelings she felt when describing her experience of delirium as the maze of nightmares. Mabel said *'it was frightening'* when she felt useless and could not help herself. Henry said *'it was scary'*.

Daisy's experience was so real and shocking for her that she was adamant the researcher or anyone else could not have any idea what delirium was like. Daisy's words were *'it was shocking you've no idea'*. Those words spoken by Daisy and the other participants that emphasise the intensity of feelings and emotional distress they experienced being delirious following their orthopaedic surgery emphasised to the researcher the need to tell the story of the patient's experience of delirium.

3.2.1.2 The suspicion and mistrust

Suspicion and mistrust came from the axial coding made up of the words *suspicious, did not seem to trust anyone, everyone against me, being killed, poisoning me, who was good who was bad and security*.

A patient enters a hospital with a feeling of trust for those who will care for them. They feel safe with this comfortable feeling of trust. Within their delirium the participants lost their trust in others who were in sight or contact with them. This included those who were either delivering the necessary health care to them, the co-patients of the shared ward or their own family and friends.

Charlie very clearly recalled the feeling of not being safe in his ward and the great comfort he felt when his wife was called in to sit with him. Charlie's words were *'I went looking for her'* (his wife) and when his wife arrived and sat with him it was *'just like security more or less and I kept on asking her: "please don't leave me" '*.

The presence of family is of great comfort to patients who are suffering a delirious episode, however, the family may become part of the mistrust and suspicion. The delirious patient feels the family are involved in or have knowledge of the intention of others to harm and because of the mistrust they feel, they often refuse to talk to the family when they visit.

Charlie said *'I didn't seem to trust anyone around me, even Pansy (his wife), I didn't speak to her all one afternoon, I'm not one for words, but you know I wouldn't have done that'*. In his delirium, Charlie thought his wife, Pansy had betrayed him.

George's experience of mistrusting the staff was so intense he told his wife that he *'would not be here tomorrow they have given us a couple of doses and they are on the whisky'*.

Ted became very suspicious of one particular nursing staff member and after discharge from hospital remained suspicious of the intention of this nurse. He described:

the bloke, only that one, I didn't go much on him, I thought he was killing me fiddling with my tablets, he probably was innocent, but I was suspicious, let's put it that way, and yeah I still am.

Daisy was distressed by not being able to save her granddaughter whom she believed was in the room next to her. She thought if they both went off to sleep it would be better when they woke up. *'When I woke they had gone but they were still persisting in other things, you know, to frighten us. It was shocking, you have no idea'*. Dorothy said *'it was terrifying not knowing who were the good people and who were the bad people'* when she was of the belief that *'someone was trying to kill me'*. Daisy and Dorothy described their emotional suffering of the mistrust of others they felt when they were delirious.

Lance said *'I thought they were against me, going to lock me away and there is no reason for it'*. Lance was recalling how he did not want the staff anywhere near him because he felt he mistrusted them.

The stories of the participant's mistrust of others motives, intentions and behaviours and their intense emotional feeling left no doubt of the realism of harm they felt. Many spoke of desperation to go to the trusting environment that they know, their home, and to know and see that their family were present was a very secure aspiration or goal for them while they were delirious.

3.2.2 The predicament

The difficult, confusing and very unpleasant sense of being trapped, feeling powerless, bewildered and belittled was a predicament for the participants. Because of the abruptness, feeling of no control and the uncertainty of their perceived situation, the participants knew they needed to escape but there was not a clear way out for them.

This subcategory 'the predicament' was made up of being trapped, being abandoned, the dismissal and the disconnection.

3.2.2.1 *Being trapped*

Being Trapped came from the axial coding made up of the words *trapped, could not get out, being shut in underneath, locked in the bathroom, being put out of the way, never get out of hospital, thought was dying.*

The participants had a sense of panic when they were describing their situations of being trapped and in particular when they were remembering their inability to be able to escape from the entrapments. Dorothy described her inability to escape, *'it was the feeling of I couldn't escape I was shut, like a lot of it was the terror being downstairs, shut in underneath something I couldn't get out'*.

Lance had experienced previous episodes of delirium before participation in this study and he still doubted that those previous experiences were not real. A major part of his experience this time was the feeling of being trapped. Lance said *'I thought they were going to put me away somewhere I couldn't get out'*. Lance gave a very clear description of being trapped.

Mabel described the horror she felt of going to the ward's bathroom. The nurses ensured her privacy and dignity by shutting the door, but Mabel felt an overwhelming fear of being *'locked in'* and needed to escape but could not *'because I could not get up and get myself out'*.

It is known that when the primitive physiologic response of fight or flight is activated, a person perceives everyone and everything within their existing environment as a possible enemy and fear becomes the lens through which their world is seen. The elderly, when feeling they are being pushed or asked to do things against their wishes, may become resentful and sometimes aggressive if not skilfully dealt with by the staff caring for them.

George's *'feeling of being terrified of being harmed by people inside'* was so intense he felt he needed to get out of bed, out the door and call for help as he needed to flee from the place of threat. George's need to flee resulted in the Code Black Team being called by ward staff to assist them to return George to his ward. A Code Black Team consists of 5 people who are trained to manage aggressive/violent situations that ward staff perceive as threatening.

Charlie remembered needing to throw a garbage can *'there were people everywhere and I thought there was someone there and I remember throwing a garbage tin'*, to fight his perceived enemy while he was delirious.

In a hospital setting the implementation of bed rails is for the safety of a patient and on occasions a patient will request for the bed rails to be in place for their own feeling of safety. For Daisy, the rails in place did not protect her from harm, as she described the incident: *'I could not get off the bed because*

they had rails on it, you know, and I couldn't get out, it was shocking, I couldn't save her because I couldn't get out'.

Daisy also described another occasion of being trapped. She said: *'they were supposed to let me out of the boat, but I couldn't get out, I don't know how I got out'.*

Most people fear death to some degree and this fear does not lessen with ageing. Ted said: *'I thought I was dying, I honestly and truly thought I was going to, I was on the way out, I thought this is it'.* The fear of being trapped was so intense Ted thought he was dying.

The participants were responsible persons with the ability to make choices when they were admitted to hospital for their surgery. Their descriptions of being trapped when they were delirious details their feelings of being contained and controlled.

3.2.2.2 To be abandoned

To be abandoned came from the axial coding made up of the words *no understanding; no sympathy; loss of security; no answers to my questions; need the family; sort of lost; being alone.*

Daisy's fear of being abandoned was when she was not able to recognise her own whereabouts, *'where am I'* or make reason of *'what I was doing'*. Daisy felt very alone because there were *'no answers to my questions'*.

Dorothy said *'Yes I remember clearly that I was standing outside and it was cold and I thought you would never leave me and you had left me and I had*

nobody'. Dorothy was talking about a particular time when her son left her ward to go the ward's pantry to make a cup of tea for himself and her sense of loss.

Dorothy also felt abandoned by God: *'I couldn't seem to be in touch with God, ... I was just blocked out'*. This was very frightening for Dorothy because she had never doubted her faith, and her faith had always been a great strength to her.

Charlie said *'I needed to go looking for her'*. It was the need to feel safe and not feel alone that made Charlie to go looking for his wife, and the ward nurses called her and asked her to come into the hospital and sit with him. Charlie said *'it was a great sense of security having her there'*. However he needed to frequently say to her *'please don't leave me'* to meet his need for familiarity to make him feel safe and secure. In the middle of the night when George was distressed the nurses rang his wife asking her to come and be with him and George said *'it really helped having her with me'*. Gavin also described the sense of security given to him by his wife's presence.

The morning after his operation, Ted believed he had lost his voice: *'I had no voice, and I wrote I want my wife but they took my pen from me, I was waving it around. I only wanted more paper but they took my pen, they took my pen'*. The abandonment felt by Ted was because he was left with no means to communicate. *'I got it back as soon as she (his wife) arrived'*. Ted spoke with a great sense of relief when describing the return of his voice. Ted's experience relates to the common phrase, 'I was speechless', that is

frequently used when a person describes an astonishingly negative experience they have had.

Mabel felt deserted, feared being harmed when *'I was in deep trouble, I wanted someone to come to me and support me, so I was calling out Violet (her sister), Ann, (her carer) anybody and no one would come and I felt deserted, it was awful'*. Mabel believed the sense of desertion that she felt was a harm to her. She repeated the words 'a harm' but did not delve into the meaning of the harm to her. Mabel sitting upright in the chair, nodding her head, the tone of her voice and her body language portrayed Mabel's meaning of the words abandonment and harm.

All the participants felt abandoned, they were lost and they had lost the important feeling of security.

3.2.2.3 The dismissal

The dismissal came from the axial coding made up of the words *no understanding; no empathy; no sympathy; treated as a joke; it's nothing; it's common; horrified*.

Participants also spoke of being dismissed especially when talking to the nursing staff about their experience of delirium. The interactions with the nursing staff left them with the feelings of not being cared for, unsupported and belittled. When nursing staff are talking with the patients who have been delirious they use common phrases such as 'you were away with the fairies', 'it is nothing', 'it is common'. These common phrases are also used by other health professionals.

Dorothy remembered the nurse saying to her 'gosh you have been off with the fairies a long time', then Dorothy said:

they didn't seem to think it was anything, I really was horrified because like it was supposed to be a big joke, but it wasn't a big joke. She just dismissed it as nothing, it was not nothing, it was a terrible, terrible thing.

Dorothy's statement clearly describes her distress about the staff having no apparent understanding of, or care about what being delirious was like.

Dorothy said she also had been told 'it's very common and it's nothing'. '*It is absolutely no fun*' was another statement describing the distress of being dismissed and not supported from Dorothy. Dorothy quoted her son as saying '*Just put it out of your mind and don't think about it*'. Dorothy also felt not only dismissed by the staff but on one occasion she felt her son was dismissive of her experience.

Mabel also said:

I thought the care wasn't really there, because no one answered me when I asked them to get me out. Frightening that staff could do that to you, when they know you were useless, couldn't help yourself and dependent on other people. I couldn't get out of that ward quick enough.

Mabel was explaining the hurt and betrayal she felt by being ignored by staff in her time of need.

Ted talked about his experience with one nurse: Ted said '*he was a nurse and he came and told me to shut up because I was too expensive to keep, that's the words he said to me. I just moaned, or doing something, you know*'. Ted was very distressed when talking about this incident of being dismissed as an unworthy person by the nurse.

Gilbert recalled: *'Rose (his wife) said I was off the planet and that is not unusual for me I get off the planet'*. Gilbert was being dismissive of a characteristic of himself as described by his wife.

Mabel described a period when she dismissed her carer because of her own incoherence *'she couldn't get any communication from me I was away with the birds well and truly'*. Mabel herself used one of the common dismissive phrases with no distress while chastising herself for not being able to communicate with her carer.

Dismissal of others by the patient who is delirious may be evident. Alfred's wife said: *'he didn't seem like he wanted to talk to us, not interested in our visit, he seemed not to want to be bothered with us, he kept going off to sleep he seemed to be terribly tired, I just let it go'*. Alfred's wife felt hurt from being dismissed by her husband during her visit.

The participants described the manner in which health care staff dismissed their experience with feelings of hurt, overwhelming powerlessness and loss of self-respect. This was difficult for them to understand.

3.2.2.4 The disconnection

The disconnection comes from the axial coding words *imagined; heard voices; confused; taking me away; TV was a camera; co patient was spy; building on fire; I was fighting through the bush; plates were bombs; tissue box became the dog; everyone against me; black knobs in every corner; they made a boat; floating around the room on bits of timber; everyone was there;*

putting spiders in the room; all the roots in the ceiling; granddaughter in the next room; room moved; on a river's edge.

The disorganised and fluctuating nature of the cognitive process in delirium appear to cause abnormal thought processes such as hallucinations and illusions. Illusions have a basis in fact and represent a misinterpretation of the environment. Hallucinations occur without any external stimulus and visual and auditory or mixed are the most common types of hallucinations experienced by the delirious patient. These hallucinations are experienced as real moving bright images of people or non-human objects and mostly are described as terrifying, but they may be a pleasant experience.

While the participants were delirious they entered a very dramatic, frightening delusional and hallucinating state. Daisy said *'I was locked in the room and our granddaughter was in another room and they were putting spiders and everything like that in the room.'* For Daisy this experience was very real and terrifying for her and this was also expressed in the tone of her voice.

Daisy also recalled *'another time I was in the bush somewhere - don't know where - and I was hiding, fighting through the bush I don't know what happened there'*. Dorothy continued to say *'they got to this place and there was a big boat, they put all clothes and things in there to stop me from seeing things'*. These times were dreadful for Daisy because of her perception of the reality of the threat that was happening to her.

Dorothy pleaded to the nurse *'look I want to go upstairs, can't you see all the roots coming out of the ceiling?'* This was an unpleasant, vivid and frightening experience for Dorothy which she felt the need to escape from.

Alfred remembered:

I knew I was in the ward but it did not look to be same, felt I had been moved somewhere else. I actually thought I was on a river edge and looking along the edge of the creek and Joyce's brother, he was sort of there. Three years ago we lost Joyce's brother.

After waking up one morning in his ward Alfred remembered this experience that had occurred and that it was frightening.

Lance talked about

floating and the bed turning up and standing on its end and I was hanging on to the side of the bed staying there. I was also floating away on bits of wood around the room... Half the time I didn't think there was anyone there, most of the time I could not see anyone but I'd be hanging off trying to stay in there and I'd go down and then after furniture would disappear, as people had changed the room completely around. They'd get in there.

Lance also described 'pulling a four wheel drive to pieces and making it into a helicopter so we could fly in and out of places'. For Lance these were very frightening, funny sensations for him and it was a queer feeling in his head.

Lance's tissue box on his bed table had changed into Sonny the white pup he owned. He became agitated with his daughter saying to her 'why did you bring Sonny in, you know you can't bring dogs in'.

George described when he was terrified of the bomb that he needed to throw out the door and to flee from his bed. He said 'it was the time it looked like one of those plates with a bomb in it'.

Mabel misinterpreted Iris, her carer, for her younger sister, Violet who had died seven years before. Mabel said 'I got Violet mixed up a lot with Iris during

this period because they are similar in their walk'. Mabel also described this period as a *'nightmare'*.

Charlie said *'there seemed to be a lot of strange noises, it sounded like at one stage like a roller door going up'*. Charlie accepted the explanation given by the staff that the noise was from the ward's pan room and not from a garage. Charlie also said *'I could hear the voices, so plain, I would get up and no one was there but I could hear these voices of lots of people I knew and I named them all and it was so plain'*. Charlie was amazed at the sense of reality he had for hearing the voices of the people well known to him.

Charlie said:

A co patient was a spy and I thought the TV was a camera and there was a little man sitting up there, I think it was a black knob and there was people everywhere they were in all the four corners, and there was little men on the top of the rails and I went to hit them with the jug and spilt my water, I thought I was being taken away and the building was on fire right around the outside and friends came and put it out.

Charlie said he cried a lot during these times and it was like it was very real for him. Charlie was very pleased to be discharged to the secure environment of his own home.

Delirium has a negative connotation and hallucinations are mostly described as being terrifying but some altered states can be pleasant as Dorothy described very clearly: *'that dress it was in a creamy sort of cotton material, very old fashioned Peter Pan collar and then across the midriff here I had worked all these daisies and things. It was really very pretty and sweet.'* Dorothy was able to recall with pleasure the conversation with her daughter

who told her about sewing the bed sheet whereas Dorothy believed she was sewing a wedding dress.

Although the experience of hallucinations and illusions are not real, the impact and degree of persisting distress were themselves real and remarkable for the participants. Being delirious for the participants was a time when the world around them was seen as a frightening place where horrible things happened and deprived them of safety, trust, control and self-worth for which emotional security depends. The participants when delirious constantly felt unsafe with the feeling of security only returning when their loved ones were present. They tended to feel very suspicious of the motives and intentions of staff and others. They believed they were powerless and had no control over the level of care and support that was given when they were trying to make sense of what has happening to them. Their perceptions of dismissal of the experience of being delirious was something they found difficult to accept.

The core category of Living the Delirium is strongly identified from the participants' rich descriptions of their profound emotional sufferings when they were experiencing the clinical syndrome of delirium following their orthopaedic surgery. The profound suffering is the emotional wound/injury of being delirious which may create a long-term emotional scar. This emotional wound/injury can be more crippling than a physical wound/injury.

3.3 Living after the Delirium

Living after the delirium was identified as a core category. Participant's descriptions were associated with disparate feelings of shame, guilt and

feelings of going mad and a sense of relief. Living the delirium was an emotional wound and living after the delirium was the formation of the emotional scar which identified a certain level of psychological healing.

The attitudes we have about ourselves are driven by how we feel about ourselves and our body, the concerns we have about how other people perceive us and how we view our own abilities and limitations with pride and shame. This is our own way of striving to protect and maintain the person we are.

All of the participants of this study were protecting and maintaining this personal evidence with the need to frequently validate to the researcher a picture of themselves prior to their experience of delirium. They needed me to see them as they see themselves because of the possible belief that I had developed a wrong impression of them as a person during the interview.

3.3.1 How I was before

This subcategory of 'how I was before' describes the participants' stories of their emotional stability and strength before experiencing the emotional wound of delirium.

3.3.1.1 *Their strength*

Their strength was evident from the axial coding words *strong willed; resilient; sound mind; level headed; strong in mind; never like that; wouldn't do it normally; never been in hospital.*

In defending her strength Daisy said '*I have always been level headed, resilient and of sound mind*' and said this with emphasis and pride about herself and her abilities. Daisy also said '*I've always been level headed person and to think something like that went to my brain*'. Daisy was ashamed about her behaviour.

'I'm not a woman who swears and I am a loving mother' said Dorothy when she was recalling her behaviour towards her son. Validating her personality and her ability as a mother was very important to Dorothy.

Gavin said '*I am pretty strong willed and hard to scare*' but his delirium was more than scary, it was beyond his capability of being '*pretty hard to scare*'. George explained this was '*the first time in hospital*'. George was proud of his strength of maintaining his good health during his lifetime of being a farmer, orchardist, bulldozer driver and a saw-miller.

Mabel described herself '*I was really like a little child and depending on others*'. Mabel was distressed by her regressive behaviour.

Alfred said '*I was not confused or anything like that*' when he was describing the terrible pain he suffered for two nights. Alfred was emphasising his awareness of his real pain with pride and not something that he had imagined.

Throughout the interview Ted was very talkative about his losses over recent years, especially his driver's licence and the consequence of not being able to drive his vintage cars. This was Ted identifying himself in the past.

The participants needed to identify themselves as normal, capable people because they were very aware their stories of their terrifying experience of

delirium had possibly portrayed them as terrible people doing terrible things. However whilst identifying their own strengths and their capabilities as a person, they were also seeking reasons for the cause of the delirium. They asked questions around the functions of the brain, was ageing a factor, were their other medical conditions and prescribed medications causative factors for them to become delirious.

3.3.1.2 Why was this happening to me?

The 'why was this happening to me' was made up from the axial coding words and phrases: *why; couldn't think straight; previous episode; all the medication; what causes it; I thought I was going silly; my other conditions; loss of mind; muddled mind; something that just happened.*

The participants struggled to make sense of the experience and looked for explanations. Daisy said *'it was the infection in my water'*. Daisy was acknowledging the information she had been given about urinary tract infection being a common cause for becoming delirious. Daisy also said *'I thought it might have been my age'*. Daisy was querying if her age was a cause for her being delirious and she was horrified by the knowledge that her brain was vulnerable *'and to think that something like that went to my brain'*

Some participants queried the variety of explanations they were given for being delirious. Lance described his astonishment that he had become delirious while he was in hospital and questioned

there was no reason for it, I don't know whether it is the amount of drugs that I've had in my lifetime. Could be the drugs but why? It is unbelievable how your mind works. I don't know what causes it. I was all right but when I woke up don't know what happened.

Gavin identified having an epidural anaesthetic for his total knee replacement as the cause of his delirium: *'I think if I was, had any delirium after the operation, it was most likely caused through the experience'*.

Gilbert said *'I just think it's probably the drugs they give me plus the drugs I'm taking that brings about a situation where I am not aware of what I'm saying and doing'*. This was Gilbert searching for a cause for the delirium.

Dorothy queried *'I don't know if there is something in the back brain somewhere'* as a cause for her experience of delirium. Dorothy also asked *'do you have many people that have this?'* The researcher explained to Dorothy that delirium is not an uncommon experience for the older person who undergoes surgery.

Dorothy said *'don't know what did it, but it did it'*. Dorothy used the word 'it' to describe delirium. The word 'it' used by Dorothy describes the need of not wanting to own or be responsible for the delirium.

For some there were concerns about their state of mind and for others there were concerns about independence and the ability to return to their own homes. Daisy, with panic in her voice, stated *'It was that business in my head that set it off'*. Daisy was very frightened that her experience of being delirious would convince others that she needed to be placed in a nursing home.

Charlie said with doubt in his voice that he felt *'it would never get out of my mind'*. Charlie was very concerned that being delirious had damaged his brain permanently. Charlie also said *'I thought I was going really silly, no, it wasn't*

very nice at all. As an older person, Charlie was concerned that he was going senile.

The relatives of the participants that were present at the interviews identified sleep as being a very important reason for their loved one not being delirious any longer. George's wife said '*once he had slept the next day he was right*'.

Trying to come to terms with having been delirious seemed painful for participants, they pondered over and struggled to make sense of why they had become delirious and they were only able to understand the reasons by the questioning of their own physical health prior to their orthopaedic surgery. They were concerned about the implications for their state of mind. They were searching for the meaning of why this has happened to me.

3.3.2.How am I now?

The participants described negative reflections of themselves for the delirious experience. This sub category of 'how am I now' describes the shame, the guilt and the self-blame they all felt about their verbal and physical behaviours while they were delirious in hospital. Shame is a discomfort felt when a person feels they are not living up to other people or society's expectations.

3.3.2.1 *The shame and guilt*

The shame and guilt developed from the axial coding words *it was me; I was evil; need to keep apologising; I am to blame; ashamed; remorseful; guilty; idiot; embarrassed; really horrified to think it was me; the disgust; I was a nightmare; I was weird but not wild.*

While they were trying to make sense of their behaviour they spoke of shame and guilt. Dorothy said *'I was pretty evil and telling all those lies, it was me, it was me that said the things'*. Dorothy was describing the shame and disgust she felt about herself following her experience of delirium and her remorse, *'I would never speak to Bill (her son) like that'*, and this was not able to be abated with the reassurance from the health staff *'they told me it was not my fault'*.

Dorothy was worried about what people would think of her and she was not able to tell her friends about her experience because she was too embarrassed and too ashamed to do so. The shame Dorothy felt was so deep she found she needed to apologise for her perceived shameful behaviour for a long period after being discharged from hospital, *'I have stopped apologising about it now'*. Dorothy bowed her head when she was describing the shame she felt.

Charlie said *'I feel an idiot'* as he spoke and cried about the disgust he felt when he was remembering the time when his wife was visiting him and he did not talk to her for some hours because of his perception that she was involved with the need to harm him. Also Charlie said *'I really went off, weird but not wild. I feel shocking about it now'*.

Lance said he was *'doing ungodly things and being an idiot'*. Lance's posture at this time was indicating his discomfort and embarrassment when talking about his experience of being delirious.

Gilbert remembered *'doing silly things and saying silly things'*. Gilbert was expressing the shame he felt as the disapproval of himself.

Daisy appeared uneasy about her experience. Daisy said *'don't know what to say, I thought what am I doing, why did I do it'*. Daisy was ashamed about her behaviour.

Gavin repeated during the interview *'it was partly my fault for not talking to the anaesthetist enough about the operation so if I had any delirium it was because of that'*. Gavin was embarrassed and so blamed himself for not having more knowledge of the risks of having surgery.

Mabel said *'I have always been in control of my own life, I did not like Ann (friend) knowing something I did not know'*. The weight of the shame Mabel felt for losing her control was lifted by asking Iris (her carer) to explain to her everything that had happened while she was in hospital.

The participants were uneasy and their discomfort when encountering the memories of their physical and verbal behaviour during their experience of delirium was of shame, remorse, and embarrassment. They needed to chastise themselves and it felt like a raw wound for them.

3.3.3 How have I been left?

This sub category, 'how have I been left', is the description of the emotional scarring that is left, the strength that has been gained and the future concerns that remain for the participants of this study after this experience of delirium.

3.3.3.1 The remaining scars

The remaining scars was developed using the axial coding words of *never again; never want it again; still persisting; still concerned; one of the worst;*

needs continue to clarify; remains unsure; affected physically and mentally; ongoing fear.

The scar is a symbol of the emotional wound the delirium experience has left on the participants. The most concerning scars for them were the continuous doubt of the reality, fear they would not forget the frightening experience and the negative reflections of themselves for being delirious.

Dorothy said *'it affected me in every way, not just mentally, but physically, it knocked my confidence terribly'*. Dorothy also said *'it was something I never want to go through again'*. Dorothy was describing the scar, of being affected in every way by that scar, and expressed her wish to never experience delirium again.

After discharge, Ted continued to be suspicious of the nurse he believed wanted to kill him and feared the possibility of meeting the nurse again. Ted said *'I hope I don't have to meet that nurse again'*.

Charlie was also scared. He said *'it left its mark, I don't think it will ever get out of my head, it still rolls through my mind.'* Charlie also said *'it felt really real, obviously it wasn't, but I still feel some of it happened because it seemed so real'*. And he said *'I would need to be pretty bad to have more operations, no would not go through it again'*. Charlie spoke very definitely about still being troubled by the experience and his wish not to have to experience delirium again.

'It was very frightening', said Lance, *'I would not like to go through it again, I don't want it again.'* Lance expressed ambivalence about seeking help in the

future if his health failed or required medical assistance. Lance also said *'I still can't get it through my head'*. Lance was shaking and nodding his head from side to side when he was talking about his continuing disbelief about being delirious when he was in hospital.

George said *'I still saw things when I got home'*. George was able to tell to his wife and was reassured by her when she confirmed for him that his hallucinations were not real. George explained that although this had been his first admission to hospital, and even though the delirium he experienced was *'terrifying'* and he continued to hallucinate for a short period of time after his discharge from hospital, it would not stop him from having further surgery if it was necessary for him to do so, *'No it would not stop me'*.

Alfred said *'no, not the delirium but I was concerned about losing weight and not being able to eat when I got home and I still can't sit in a chair or lie in bed'*. Alfred's concerns were the decline in his health since discharge from hospital and these dominated his current thoughts.

Participants said the delirium was the scariest experience they have ever had in their lives and they spoke of never wanting to experience delirium again. Even those who had experienced delirium before this recent episode spoke of never wanting to have the experience again. As Charlie said *'I'd really, really, have to be very bad I think before I have it, surgery again'*. Henry said *'No not again, I was too lost'*.

The experience of being delirious was the worst experience they had ever had. And for some of them the thought of a re-occurrence of an episode of

delirium influenced them to the degree that they believed they would never agree to further surgery if the necessity arrived.

3.3.3.2 *The strength of healing*

The 'strength of healing' was developed by using the axial coding words *conquered; not afraid of further surgery; don't worry about it; regained confidence; can't do anything about it; knowledge of others having it; important to tell about experience.*

What the data revealed was that although their delirium was a terrible experience, the participants drew strength from themselves in surviving their episode of delirium. This strength was similar to the personal strength they described prior to suffering their delirious episode.

After being discharged from hospital, Dorothy was delighted with the return of her strength and willpower:

I conquered it, I made myself every night to sit up an hour longer each night and say to myself "now I have sat here and it hasn't come back", then I would get up and go to bed, read and pat the cat and that was that. It took a lot of willpower to do it.

Alfred said *'I had two nights where I did not sleep at all. I had pain badly, I was aware of that, I was aware of that, I wasn't confused or anything about that'*. Alfred was very clear that his pain was real and that he had not imagined it.

Charlie said *'it is the comfort of knowing other people who have experienced it'*. This was a great comfort for Charlie who felt great shame about his behaviour when he was delirious.

Daisy said *'I am alright in the head now'*. Daisy was saying this with tears in her eyes which indicated the fright she felt when she was in hospital and at the end of the sentence, her sigh was of relief.

Mabel said *'I can't imagine being in that position again'*. Mabel had bilateral knee replacements and so therefore there would not be any reason for her to be in hospital again for similar reasons. Mabel spoke very definitely about this.

Gilbert said *'it is not a thing to remember, others are aware of what is happening, I wasn't, if something goes wrong again, nothing I can do about it'*. Gilbert was discussing his acceptance of the risks of surgery and his emotional strength for being able to dismiss the details of his experience of being delirious.

Listening and being able to talk about the experience appeared to have a therapeutic value, yet this was something that did not seem to have happened during their time in hospital. It was very important to Dorothy to talk about her experience of being delirious in order to help health staff gain more understanding about the experience of being delirious which would hopefully, prevent others suffering being delirious. *'I would be pleased if it never happened to anyone else'*.

The findings from this study demonstrated the participants had been emotionally wounded by the experience of being delirious which was so real for them all. They could not grasp what had happened because the experiences were so real. It was through their healing strength that they found their self again, but regardless of their strengths they were left with the scar of the emotional wound. The most salient part of the participants' hospital stay

was the frightening experience of being delirious. They feared not being able to forget the experience, they remained uncertain about the reality of the experience and feared the possibility of needing surgical treatments in the future because they may become delirious again.

The main categories of the delirious experience, living the delirium and living after the delirium, can be illustrated with the following metaphor (Jimi Hendrix). The experience was an emotional wound and living after the experience has led to the formation of the emotional scar, identifying a certain level of psychological healing but being left with a sign of the emotional wound.

Jimi Hendrix, Purple Haze 1967 (Chabot 2010). (Hendrix denied the drug relation of the song, but was inspired by a dream where he was under the sea, the purple haze surrounded him, engulfed him and lost him. It was a traumatic experience.)

Purple haze all in my brain,
Lately things don't seem the same
Actin' funny, but I don't know why,
'Scuse me while I kiss the sky
Purple haze all around
Don't know if I'm comin up or down
Am I happy or in misery?
Whatever it is, that girl put a spell on me
Help me help me
Oh no no ...no
Yeah

Purple haze all in my eyes

Don't know if its day or night

You've got me blowin, blowin my mind

Is it tomorrow or just the end of time?

No, help me aw yeah !oh no no oh help me

The next chapter will outline the discussion, implications, recommendations and conclusion of this study.

CHAPTER FOUR: DISCUSSION, IMPLICATIONS, RECOMMENDATIONS AND CONCLUSION

What wound did ever heal but by degrees

(William Shakespeare, Othello)

This study was conceived from concerns I had over a long period of time that my nurse colleagues did not have a clinical appreciation of how frightening it was for a patient to be hallucinating and deluded. I was aware of this on a daily basis in my role as Clinical Nurse Consultant, Consultation Liaison (C-L) Psychiatry, in a tertiary hospital. This awareness was driven by, first, delirium being one of the top five reasons for nurses working in general wards to refer to a C-L Psychiatry service, and second, a physician having received a detailed account from a patient of his experience of being delirious following orthopaedic surgery, discussed this experience with the Nurse Unit Manager of the orthopaedic ward and myself.

As the population becomes older, older people who are admitted to hospital for surgery are likely to experience the unexpected complication of delirium (Harding 2004; Inaba-Roland & Maricle 1992; Segatore & Adams 2001; Ski & O'Connell 2006). The impact of an acute onset of delirium is poorly understood and there has been very little research undertaken that focuses on the experience during and after being delirious. This study highlights how delirium becomes an ongoing health issue for each participant.

A comprehensive study of this lived experience has been undertaken to enable effective methods of management and care for the delirious patient to

be developed taking into account the perspective of people who have undergone the experience of being delirious. The aim of this study was to explore, clarify and record the experience of an acute onset of delirium from a patient perspective with the anticipation that greater knowledge of these patient experiences will contribute to improving understanding and nursing management of this population. Also, the results will add an important perspective to the extant knowledge of post-operative delirium in older people.

The results in Chapter Four depict the participants' experiences during the delirium and after the delirium. In this chapter findings are discussed and following that discussion, implications for nursing practice will be examined. In conclusion due consideration will be given to the limitations of this study with recommendations for future clinical practice, educational guidelines and research. The results identified the experience of being delirious post-operatively as an emotional wound of intense suffering.

This study is of a qualitative descriptive design (Sandelowski 2000) utilising techniques of grounded theory data analysis as described by (Corbin & Strauss 2008; Sandelowski 2000; Strauss & Corbin 1998). The method used for this study enabled me to gain a sense of the lived experience of delirium, the intense emotions while delirious and the emotional scarring of having been delirious. The qualitative descriptive design and the constant comparison analysis technique enabled me to produce rich information about the participants emotions attached to the experience of an acute episode of delirium. By offering illustrative quotes and diagrams I have allowed the reader to judge the fit between the data and my interpretations and I believe

the findings have offered further reflections on the issue of vivid and intense emotional suffering and the impact of the lived experience of delirium. The personal stories and narratives of Daisy, Lance, Charlie, Gilbert, Gavin, Dorothy, Mabel, Ted, George and Alfred captured this emotional suffering of being delirious, post their orthopaedic surgery.

4.1. Discussion of the Main Findings

The major findings of this study showed living through an experience of delirium is an emotional suffering and predicament associated with feelings of terror, horror, suspicion, being trapped, powerlessness, being disconnected. Living after an experience of being delirious is a period of resilience leading to a path of possible self-recovery, searching for a reason, regaining respect for self, being scarred by shame and guilt and the fear of recurrence.

4.1.1 Living the delirium

The graphic in-depth nature of the description used by the participants gave the researcher a vivid understanding of the significance and meaning of their terrifying experience and emotional suffering of being delirious which was an unexpected complication of their orthopaedic surgery. They not only experienced the pain of their surgical wound, but even more traumatic for them was the ability to remember their lived experience of the incomprehensible emotional pain of intense fear, suspicion, panic and insecurity. Some of the participants during their interview recalled previous episodes of delirium they had experienced. The interviews brought on strong feelings for the participants, not one of them wanted to withdraw from the

interview as it appeared they had a personal need to describe their experiences. Throughout the literature there are contradictions on the subject of the patient being able to recall the experience of delirium. The studies of Andersson et al. (2002); Dupplis and Wikblad (2007); Fagerberg and Jonhagen (2002); McCurren and Cronin (2003) identified that participants spoke of the delirious experience as being frightening, fearful and difficult to understand. Contrary of the findings of this and other studies, Schofield (1997) noted that the participants showed little interest in their experience of delirium. Breitbart, Gibson and Tremblay (2002) highlighted the value of patients being able to talk about their delirious episodes and the importance of nurses listening to the explicit and implicit questions put by the patients. Participants of this study spoke of the relief of being able to talk about their experience and appeared relieved with the reassurance given during their interviews that the delirium is not an uncommon complication post orthopaedic surgery.

The symptoms of delirium included hallucinations, illusions and misinterpretations which may appear as a dream-like change in consciousness with the patient not able to distinguish between mental images and perceptions which lead to these symptoms of hallucinations and illusions. The periods of perceptual disturbance of delusions and hallucinations are associated with fear and terror, which does not always abate as reality returns (McCurren & Cronin 2003). Associated with this predicament are bewilderment, perplexity and agitation. A bewildered anxious patient misinterprets stimuli and they perceive innocent gestures of others as threatening (Fagerberg & Jonhagen 2002). This was the case for the

participants in this study in their description of their incomprehensible experiences of threat, suspicion, hallucinations and illusions while they were delirious. They described their feelings of being threatened which were associated with being suspicious and not able to trust the environment of the ward or the actions and words of those who delivered their health care or their family. This was a predicament for them because they did not have any understanding of what was happening to and around them with all kinds of impressions invading their minds. Charlie threw a jug of water at what he believed was someone with the intent to kill him and Ted misinterpreted dispensing of medication for treatment as dispensing medication for killing purposes.

It appears that delirium, dreams and nightmares are associated with emotional responses ranging from exciting to bizarre. A dream is a series of thoughts, images and sensations which occur when a person is sleeping and may range from normal to bizarre and from exciting to frightening. A nightmare is an unpleasant dream with strong emotional responses that typically range from fear to horror and cause the person to wake. The Andersson et al.(2002); Fleminger (2002); McCurren and Cronin (2003) studies used words of dream-like images to give shape and form to the experience. Dorothy described her experience as a maze of nightmares. Subjects in the Duppils and Wikblad (2007) study described that the delirium episodes appeared as nightmares and they thought they were dreaming. Crammer (2002) noted his delirium was of greater vividness and with more intense feelings of fear and terror than his dreams.

Within the extreme vividness of terror and fright of what they saw and misinterpreted it was not surprising that the participants had the need to fight for their own lives and flee from the images and threats. This need to escape from the personalised perceived threat may precipitate adverse behaviour if the person is prevented from escaping. The person may become combative, be resistive to medical and nursing interventions and to try and escape from their environment (Fagerberg and Jonhagen 2002). For some of the participants of the study, they needed to wander around the room or the ward environment searching for the threat they sensed, other participants became agitated while searching for the threat or trying to remove or get away from the threat in their environment. George when he thought he was being harmed began to flee from his ward and this situation required intervention by the emergency team trained in the management of aggressive behaviours. Surrounded by misinterpretation the participants had a great sense of insecurity, powerlessness and loneliness in their struggle to maintain safety and security for themselves. Their sense of security was relieved when their spouses were with them. McCurren and Cronin (2003) found that contact with loved ones helped the subjects of the study during their delirious episodes. Guidelines for the management of delirium include the importance of the inclusion of family presence and the employment of sitters for providing assistance to reassure and calm the delirious patient (National Institute for Health and Clinical Excellence [NICE] 2010). Nurses find it difficult to communicate with delirious patients whose sense of reality appears different to theirs (Andersson, Hallberg & Edberg 2003). The participants reported feeling abandoned and dismissed in relation to communication with the

nursing staff, they felt no one was listening to them when they had a strong need to be emotionally comforted. The issue of poor communication may play a part in the poor detection of delirium (Duppils & Wikblad 2007; Inouye et al. 2001; Neitzel, Sendelbach & Larson 2007; Rogers & Gibson 2002; Schofield, Tolsan & Fleming 2011; Segatore & Adams 2001).

The symptoms of hallucinations, illusions and misinterpretations raised the concerns of the participants in regards to their own mental health. For many older people “losing their mind” is a major fear alongside the fear of the loss of independence. For the participants of this study their fear was having lost their mind and the stigma of being mad or being labelled mad by staff and family. The stigma of mental illness may explain the fear of the stigma of being delirious. This fear was identified in the study of Harding, Martin and Holmes (2008) where three subjects had asked the interviewer that staff not be told of their experiences. Duppils and Wikblad’s (2007) study, subjects expressed fear of becoming senile or mad after being delirious. There are some notable similarities between the experiences of people with delirium and other mental illnesses. As previously indicated in Chapter Two the psychomotor behaviours of the types of delirium are similar to schizophrenia and depression (Duppils & Wikblad 2007; Inaba-Roland & Maricle 1992; Inouye et al. 2001; Neitzel, Sendelbach & Larson 2007; Rapp 2001; Segatore & Adams 2001; Ski & O’Connell 2006). However despite the similarities delirium is markedly different from other mental illnesses with similar symptoms (APA 1994).

The distress related to delirium is described within the literature almost exclusively in terms of medical complications with very little mention of the

psychological scar from the experience of the patient. Breitbart, Gibson and Tremblay (2002) suggest that the presence of perceptual disturbance and hallucinations contribute significantly to the highly distressing experience of being delirious. The trauma suffered from hallucinating will be discussed later in this chapter.

4.1.2 Living after the delirium

The participants' experiences of living through their delirium were described as scenes of terrifying sights which aroused intense feelings of fear and panic. Living after their experience was a period showing their resilience in the attempt to heal from the emotional wounds of hallucinating, mis-interruption and suspicion.

When a person is physically wounded, the expected outcome of healing is the formation of a mark, known as the scar. The emotional scar is a lingering sign of mental damage, for example, feeling anxious, agonising over the mental injury and the anguish of ruminating thoughts. The participants talked about the ongoing effect of their emotional scar by describing their wounded feelings, their expressed fear of recurrence, and their reluctance to seek medical advice in the future. These comments are suggestive of future morbidity and mortality implications for this group of elderly people. These findings are supported by the studies of Duppils & Wikblad (2007) and Fagerberg & Jonhagen (2002). The participants of this study ruminated about their incidents of delirium with feelings of guilt and shame. They had grave doubts that the thoughts would never leave their minds.

As if to confirm the negative effect of the episode of delirium and their hitherto impeccable characters, the participants referred to their life-long emotional stability. This need to identify their personal strengths and abilities were intensely felt and articulated by the participants. They believed when they were delirious they were portrayed as terrible people doing terrible things and they had a strong desire to emphasise that they had not always been old and delirious. This striving to protect and maintain the precious evidence of their identity and integrity is supported by the findings of Andersson et al. (2002) who identified that older adults who are delirious will draw on previous life experiences as a means to make meaning of the present. The struggle to make sense of their delirium suggests that there is a need for patients to be given the opportunity to talk about their delirious episode.

When describing their mental strength, the participants needed to question and consider the reasons why their sound minds were affected and they struggled to make sense of their delirium. Participants anguished over why they had become confused, some questioned the connection between their existing illnesses and the medications they were prescribed. Others, like, Daisy, spoke of the utter disbelief that “*it*” had happened. This is contrary to Schofield’s study (1997) description that there was very little curiosity for what had caused the delirium. The findings of my study were consistent with the studies of Harding, Martin and Holmes (2008) who found patients wanted validation of their experience and Fagerberg and Jonhagen (2002) subjects showed feelings of guilt and humiliation when they were looking for reasons for the experience of being delirious and the fear of recurrence of an episode of delirium.

As previously mentioned at the beginning of this chapter, participants of this study spoke of the relief of being able to talk about their experience and the reassurance that the complication of delirium is not uncommon post orthopaedic surgery. It was their feelings of shame, unworthiness and embarrassment that prevented them from being able to talk about their experiences to their families and the health care staff. Through the process of interviewing patients who have experience and who have been able to recall their experience of delirium, studies have identified the importance of empathetic communication. Studies by Duppils and Wikblad (2007); McCurren and Cronin (2003); Schofield (1997) highlighted the value to the patient in being able to talk about the delirium. This study's finding is suggestive that there is a need for the patient to be given more than one opportunity to talk over their delirious episode at a pace that suits the patient and validates their self-worth.

Guilt is remorse and regret for what a person has done. The term 'guilty' is also used to describe the feeling of being ashamed or being embarrassed or it may also be used when someone feels guilty about something that happened for which they are not responsible. Shame can be either defined as the discomfort that is felt when a person does not live up to the expectations of others or the powerful and destructive self-disapproval which makes a person feel ridiculous, disgraced or dishonourable (Anxiety Care UK 2014). The disgust the people felt about their sound minds becoming delirious was not of the same depth as the shame and guilt they felt for their behaviour towards their families, friends and staff when they were delirious (Duppils & Wikblad 2007; Fagerberg & Jonhagen 2002; McCurren & Cronin 2003). It was a

feeling of disgust of themselves that was tied to their personal beliefs, their moral codes of what is right and what is wrong for them as a person living within a society. Their personal integrity had been assaulted. The study by Andersson et al. (2002) showed that the behaviour displayed while delirious was not consistent with the subject's moral behaviours. The participants had been emotionally wounded by the experience of being delirious, possibly leaving them a psychological scar.

The participants of this study had difficulty in understanding their experiences in the context of who they were prior to their hospital admission. In the process of trying to understand this traumatic experience it may cause psychological distress such as fear and anxiety. The difficulties described by the participants in understanding their experience of delirium in the context of who they normally are may suggest they are at risk of developing psychological symptoms of trauma. Bowker (1995) noted the published literature evidence for significant psychological trauma arising from delirium experiences with later psychiatric morbidity. Breitbart, Gibson and Tremblay (2002) identified that delirium is like pain, it is a distressing experience and equally distressing for hyperactive and hypoactive types of delirium. In recent years the literature provides evidence of the increasing recognition being given to post-traumatic stress disorder (PTSD) as a result of life-threatening medical experiences. Details of the studies starting to inquire into psychological morbidity will be discussed under 'Implications for Clinical Practice'.

Psychological trauma occurs after surviving an extraordinary frightening experience, that is, any situation that results in a person feeling emotionally overwhelmed or devastated. The importance of researching the lived experience of delirium allows delirium to be seen as being more than a complicated and multifactorial system of pathological disease processes but being a wound of terrifying emotions that may heal leaving a long-term psychological scar.

4.2 Implications and Recommendations for Clinical Practice

4.2.1 Living the delirium

The majority of a general hospital's in-patient population is over 65 years old and of this group approximately 61% will have delirium (ABS 2012, Bickel 2006, Inouye 2006), which highlights all older people may be viewed as being at a risk of experiencing delirium. Delirium is one of the most common preventable adverse events among the older hospitalised person and many aspects of hospital care contribute to the onset of delirium.

This study's individual accounts of being delirious emphasised significant psychological distress that resulted from the terrifying hallucinations and delusions they experienced. When Daisy was locked in a room and 'they were putting spiders and everything like that in the room' her experience was terrifying. It is paramount that clinicians have knowledge to prevent the characteristics of delirium especially hallucinations, illusion and delusions and to implement nursing care interventions to lessen the intense suffering experienced by delirious patients. A lack of knowledge of prevention and

quality care interventions has implications for clinical governance as Schofield's study (2008) argued that delirium is an indicator of the quality of hospital care for older people impacting on key clinical outcomes, care process and patient and staff safety.

The presence of delirium requires prompt timely and scrupulous evaluation through thoughtful targeted interventions to prevent emotional suffering of the elderly who undergo orthopaedic surgery. This study has emphatically shown that delirium is not a normal response to surgery from which patients recover and forget and thus the following are the recommendations arising from the study.

Recommendation One

- Surgical wards have protocols for observations of the elderly that include the early detection of deteriorating mental states.
- Health professionals working with people who undergo orthopaedic surgery are required to have access to specialist knowledge of the prevention and care of older people with delirium post-surgery. Particular attention should be paid to pharmacology and long-term effects of delirium.

The lack of formal assessment, under-appreciation of the clinical consequences and the failure to consider the diagnosis all contribute to delirium often either being misidentified or missed (Foreman et al. 2001; Inouye 2006; Kyziridis 2006; Maldonado 2008; McCurren & Cronin 2003; Meagher 2001; Menzies et al. 2012; Milisen et al. 2002; Neitzel, Sendelbach & Larson 2007; Paulsen et al. 2011; Robertson & Robertson 2006; Schofield,

Tolsan & Fleming 2011; Tsai et al. 2012; Wiltlox et al. 2010). The complexity of misidentification lies can in part be attributed to the overlap of symptoms of delirium, dementia and depression, the diagnostic tools utilised by specialised teams, the presence of hallucinations and illusions, pharmacological interventions and the modern health care strategy involving early discharge.

The literature discusses the impact misidentification has on the potential to develop mental health /psychological morbidity. Linking the potential mental health /psychological morbidity with the participant's voices of this study highlights the importance of appropriate diagnosis to provide effective interventions to prevent the terrible suffering of being delirious.

Recommendation Two

- A systematic assessment, pre-operatively and post-operatively for delirium using a standardised validated instrument is agreed upon by medical and nursing disciplines.
- Education for the clinical workforce so that is able to respond appropriately when post-surgery patient's mental state is deteriorating.

Once the delirium has been identified, immediate safety needs have been met and treatment is underway, the practical management strategies that have been suggested over an expanse of time remain relevant. These practical management strategies may include quiet non-stimulant or stimulant environments depending on the type of delirium that is being treated, ensuring adequate rest and most importantly and relevant to this study the provision of emotional support (Schofield 1997; Andersson 2002).

Hildegard E. Peplau (1909-1999) was an American nurse and the first published nursing theorist since Florence Nightingale. Peplau emphasised the nurse – patient relationship as the foundation of nursing practice. Her book “Interpersonal Relations in Nursing” was published in 1952. The trust of the nurse patient relationship provides feelings of safety and people are there to provide help for the patient. The participants’ descriptions of feelings of insecurity, loneliness, dismissal and abandonment were reflected their lack of trust within the relationships they had with the nurses caring for them. The nurse’s role in caring for the delirious patient is crucial. However in a busy, high acuity environment there is difficulty in forming a trusting relationship. Blunting of this relationship may lead to a sense of loneliness for both the patient and the nurse, creating a distance between the two.

For Charlie, George and Gavin their sense of insecurity and loneliness was relieved by the presence of their wives. Mabel was in the toilet felt alone and not cared for when there was no response from the nursing staff to her call for help. Increased patient acuity and nurses’ increased workload have implications for the time to interact with the patient and provide emotional support. It also may make it more difficult to identify the subtle cues of delirium. Andersson, Hallberg and Edberg (2003) identified that nurses had difficulties in understanding and establishing contact with delirious patients, and Milisen et al. (2002) highlighted that it is not easy for nurses to understand and react to the behaviour of delirious patients. Nursing staff can support the person with dementia by encouraging family and friends to stay at the bedside, which gives familiarity, and the utilisation of patient sitters who assist with activities of daily living and companionship.

Recommendation Three

- All surgical wards have a model of care that gives particular attention to the development and delivery of therapeutic relationships.
- Models of care adopt non-pharmacological strategies that include open visiting hours and patient sitter policies.

4.2.2 Living after the delirium

The Therapeutic Conversation

The participants told me how beneficial it was to be interviewed as it enabled them to talk about their experience and to gain reassurance that they were not alone in being a sufferer of the unexpected complication of delirium and the complication was common post orthopaedic surgery.

Delirious patients are vulnerable human beings whose dignity could be under threat if they were told about their behaviour while temporarily out of control.

Schofield's study (2011) of the nurse's experience of caring for the delirious patient identified that not talking to patients about the behaviours they exhibited while delirious preserves the patient's dignity. However, the studies of Duppils & Wikblad 2007; Schofield 2008) found talking with the patient about their delirious episode can assist in preserving the person's dignity with the reassurance they are not terrible people doing terrible things.

McCurren & Cronin (2003) demonstrated that the need for explanation and therapeutic communication gives the patient the opportunity to talk about their experience and the opportunity for the nurse to explain and give reassurance about the causes of and how commonly delirium occurs.

While interacting with the patient the nurse's conversation may include the use of a joke or lay language as a means of conveying emotional support of reassurance and alleviating feelings of embarrassment. However, Sparks (2008) noted Hildegard Peplau's warning of the danger of social talk with patients and she believed nurses should not converse with patients in the same manner as a nurse converses within her own social environment.

When a nurse used a common slang term such as 'away with the fairies' to describe being delirious, for Dorothy that social interaction with the nurse was one of horror and dismissal. Dorothy interpreted the nurse's slang term describing her experience of being delirious as a joke. For Ted, he felt dismissed as an unworthy person when he was told 'to shut up' by a nurse.

Recommendation Four

- Patients who have recovered from an episode of delirium are given formal and unhurried opportunities to discuss their experience with nursing staff.

This study's individual accounts of being delirious emphasised significant psychological distress that resulted from the terrifying hallucinations and delusions, the shame and guilt they felt about their behaviours, and their belief

that they would avoid seeking health care advice for the fear of recurrence of becoming delirious.

The word trauma means wound, injury or shock and in psychological terms a traumatic event is considered as the harm to the psychological integrity of a person. I describe trauma as an event during which an individual is confronted with a threat to their own or to someone else's integrity. If intense fear, horror and helplessness are experienced during the event there may be psychological traumatising. This is supported by the definition of trauma in the Sanctuary Model (Bloom 2010, pp 295-311)

a traumatic experience impacts the entire person. The way we think, the way we learn, the way we remember things, the way we feel about ourselves, the way we feel about other people and the way we make sense of the world.

The impact of being delirious for the participants of this study is magnified within this definition. For example Dorothy's plea to go upstairs because of all the roots coming out the ceiling, George's terror that the plate had a bomb in it, and Charlie's emotional distress that a co patient was a spy.

An increase in the recognition of the psychological impact of delirium is beginning to be identified in recent literature. Findings from studies inquiring into the reactions of an episode of delirium include:

- DiMartini et al. (2007) discovered that the subjects of their study within an Intensive Care Unit did not develop post-traumatic stress disorder (PTSD) symptoms from their medical experience but rather from the content of the terrifying hallucinations and delusions they experienced as a result of their medical condition.

- The study of Jones et al. (2001) set in a critical care unit also proposed the development of acute PTSD related symptoms may be related more to the recall of delusions alone.
- Maldonado (2008) discussed the increasingly recognised phenomena of the developing of PTSD secondary to the dramatic and bizarre delusional and hallucinatory experiences that occur during a delirious state. Maldonado also stated that the strong emotional tone of the frightening delusions may have contributed to the development of PTSD.
- Schofield's (1997) study of 19 elderly patients described they had been left with unresolved feelings of anxiety.
- Holmes (1996) noted that elderly patients with hip fractures often have unmet psychological needs.
- Bowker, in his personal view of being delirious (1995), noted that it did not surprise him that there is published evidence for significant psychological trauma arising from some experiences of delirium with later psychiatric morbidity.
- Breitbart, Gibson and Tremblay (2002) suggested the presence of perceptual disturbance and hallucinations contribute significantly to the highly distressing experience of being delirious.

The terrible emotional/psychological suffering of being delirious has the potential to go on to the development of an acute stress disorder and if those symptoms are not detected, long-term symptoms of post-traumatic stress disorder may develop. This would be a very serious poor outcome for the person who has experienced delirium.

Recommendation Five

- Discharge follow up programs are designed and implemented to assess and identify discharged patients who have been delirious post joint surgery to assess for symptoms of acute stress disorder to enable early intervention strategies to be instituted. These programs should be directed to follow up 2 weeks post discharge with a follow up at 3 months for those who have been identified at risk of the development of post-traumatic stress disorder.

This research highlights the need for further study in this area of the lived experience of delirium and of the impact delirium can have. Further study will increase our understandings of the morbidity of delirium in various medically ill and vulnerable patient populations.

4.3 Limitations of this study

This study was undertaken because of a problem that was identified by clinicians in a specific locale and the lack of qualitative research on the patient experience. Personal accounts have been collected to inform these clinicians and provide vivid accounts of the trauma associated with being delirious. The research has the potential to be of use beyond the context in which it was undertaken because of the similarities across Australian health contexts. Transferability of the results to other contexts will be determined by those who access this research and consider it in relation to their own practice context.

However the size and context specific nature of the study could be seen by some to limit the generalizability of the findings. Recommendations from this

study concerning follow up should be rigorously investigated in larger research studies to determine the size of the problem in Australia and the efficacy of mental health intervention.

4.4 CONCLUSION

This study has been conducted because over a period of time I realised there was a gap in understanding and appreciation nurses have for the fright and terror that is felt when a person is hallucinating. This is especially so when they were caring for patients who were delirious following orthopaedic surgery. Their lack of understanding was also apparent to me when I was feeding back to them the results of my assessment of the patient they had referred to my nursing service. The nurses were “shocked” by the patient’s stories of terror, fear and suspicion they experienced. The nurses only recognised hallucinations and delusions in terms of agitated behaviours and they had no recognition that patients could be hallucinating without exhibiting the agitated behaviour. The literature I accessed told me there was a gap in the number of studies that had researched the topic of the lived experience from the patient’s perspective.

I set about to explore further the lived experience of delirium with an the intention of improving nurses’ understanding and knowledge. I believed the only way to improve this understanding was to study the lived experience of patients.

This qualitative study was conducted in a systematic way, adapting the coding process of Strauss & Corbin (1998) and the techniques of qualitative

description as described by Sandelowski (2000). Qualitative description offers a detailed summary of a situation in everyday language. The semi-structured interviews 'and the question guide allowed a qualitative exploration of the patients' experience and also allowed the participants flexibility in their responses.

The findings of this study, which are detailed in Chapter Three, were consistent with and added to existing delirium literature. The literature and the participants in this study described the experiences:

- As being one of horror and terror, suspicion and mistrust of people and the environment around them;
- Where the hallucinations were of explicit objects;
- The misinterpretations of the words and the actions of those caring for them and paranoia of being harmed;
- The disbelief, shame and guilt they expressed about their behaviour when they were delirious; and
- Their fear of recurrence and their doubt about seeking medical advice in the future.

The most salient part of this study's participant's hospital stay was the frightening experience which was an incomprehensible emotional pain for them. Their perceptual disturbances and hallucinations contributed significantly to their distress. The traumatic experience recounted to me by the participants conjured up for me the metaphor of a wound leaving an emotional scar. It is this emotional scar that promotes the discussion of the possible mental health morbidity of delirium.

The study's recommendations include consideration to be given to provide opportunity for patients to express their feelings post the delirium episode and within discharge planning for there to be provision for a psychological/mental health assessment to enable early detection of symptoms that may represent post-traumatic stress disorder. Beyond these specific recommendations there is an implicit call for holistic assessment and care of patients that is based on an empathetic understanding of their predicament.

Furthermore the opportunity for patients who have been delirious to talk about the acute trauma of the experience may reduce the incidence of the psychiatric morbidity outcome within this patient population. It will also go some way to helping patients and their families to feel that the health service recognises their suffering and wants to help beyond the episode of delirium.

The importance of this study is that it has given a space for patients' voices to be heard and the opportunity for clinicians to understand the significance of an episode of delirium. This study has provided the participants the opportunity to talk about what terrible things happened to them during their delirious episode.

The lived experience and insights of the participants with delirium and the expertise and skills of the clinician in the medical management of delirium offer opportunities for profound change in the nurses' understanding and knowledge., This has the potential to influence the design and development of services to improve the outcomes and the quality of life of the people who experience delirium.

While completing this study I have been profoundly affected by the lived experiences of delirium that have been shared with me. While recognising the valuable information I have been able to gather and to share with professional colleagues, it is the words given to me by the participants that will be remembered by me, not the fact that they were 'delirious patients'.

RIP Mabel and Ted



REFERENCES

- Adamis, D, Treloar, A, Martin, F & McDonald, A 2007, 'A brief review of the history of delirium as a mental disorder', *History of Psychiatry*, vol. 18, no. 4, pp. 459-469.
- Agnoletti, V, Ansaloni, L, Catena, F, Chattat, R, De Cataldis, A, Di Nino, G, Franceschi, C, Gagliardi, S, Melotti, R, Potalino, A & Taffurelli, M 2005, 'Postoperative delirium after elective and emergency surgery: analysis and checking of risk factors, a study protocol', *BMC Surgery*, vol. 5, no. 12, pp. 1-6.
- American Psychiatric Association 1994, *Diagnostic and statistical manual of mental disorders: DSM-IV*, American Psychiatric Association, Washington DC.
- American Psychiatric Association 2000, *Diagnostic and statistical manual mental disorders: DSM-IV-TR*, American Psychiatric Association, Washington DC.
- Andersson, E, Hallberg, I & Edberg, A-K 2003, 'Nurse's experience of the encounter with elderly patients in acute confusional state in orthopaedic care', *International Journal of Nursing Studies*, vol. 40, no. 4, pp. 437-448.
- Andersson, E, Hallberg, I, Norberg, A & Edberg, A-K 2002, 'The meaning of acute confusional state from the perspective of elderly patients', *International Journal of Geriatric Psychiatry*, vol. 17, pp. 652-663.
- Anxiety Care UK, *Guilt and Shame*, viewed 6th February 2014.
<<http://www.anxietycare.org.uk/docs/guilt.asp>
- Australia Bureau Statistics 2012, Year Book Australia, Cat. No1301.0, viewed 19 July 2013, ABS Canberra. <<http://www.abs.gov.au/ausstats/abs@nsf/mf/1301.0>>
- Australian Orthopaedic Association 2012, *The Australian Orthopaedic Association National Joint Replacement Registrar Annual Report*, University of Adelaide.
- Bailey, H 1920, *Nursing mental disease*, The Macmillan Company, New York.
- Beck, C 1993, 'Qualitative research: the evaluation of its credibility fittingness and auditability', *Western Journal of Nursing Research*, vol. 15, no. 2, pp. 263-266.
- Bellelli, G, Morghen, S & Torpilliesi, T 2009, 'Dementia, delirium and depression in patients with hip fracture': 1+1 doesn't always make 2', *Journal of the American Geriatrics Society*, vol. 57, no. 1, pp. 179-180
- Bickel, H, Gradingner, R, Kochs, E, Wagner, K & Forsti, H 2004, 'Incidence and risk factors of delirium after hip surgery', *Psychiatry Prax*, vol. Oct 31, no. 7, pp. 360-365.
- Birks, M & Mills, J 2011, 'Grounded theory a practical guide', Sage Publications Los Angeles.
- Bloom, S 2010, 'Organizational stress as a barrier to trauma-informed service delivery', in B Levin & M Becker (eds), *A public health perspective of womans mental health*, Springer, New York, pp. 295-311.
- Bowker, M 1995, 'Delirium: everyone's psychosis', *British Medical Journal*, vol. 310, no. 473.

- Bowman, A 1997, 'Sleep satisfaction, perceived pain and acute confusion in elderly clients undergoing orthopaedic procedures', *Journall of Advanced Nursing*, vol. 26, no. 3, pp 550-564.
- Breitbart, W, Gibson, C & Tremblay, A 2002, 'The delirium experience: delirium recall and delirium related distress in hospitalized patients with cancer, their spouses/caregivers, and their nurses ', *Psychosomatics*, vol. 43, no. 3, pp. 183-194.
- British Geriatrics Society and Royal Colllege of Physicians 2006, *Guidelines of the prevention, diagnosis, and management of delirium in older people*, Royal College of Physicians, London.
- Bruce, A, Ritchie, C, Blizard, R, Lai, R & Raven, P 2007, 'The incidence of delirium associated with orthopedic surgery: a meta-analytic review', *International Psychogeriatrics*, vol. 19, no. 2, pp. 197-214.
- Camus, V 2002, 'Phenomenology of acute confusional states', *The British Journal of Psychiatry*, vol. 181, no. 3, pp. 256-257.
- Chabot, L 2010, *Purple Haze Lyrics*, online video, viewed 20 June 2012, <<http://youtu.be/e4is-ly06YA>>.
- Chiovitti, R & Piran, N 2003, 'Rigour and grounded theory research', *Journal of Advanced Nursing*, vol. 44, no. 4, pp. 427-435.
- Clegg, A & Young, J 2011, 'Which medications to avoid in people at risk if delirium: a systematic review', *Age and Ageing*, vol. 40, no. 1, pp 23-29.
- Corbin, J & Strauss, A 2008, 'Basics of qualitative research techniques and procedures for developing grounded theory', 3rd edn, Sage Publications, Thousand Oaks, CA.
- Crammer, J 2002, 'Subjective experience of a confusional state', *British Journal of Psychiatry*, vol. 180, pp. 71-75.
- Day, J, Higgins, I & Koch, T 2009, 'The process of practice redesign in delirium care for hospitalised older people: a participatory action research study ', *International Journal of Nursing Studies*, vol. 46, no. 1, pp. 13-22.
- Delirium Clinical Guidelines Expert Working Group 2006, *Clinical practice guidelines for the management of delirium in older people*, Department of Health and Ageing Canberra and Department of Human Services, Melbourne Victoria, viewed 23 June 2010. <http://www.health.vic.gov.au/acute-agedcare/>
- Department of Health and Human Services 2009, *Capacity toolkit, information for government and community workers, professionals, families and carers in Tasmania*, Aged Care and Rehabilitation Clinical Network, Department of Health and Human Services.
- DiMartini, A, Dew, A, Kormos, R, McCurry, K & Fontes, P 2007, 'Posttraumatic stress disorder caused by hallucinations and delusions experienced in delirium', *Psychosomatics*, vol. 48, no. 5, pp. 436-439.
- Duppils, G & Wikblad, K 2004, 'Cognitive function and health-related quality of life after delirium in connection with hip surgery', *Orthopaedic Nursing*, vol. 23, no. 3, pp. 195-203.

- Duppils, G & Wikblad, K 2004a, 'Delirium: behavioural changes before and during the prodromal phase', *Journal of Clinical Nursing*, vol. 13, pp. 609-616.
- Duppils, G & Wikblad, K 2007, 'Patients' experience of being delirious', *Journal of Clinical Nursing*, pp. 810-818.
- Eaves, Y 2001, 'A synthesis technique for grounded theory data analysis', *Journal of Advanced Nursing*, vol. 35, no. 5, pp. 654-663.
- Elliott, N & Lazenbatt, A 2005, 'How to recognise a 'quality' grounded theory research study', *Australian Journal of Advanced Nursing*, vol. 22, no. 3, pp. 48-52.
- Evans J & Williams T (eds) *Oxford textbook of geriatric medicine*, Oxford University Press, Oxford, p. 494.
- Fagerberg, I & Jönhagen, M 2002, 'Temporary confusion: a fearful experience.', *Journal of Psychiatric and Mental Health Nursing*, vol. 9, no. 3, pp. 339-346.
- Flaherty, J, Tariq, S, Raghavan, S, Bakshi, S, Moinuddin, A & Morley, J 2003, 'A model for managing delirious older patients', *Journal American Geriatrics Society*, vol. 51, no. 7, pp. 1031-1035.
- Fleminger, S 2002, 'Remembering delirium', *The British Journal of Psychiatry*, vol. 180, no. 1, pp. 4-5.
- Flinn, D, Deihl, K, Seyfried, L & Malani, P 2009, 'Prevention, diagnosis and management of postoperative delirium in older patients', *Journal of the American College of Surgeons*, vol. 209, no. 2, pp. 261-268.
- Folstein, M, Folstein, S & McHugh, P 1975, 'Mini mental state a practical method of grading the cognitive state of patients for the clinician', *Journal of Psychiatric Research*, vol. 12, no. 3, pp. 189-198.
- Foreman, D, Wakefield, B, Culp, K & Milson, K 2001, 'Delirium in elderly patients: an overview of the state of the science', *Journal of Gerontological Nursing*, vol. 27, no. 4, pp. 12-20.
- Franco, K, Litaker, D, Locala, J & Bronson, D 2001, 'The cost of delirium in the surgical patient', *Psychosomatics*, vol. 42, no. 1, pp. 68-73.
- Gibb, H & O'Brien, B 1990, 'Jokes and reassurance are not enough: ways in which nurses relate through conversation with elderly clients', *Journal of Advanced Nursing*, vol. 15, no. 12, pp. 1389-1401.
- Glaser, B, G 1992, *Basics of grounded theory analysis*, Sociology Press Mill Valley CA.
- Glaser, B & Strauss, A 1967, *The discovery of grounded theory strategies: for qualitative research*, Aldine Publishing Company, Chicago.
- Greene, N, Attix, D, Weldon, B, Smith, P, McDonagh, D & Monk, T, G. 2009, 'Measures of executive function and depression identify patients at risk for postoperative delirium', *Anesthesiology*, vol. 110, no. 4, pp. 788-795.

- Harding, R, Martin, C & Holmes, J 2008, 'Dazed and confused: making sense of delirium after hip fracture', *International Journal of Geriatric Psychiatry*, vol. 23, no. 9, pp. 984-986.
- Harding, S 2004, 'Delirium in older people', *Collegian*, vol. 11, no. 4, pp. 36-42.
- Heath, H & Cowley, S 2004, 'Developing a grounded theory approach: a comparison of Glaser and Strauss', *International Journal of Nursing Studies*, vol. 41, no. 2, pp. 141-150.
- Holmes, J 1996, 'Psychiatric illness and length of stay in elderly patients with hip fracture', *International Journal of Geriatric Psychiatry*, vol. 11, no. 7, pp. 607-611.
- Inaba-Roland, K & Maricle, R 1992, 'Assessing delirium in the acute care setting', *Heart & Lung*, vol. 21, no. 1, pp. 48-55.
- Inouye, S 2006, 'Delirium in older persons', *The New England Journal of Medicine*, vol. 354, no. 11, pp. 1157-1165.
- Inouye, S & Charpentier, P 1996, 'Precipitating factors for delirium in hospitalized elderly persons', *JAMA*, vol. 275, no. 11, pp. 852-857.
- Inouye, S, Foreman, M, Mion, L, Katz, K & Cooney, L 2001, 'Nurse's recognition of delirium and its symptoms.', *Arch Intern Med*, vol. 161, pp. 2467-2473.
- Inouye, S, vanDyck, C, Alessi, C, Balkin, S, Siegel, A & R, H 1990, 'Clarifying confusion the confusion assessment method', *Annals of Internal Medicine*, vol. 113, no. 12, pp. 941-948.
- Jones, C, Griffiths, R, Humphris, G & Skirrow, P 2001, 'Memory, delusions and the development of acute posttraumatic stress disorder-related symptoms after intensive care', *Critical Care Med*, vol. 29, no. 3, pp. 573-580.
- Kurlowicz, L & Wallace, M 1999, 'The mini mental state examination (mmse)', *Try This: Best Practices in Nursing Care to Older Adults*, vol 1, no. 3 January, The Hartford Institute for Geriatric Nursing, New York University.
- Kyziridis, T 2006, 'Post-operative delirium after hip fracture treatment: a review of the current literature', *GMS Psycho-Social-Medicine*, vol. 3, pp. 1-12.
- Leeman, J & Sandelowski, M 2012, 'Practice-based evidence and qualitative inquiry', *Journal of Nursing Scholarship*, vol.44, no. 2, pp. 171-179.
- Lepousee, C, Lautner, C, Liu, L, Gomis, P & Leon, A 2006, 'Emergence delirium in adults in the post-anaesthesia care unit' *British Journal of Anaesthesia*, vol. 96, no. 6, pp. 747-753.
- Leung, J, Sands, L, Mullen, E, Wang, Y & Vaurio, L 2005, 'Are preoperative depressive symptoms associated with postoperative delirium in geriatric surgical patients?', *Journal of Gerontological Medical Sciences*, vol. 60A, no. 12, pp. 1563-1568.
- Lincoln, Y & Guba, E 1985, *Naturalistic Inquiry*, 1st edn, Sage Publications, Newbury Park, California.
- Lundblad, M & Hovstadius, E 2006, 'Unreal experiences: clinical advice for the care of patients with post-operative confusion', *Connect: The World of Critical Care Nursing*, vol. 5, no. 2, pp. 56-60.

- Maldonado, J 2008, 'Delirium in the acute care setting: characteristics diagnosis and treatment', *Critical Care Clinics*, vol. 24, no. 4, pp. 657-722.
- Mangnall, T & Gallagher, R 2011, 'Postoperative delirium after colorectal surgery in older patients' *American Journal of Critical Care*, vol. 20, no. 1, pp. 45-55.
- Mantz, J, Hemmings, H & Boddeart, J 2010, 'Case scenario: postoperative delirium in elderly surgical patients', *Anesthesiology*, vol. 112, no. 1, pp. 189-195.
- Marcantonio, E, Flacker, J, Michales, M & Resnik, N 2000, 'Delirium is independently associated with poor functional recovery after hip fracture', *Journal American Geriatrics Society*, vol. 48, no. 6, pp. 618-624.
- Marcantonio, E, Flacker, J, Wright, R & Resnik, N 2001, 'Reducing delirium after hip fracture: a randomized trial', *Journal American Geriatrics Society*, vol. 49, no. 5, pp. 516-522.
- Marneros, A 2008, 'Psychiatry's 200th birthday', *the British Journal of Psychiatry*, vol. 193, no. 1, pp. 1-3.
- McAvay, G, Van Ness, P, Borgardus, S, Zahng, Y, Leslie, D, Leo-Summers, L & Inouye, S 2006, 'Older adults discharged from the hospital with delirium: 1-year outcomes', *Journal American Geriatrics Society*, vol. 54, no. 8, pp. 1245-1250.
- McCarthy, M 2003, 'Detecting acute confusiion in older adults: comparing clinical reasoning of nurses working in acute long-term, and community health care environments', *Research in Nursing and Health*, vol. 26, no. 3, pp. 203-212.
- McCurren, C & Cronin, S 2003, 'Delirium: elders tell their stories and guide nursing practice', *Medsurg Nursing*, vol. 12, no. 5, pp. 318-323.
- Meagher, D 2001, 'Delirium: optimising management', *British Medical Journal*, vol. 322, pp. 144-149.
- Meako, M, Thompson, H & Cochrane, B 2011, 'Orthopaedic nurses' knowledge of delirium in older patients' *Orthopaedic Nursing*, vol. 30, no. 4, pp. 241-248.
- Menzies, I, Mendelson, D, Kates, S & Friedman, S 2012, 'The impact of comorbidity on perioperative outcomes of hip fractures in a geriatric fracture model', *Geriatric Orthopedic Surgery & Rehabilitation*, vol. 3, no. 3, pp. 129-134.
- Milisen, K, Foreman, M, Wouters, B, Driesen, R, Godderis, J, Abraham, I & Broos, P 2002, 'Documentation of delirium in elderly patients with hip fracture', *Journal of Gerontological Nursing*, vol. 28, no. 11, pp. 23-29.
- Milne, J & Oberle, K 2005, 'Enhancing rigor in qualitative description:a case study', *Wound Ostomy Continence Nursing*, vol. 32, no. 6, pp. 413-420.
- National Health Medical Research Council, 'The National Statement on Ethical Conduct in Human Research' 2007, Australian Government, Canberra, viewed August 2012. <<http://www.nhmrc.gov.au/health-ethics/summary-national-statement-content>>.

National Institute for Health and Clinical Excellence, 2010, *Clinical Guideline 103 Delirium, Diagnosis, Prevention and Management*, National Institute for Health and Care Excellence, London, pp. 11-14, viewed July 2012. < <http://www.nice.org.uk/cg103>>.

Neergaard, M, Olesen, F, Andersen, R & Sondergaard, J 2009, 'Qualitative description-the poor cousin of health research?', *BMC Medical Research Methodology*, vol. 9, p. 52.

Neitzel, J, Sendelbach, S & Larson, L 2007, 'Delirium in the orthopaedic patient', *Orthopaedic Nursing*, vol. 26, no. 6, pp. 354-363.

Paulsen, M, Dowsey, M, Castle, D & Choong, P 2011, 'Preoperative psychological distress and functional outcome after knee replacement', *ANZ Journal of Surgery*, vol. 81, no. 10, pp. 681-687.

Petre, B, Roxbury, C, McCallum, J, DeFontes, K, Biekoff, S & Mears S, 2012, 'Pain reporting, opiate dosing, and the adverse effects of opiates after hip or knee replacement in patients 60 years old or older', *Geriatric Orthopaedic Surgery & Rehabilitation*, vol. 3, no. 1, pp 3-7.

Pretto, M, Spirig, R, Milisen, K, DeGeest, S, Regazzoni, P & Hasemann, W 2009, 'Effects of an interdisciplinary nurse-led delirium prevention and management programme (DPMP) on nursing workload: a pilot study', *International Journal of Nursing Studies*, vol. 46, no. 6, pp. 804-812.

Rapp, C 2001, 'Acute confusion/delirium protocol', *Journal of Gerontological Nursing*, vol. 27, no. 4, pp. 21-33.

Robertson, B & Robertson, T 2006, 'Postoperative delirium after hip fracture', *The Journal of Bone and Joint Surgery*, vol. 88-A, no. 9, pp. 2060-2068.

Robinson, T & Eiseman, B 2008, 'Postoperative delirium in the elderly: diagnosis and management', *Clinical Interventions in Aging*, vol. 3, no. 2, pp. 351-355.

Rogers, A & Gibson, C 2002, 'Experiences of orthopaedic nurses caring for elderly patients with acute confusion', *Orthopaedic Nursing*, vol. 6, no.1, pp. 9-17.

Sandelowski, M 1998, 'Writing a good read: strategies for re-presenting qualitative data', *Research in Nursing and Health*, vol. 21, no. 4, pp.375-382.

Sandelowski, M 2000, 'Whatever happened to qualitative description', *Research in Nursing & Health*, vol. 23, no. 4, pp. 334-340.

Sandelowski, M 2007, 'Words that should be seen but not written', *Research in Nursing and Health*, vol. 30, no. 2, pp. 129-130.

Sandelowski, M 2010, 'What's in a name? qualitative description revisited', *Research in Nursing and Health*, vol. 33, no. 1, pp. 77-84.

Sandelowski, M & Barroso, J 2003, 'Classifying the findings in qualitative studies' *Qualitative Health Research*, vol. 13, no. 7, pp. 905-923.

Schofield, I 1997, 'A small exploratory study of the reaction of older people to an episode of delirium', *Journal of Advanced Nursing*, vol. 25, no. 5, pp. 942-952.

- Schofield, I 2008, 'Delirium: challenges for clinical governance', *Journal of Nursing Management*, vol. 16, no. 2, pp. 127-133.
- Schofield, I, Tolsan, D & Fleming, V 2011, 'How nurses understand and care for the older people with delirium in the acute hospital: a critical discourse analysis', *Nursing Inquiry*, vol. 19, no. 2, pp. 1-12.
- Segatore, M & Adams, D 2001, 'Managing delirium and agitation in elderly hospitalized orthopaedic patients: part 1-theoretical aspects ', *Orthopaedic Nursing*, vol. 20, no. 1, pp. 31-46.
- Ski, C & O'Connell, B 2006, 'Mismanagement of delirium places patients at risk', *Australian Journal of Advanced Nursing*, vol. 23, no. 3, pp. 42-46.
- Smith, P, Attix, D, Weldon, B, Greene, N & Monk, T 2009, 'Executive function and depression as independent risk factors for postoperative delirium', *Anesthesiology*, vol. 110, no. 4, pp. 781-787.
- Speed, G, Wynaden, D, McGowan, S, Hare, M & Landsborough, I 2007, 'Prevalence rate of delirium at two hospitals in Western Australia ', *Australian Journal of Advanced Nursing*, vol. 25, no. 1, pp. 38-43.
- Steis, M, Shaughnessy, M & Gordon, S 2012, 'Delirium a very common problem you may not recognise', *Journal of Psychosocial Nursing*, vol. 50, no 7, pp. 17-20.
- Stenwall, E, Sandberg, J, Jonhagen, M, Fagerberg, I, 2008, 'Relatives' experience of encountering the older person with acute confusional state: experiencing unfamiliarity in a familiar person', *International Journal of Older People Nursing*, vol. 3, no. 4, pp. 243-251.
- Strauss, A & Corbin J, 1990, *Basics of qualitative research:grounded theory procedures and techniques*, Sage Publications, Thousand Oaks, CA.
- Strauss, A & Corbin, J 1998, *Basics of qualitative research: techniques and procedures for developing grounded theory*, 2nd, edn, Sage Publications, Thousand Oaks, CA.
- Tsai, M-C, Weng, H-H, Chou, S-Y, Tsai, C-S, Hung, T-H & Su, J-A 2012, 'Three -year mortality of delirium among elderly inpatients in consultation - liason service ', *General Hospital Psychiatry*, vol. 34, no. 1, pp. 66-72.
- Voyer, P, Cole, M, McCusker, J, St-Jacques, S & J., L 2008, 'Accuracy of nurse documentation of delirium symptoms in medical charts', *International Journal of Nursing Practice*, vol. 14, no. 2, pp. 165-177.
- Waszynski, C 2001, 'The confusion assessment method (CAM)', *Try This:Best Practice in Nursing Care to Older Adults*, vol 13, November, The Harford Institute for Geriatric Nursing, New York University.
- Wiltlox, J, Eurelings, L, deJonghe, J, Kalisvaart, K, Eikelenboom, P & vanGroot, W 2010, 'Delirium in the elderly patients and the risk of post discharge mortality institutionalisation and dementia: a meta- analysis ', *JAMA*, vol, 304, no. 4, p 443

Appendix 1: Information Sheet

Delirium: the lived experience of confusion in hospital.

Why have I been invited to participate in this research?

When you were in hospital you experience an episode of delirium. Delirium is usually a short lived confusional state which may appear suddenly and be very distressing to both you, your family and the staff caring for you. We at the Royal Hobart are investigating what it is like for a person to experience delirium. We would like to and would like to include your experiences of being confused when you were at RHH.

Why are we researching delirium experiences?

The impact of delirium on patients admitted to an orthopaedic ward is poorly understood. We hope that understanding your experience of delirium will improve staff knowledge and management of this condition.

It is very important to understand how you felt and were treated while you were confused in hospital. We hope a better understanding of this will improve knowledge and management of this condition by staff.

What does the Study involve?

In this research study you will be interviewed one month after you are discharged from the Orthopaedic Unit. Each interview will be approximately 45 minutes in duration. The interview will take the form of a discussion where we talk about your experience of delirium.

You will be interviewed by two of the Chief Investigators Cecily Pollard (Mental Health Liaison Nurse, Royal Hobart Hospital) and Trish Beck (Clinical Nurse Manager, Ward 2A, Royal Hobart Hospital). With your permission, this interview will be tape-recorded. Your participation is voluntary and you are free to withdraw from the study at any time, for any reason, without comment or penalty.

What are the risks to me if I take part in this study?

Your participation is voluntary and you are free to withdraw from the study at any time, for any reason, without comment or penalty.

If you experience any emotional distress while being interviewed, or afterwards, you will be given the opportunity to discuss this with a free, independent support person (psychologist at RHH).

To ensure your confidentiality, only the researchers will know the identities of the participants in this study. All tape recordings and written records of your interview will be kept in a secure cabinet.

If you decide to take part, please complete the attached consent form.

For further information, comment or complaint.

Should you have any concerns, questions or complaints with regard to the ethical conduct of this research please contact the Executive Officer of the Human Research Ethics (Tasmania) Network on 62267479 or Human.ethics@utas.edu.au (you will need to quote ethics reference number H9761).

For any further information, please contact the investigators:

Cecily POLLARD	Ph: 62228308	Pager: 3672
Trish BECK	Ph: 62228566	Mobile: 0407303847

THANKYOU

Appendix 2: Consent Form

"Delirium: The Lived experience of confusion in the hospital"

I have read and understood the "Information sheet" for this study.

The nature and possible effects of the study have been explained to me.

I will voluntarily share my experience at a mutually agreed time and date.

I understand that the interview will be conducted by one of the researchers.

I understand that there is a minimal risk that I may experience some emotional distress while describing my experience.

I also understand that support will be available to me if I become distressed.

I have been informed that a copy of the interview will be sent to me for verification.

I have been informed that the result of the research may not be of any direct benefit to me

Any questions I have asked have been answered to my satisfaction.

I agree to participate in this research and understand that I may withdraw at any time without prejudice to me.

I agree that the research data gathered for the study may be published provided that I cannot be identified as a subject.

Number of subject:

Witness:

Date:

Signature:

Appendix 3: Interview Guide

1. Why were you recently admitted to the orthopaedic ward?
2. How long were you in hospital for?
3. What was your experience as a patient like?
4. Were you confused during your stay?
5. What was it like?
6. How did you feel during that time of being confused?
7. What helped you during that time?
8. Have you spoken to your relatives about your experience?

Appendix 4: The Confusion Assessment Method Instrument

1. [Acute Onset] Is there evidence of an acute change in mental status from the patient's baseline?

2A. [Inattention] Did the patient have difficulty focusing attention, for example, being easily distractible or having difficulty keeping track of what was being said?

2B. [If present or abnormal] Did this behavior fluctuate during the interview, that is, tend to come and go or increase and decrease in severity?

3. [Disorganized thinking] Was the patient's thinking disorganized or incoherent, such as rambling, or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject?

4. [Altered level of consciousness] Overall, how would you rate this patient's level of consciousness? (Alert, [normal]; Vigilant [hyperalert, overly sensitive to environmental stimuli, startled very easily]; Lethargic [drowsy, easily aroused]; Stupor [difficult to arouse]; Coma [unarousable]; Uncertain.

5. [Disorientation] Was the patient disoriented at any time during the interview, such as thinking that he or she was somewhere other than the hospital, using the wrong bed, or misjudging the time of day?

6. [Memory impairment] Did the patient demonstrate any memory problems during the interview, such as inability to remember events in the hospital or difficulty remembering instructions?

7. [Perceptual disturbance] Did the patient have any evidence of perceptual disturbances, for example, hallucinations, illusions or misinterpretations (such as thinking something was moving when it was not)?

8A. [Psychomotor agitation] At any time during the interview did the patient have an unusually increased level of motor activity such as restlessness, picking at bedclothes, tapping fingers or making frequent sudden changes of position?

8B. [Psychomotor retardation] At any time during the interview did the patient have an unusually decreased level of motor activity such as sluggishness, staring into space, staying in one position for a long time or moving very slowly?

9. [Altered sleep-wake cycle] Did the patient have evidence of disturbance of the sleep-wake cycle, such as excessive daytime sleepiness with insomnia at night?

THE CONFUSION ASSESSMENT METHOD (CAM)

DIAGNOSTIC ALGORITHM

Feature 1: *Acute Onset and Fluctuating Course*

This feature is usually obtained from a family member or nurse and is shown by positive responses to the following questions: Is there evidence of an acute change in mental status from the patient's baseline? Did the (abnormal) behavior fluctuate during the day, that is, tend to come and go, or increase and decrease in severity?

Feature 2: *Inattention*

This feature is shown by a positive response to the following question: Did the patient have difficulty focusing attention, for example, being easily distractible, or having difficulty keeping track of what was being said?

Feature 3: *Disorganized thinking*

This feature is shown by a positive response to the following question: Was the patient's thinking disorganized or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject?

Feature 4: *Altered level of consciousness*

This feature is shown by an answer other than "alert" to the following question: Overall, how would you rate this patient's level of consciousness? (alert, [normal]; vigilant [hyperalert, overly sensitive to environmental stimuli, startled very easily]; lethargic [drowsy, easily aroused]; stupor [difficult to arouse]; or coma [unarousable].

The diagnosis of delirium by CAM requires the presence of features 1 and 2 and either 3 or 4.

CAM Instrument and Algorithm adapted from Inouye, S, vanDyck, C, Alessi, C, Balkin, S, Siegel, A & R, H 1990, 'Clarifying confusion the confusion assessment method', *Annals of Internal Medicine*, vol. 113, no. 12, pp. 941-948.

Appendix 5: The Mini-Mental State Exam

Patient _____ Examiner _____ Date _____

Maximum Score

Orientation

- 5 () What is the (year) (season) (date) (day) (month)?
- 5 () Where are we (state) (country) (town) (hospital) (floor)?

Registration

- 3 () Name 3 objects: 1 second to say each. Then ask the patient
all 3 after you have said them. Give 1 point for each correct answer.
Then repeat them until he/she learns all 3. Count trials and record.
Trials _____

Attention and Calculation

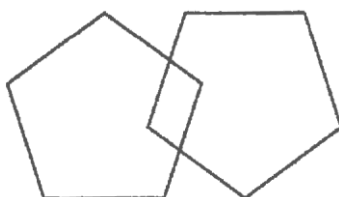
- 5 () Serial 7's. 1 point for each correct answer. Stop after 5 answers.
Alternatively spell "world" backward.

Recall

- 3 () Ask for the 3 objects repeated above. Give 1 point for each correct answer.

Language

- 2 () Name a pencil and watch.
- 1 () Repeat the following "No ifs, ands, or buts"
- 3 () Follow a 3-stage command:
"Take a paper in your hand, fold it in half, and put it on the floor."
- 1 () Read and obey the following: CLOSE YOUR EYES
- 1 () Write a sentence.
- 1 () Copy the design shown.



_____ Total Score

ASSESS level of consciousness along a continuum _____

Alert Drowsy Stupor Coma

Folstein, M, Folstein, S & McHugh, P 1975, "Mini mental state": a practical method of grading the cognitive state of patients for the clinician', *Journal of Psychiatric Research*, vol. 12, no. 3, pp. 189-198.

Used by permission.