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An exploration of patients' reconstructive memories of critical care and nurses' understanding and response to these: a qualitative study

Sarah McGloin

A thesis submitted in fulfilment of the requirements of Doctor of Philosophy in Nursing

City, University of London

School of Health Sciences, Division of Health Services Research & Management

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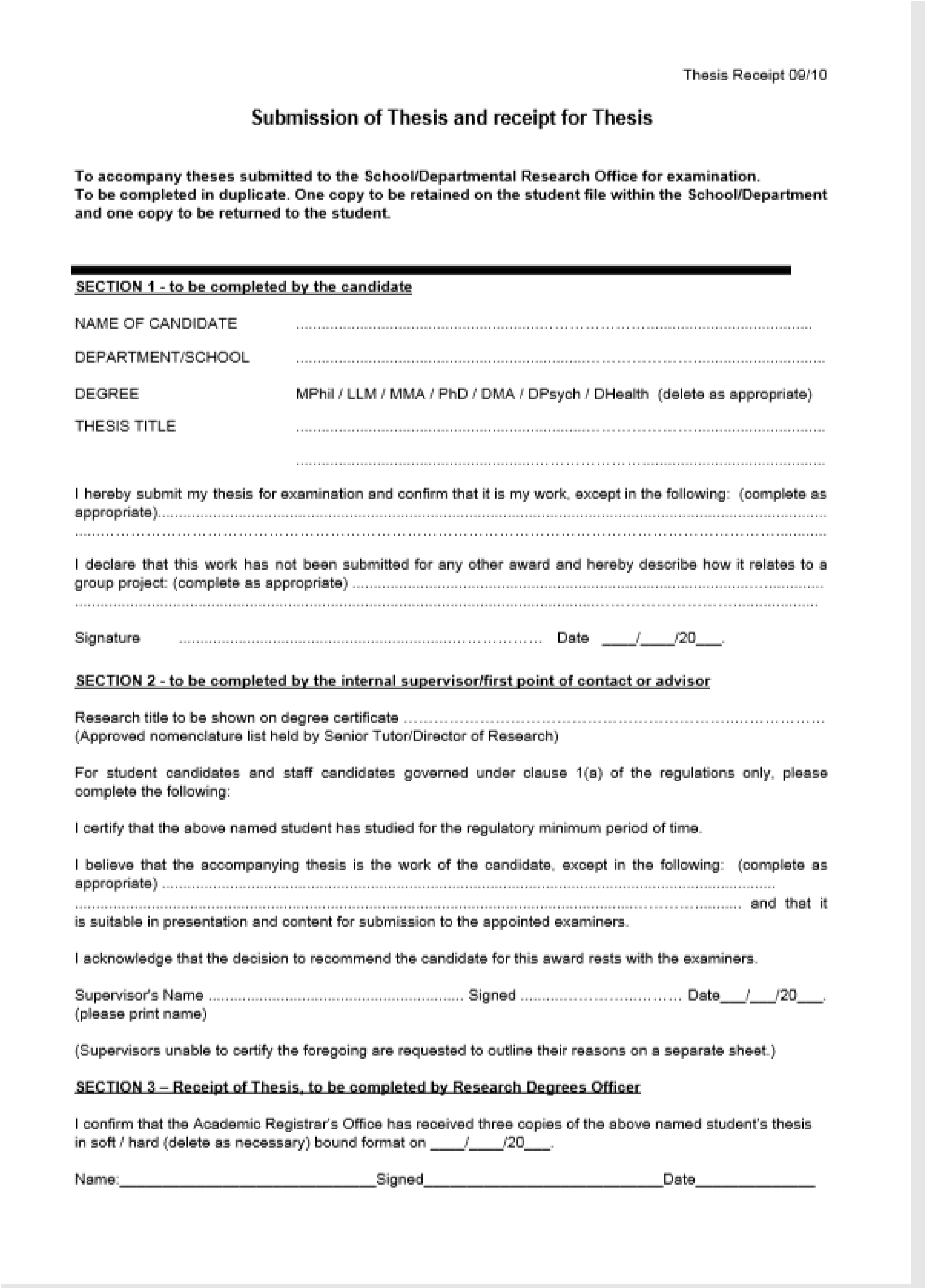
Declaration



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Abstract

Background

As greater numbers of individuals survive critical care, critical care nurses require an understanding of patients' memories of this experience. This is important because the critical care that nurses deliver may contribute to patients' memories of this episode in their life which irrespective of their objective accuracy and may have implications for patients' emotional well-being and longer-term critical care survivorship. This involves moving on with life, with individuals' often needing to redefine themselves as a result of the legacies of a critical care stay and regaining control of their life.

Aims of the research

Through the theoretical lens of Bartlett's (1932) theory of reconstructive memory, this research aimed to explore patients' reconstructive memories of critical care and to develop an understanding of how nursing practice may contribute to these and patients' longer term critical care survivorship. Through identifying similarities and differences between patients' reconstructive memories of critical care and nurses' understandings of these, this research also aimed to make recommendations for nursing practice, research and education.

Research design and methods

Drawing upon the work of Creswell and Plano Clark (2011) this qualitative research adopted an exploratory sequential design entailing one study with separate phases. Phase one involved interviews with former critical care patients (n=15) to collect qualitative data that were analysed through the constant comparative analysis method. A second phase involving focus groups collected and analysed further qualitative data from nurses (n=33) who all practised on critical care units (CCUs). A final phase explored convergence and divergence between patients' reconstructive memories of receiving critical care and the understanding of these demonstrated by critical care nurses.

Findings

Critical care patients reported missing memories of critical care. They demonstrated a need to address these and make sense of their situation and experiences. They felt only then could they achieve closure on this episode of their life and move on with their survivorship and the second chance of life that critical care had provided. To try to address these gaps in memories, patients developed rich reconstructive memories of critical care. To do this, they placed extreme value on family members experiences, understanding and support along with those provided through critical care follow-up services.

In contrast, the critical care nurses demonstrated a limited understanding of patients' memories of critical care, confining their considerations to the CCU stay. There was a lack of awareness of the value patients place on family members to support their memories and critical care survivorship. Instead, nurses drew heavily upon the medical model to explain patients' memories of critical care.

Conclusion

Nurses working within CCUs demonstrated an overreliance on the medical model which focuses on organ dysfunction and disease, to understand patients' memories of critical care. In contrast, patients' focus was more on their personal experience of receiving care on the CCU and then their recovery and ability to achieve closure on this episode and to move on with their life. Central to this for patients, was the role their family members played to help them address their missing memories of critical care and make sense of and understand their experience. Thus it is recommended that critical care nursing practice moves towards a holistic, patient-family-centred approach to care which supports the development of patients' reconstructive memories. This may contribute to patients' ability to achieve closure on this period of their life and move on with their critical care survivorship.

Glossary of terms and abbreviations

A & E	Accident and Emergency Department
AGCCU	Adult General Critical Care Unit
Art & Science of Nursing	The art of nursing focuses on three elements: medium, process and product whilst the science consists of systemised knowledge
CC3N	Critical Care Network National Nurse Leads
CAM-ICU tool	Confusion Assessment method for the ICU
Cardiothoracic CCU	Critical care unit caring for patients who have received cardiac surgery
CCORT	Critical Care Outreach Team – a group of specialist nurses who provide support on the ward for deteriorating patients and those recently discharged from CCU
CCA	Constant Comparative Analysis
CAQDAS Software	Computer Assisted Qualitative Data Analysis
CPAP	Continuous Positive Airway Pressure
Critical care follow-up	Aims to support patients and their relatives following critical illness.
CCU	Critical Care Unit
DGH	District General Hospital
DH	Department of Health
Emic	Insider researcher
Etic	Outsider researcher
ETT	Endotracheal Tube

Family-centred care	Family-centred care (FCC) is a partnership approach to health care decision-making between the family and health care provider.
FICM	Faculty of Intensive Care Medicine
GCS	Glasgow Coma Scale
HDU	High Dependency Unit
HRQoL	Health Related Quality of Life
HSCIC	NHS Health and Social Care Information Centre
ICU	Intensive Care Unit
ICS	Intensive Care Society
IRAS	Integrated Research Application System
Medical Model	The approach to care where the focus is the treatment of dysfunction and disease.
MMAT	Mixed Method Appraisal Tool
MMR	Mixed Methods Research
MRI	Magnetic Resonance Imaging Scanner
MSR	Mixed Studies Review
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIV	Non Invasive Ventilation
NMC	Nursing and Midwifery Council
NRES	National Research Ethics Committee Service
NVivo 11™	A desktop application which lets users organize, analyse and visualise information
PEOT	Population, Exposure, Outcome and Type
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PROSEPRO	International prospective register of systematic reviews
PTSD	Post Traumatic Stress Disorder
QUAL	Qualitative research
QUAN	Quantitative research
RA	Rehabilitation Assistant
Refworks™	Referencing data management system
Regional CCU	Tertiary referral centre for specialist critical care such as neurosurgery and advanced respiratory interventions
WFCCN	World Federation of Critical Care Nurses

Chapter One: Introduction

It is only in recent years as critical care survival rates increase that healthcare practitioners are beginning to appreciate the impact a critical care stay can have on an individual's emotional well-being (Allum et al. 2017) long after they leave the critical care unit. To develop this understanding further, this thesis presents a qualitative exploratory study of patients' reconstructive memories of receiving critical care and critical care nurses' understanding and response to these. Reconstructive memories relate to individuals' search for meaning from their memories (Bartlett, 1932).

This chapter provides a background to the area under exploration and defines the terms critical care, survivorship and reconstructive memories. It describes the international and national context for critical care and the changing demographics of this speciality. The role of the critical care nurse is explained and the rationale for the study, the overarching research aims, and the research questions are presented. The chapter concludes with an overview of the structure of the thesis.

1.1 Background

> *"If I could just try and get staff who deal with patients not to be so desensitized to them...all of your things are fed into a computer and they have to respond to the computer. And actually, they are becoming dehumanised."*
>
> (Healthtalkonline.org, 2017)

This quotation is from a 55-year-old woman with sepsis, following a six-day stay in a critical care unit (CCU). It illustrates some of the difficulty's patients experience as they receive critical care. The extract reveals how some patients feel invisible recipients of care (Stayt et al. 2015) and demonstrates how some individuals believe that critical care nurses have become detached, desensitised and dehumanised providers of care. Clearly, this is counter to the ethos of Compassion in Practice (Cummings and Bennett, 2012) and the 10 Commitments of Nursing presented in Leading Change, Adding Value (National Health Service [NHS], 2016), two influential policy documents which underpin contemporary nursing practice within the United Kingdom (UK).

The research presented here explores patients' reconstructive memories of receiving critical care and compares these with critical care nurses' understanding of these. An important first step is to define the term critical care.

1.1.1 Defining critical care

The terms critical care and critical illness are used interchangeably throughout the research, literature and clinical practice; however they are two separate phenomena (Intensive Care Society [ICS] 2015; Adhikari et al. 2010). Critical illness is a significant life event, associated with serious illness, suffering and often long-term physical and psychological morbidities (Cutler et al. 2013; World Federation of Critical Care Nurses [WFCCN] 2005), whilst critical care relates to the care patients receive as the result of a critical illness (Intensive Care Society[ICS], 2009). This research focuses on the *care* patients receive and not their *illness,* which has been the subject of extensive research studies in the past (Samuelson 2006; Egerod and Christensen 2009; Vincent 2010; Cutler et al. 2013; Page 2016). The delivery of critical care often necessitates a stay in an intensive care unit (ICU) (ICS, 2015). An international consensus meeting (Marshall et al. 2017) provided a useful definition of the ICU as:

> *"...an organised system for the provision of care to critically ill patients that provides intensive and specialised medical and nursing care, an enhanced capacity for monitoring and multiple modalities of physiologic organ support to sustain life during a period of acute organ system insufficiency. Although an ICU is based in a defined geographical area of a hospital, its activities often extend beyond the walls of the physical space to include the emergency department, the hospital ward and follow-up clinic."*
>
> (Marshall et al. 2017 p.274)

Historically, critical care in the UK has been delivered within the confines of the ICU. However, whilst the terms ICU and CCU are used interchangeably within the literature and clinical practice (ICS, 2015), nationally, the term ICU has been superseded by 'adult general critical care unit' (AGCCU) despite the international consensus of referring to the ICU (ICS 2015; Marshall et al. 2017). AGCCU is further abbreviated in the UK to the critical care unit (CCU) and as this research took place within the UK, the term CCU is used throughout this thesis to describe this specially staffed and equipped area of a hospital which provides the resources and facilities for critical care (ICS 2009; 2015; Marshall et al. 2017).

In January 2010 the UK Government Statistical Service (2010) reported there were three critical care beds per 100,000 of the population in the UK. This had doubled to six beds per 100,000 of the population by 2016 (presented in Figure 1.1). Figure 1.1 also shows the 25% increase in critical care admissions between 2010 – 2016 from 479,947 to 599,586, (NHS Digital [formerly Health and Social Care Information Centre (HSCIC)], 2017). An explanation for this growth could be provided by the concept of ‘critical care without walls’ which is not only set out nationally through the policy Comprehensive Critical Care (Department of Health [DH], 2000) but internationally, with Medical Emergency Teams providing critical care across the entire hospital in Australia (Hillman, 2002).

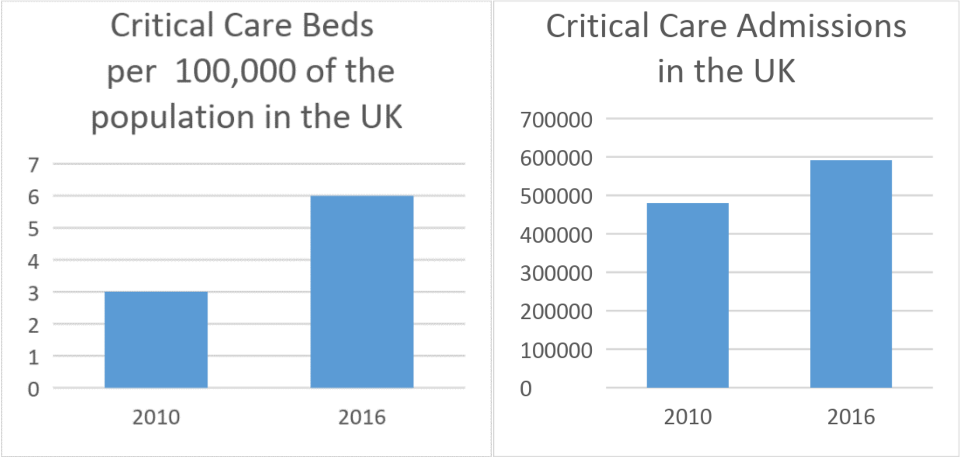


Figure 1.1 Critical care beds and critical care admissions in 2010 and 2016

1.1.2 Comprehensive critical care: the philosophy of critical care without walls

The fundamental principle of the Comprehensive Critical Care policy (DH, 2000) was that the level of physiological support required by a patient should be determined by their level of dependency and not their geographical location (DH 2000; ICS 2015; Hillman 2002). Consequently, ‘critical care without walls’ proposed that critical care practitioners should expand their roles beyond the walls of the CCU to manage deteriorating patients wherever they were located in the hospital (Hillman, 2002). The guidance within Comprehensive Critical Care (DH, 2000) proposed that critical care within the UK should be delivered in a range of settings to include emergency care, acute care wards and critical care follow-up services and not just the CCU (DH 2000;

Hillman 2002; Marshall et al. 2017). To assist practitioners with this new model of critical care, the ICS (2009; 2015) devised the levels of care framework presented in Table 1.1.

Table 1.1 The levels of care framework as proposed by the UK Intensive Care Society (ICS, 2009)

Level 0	Patients whose needs can be met through normal ward care in an acute hospital.
Level 1	Patients at risk of their condition deteriorating, or those recently relocated from higher levels of care, whose needs can be met on an acute ward with additional advice and support from the critical care team.
Level 2	Patients requiring more detailed observation or intervention including support for a single failing organ system or post-operative care and those 'stepping down' from higher levels of care.
Level 3	Patients requiring advanced respiratory support alone or basic respiratory support together with support of at least two organ systems. This level includes all complex patients requiring support for multi-organ failure.

If a patient dependency level progresses from level 2 to level 1, they are usually transferred from the CCU to an acute care ward where they continue to receive physical and psychological support (ICS, 2015). Patients are normally then discharged from the ward into the community (the patient's home or a community-based facility) (ICS, 2015).

Following the publication of the National Institute for Health and Care Excellence (NICE) Clinical Guideline 83: Rehabilitation after Critical Illness in Adults (NICE, 2009) NHS Trusts provide critical care follow-up services which range from *ad hoc* clinics concerned with clinical survival to structured, holistic programmes focusing on physical and psycho-social rehabilitation (Coombes and Dillon 2002; NICE 2009; ICS 2015). Some former critical care patients may also choose to attend support groups such as 'ICU Steps' which was founded by former critical care patients', their relatives and critical care staff to support patients and their families through recovery from a critical illness (NICE 2009; ICS 2015; Peskett and Gibbs 2009). Whilst there is a wider interprofessional critical care team, the role of the critical care nurse is arguably central to the provision of critical care.

1.1.3 The critical care nurse

Critical care nurses are members of a wider interprofessional critical care team including intensivists, anaesthetists, physiotherapists, dieticians and psychologists. Critical care nurses play a pivotal role in patients' experience of critical care as the one constant at the bed-side through the provision of one-to-one, twenty-four-hour nursing care (Faculty of Intensive Care Medicine [FICM], 2013). Internationally, the critical care nurse is considered to provide the specialist nursing care to a variety of critically ill patients with a unique combination of knowledge and caring (WFCCN, 2005) which involves assisting, supporting and restoring patients towards health – which is pertinent to the focus of this research. Critical care nurses strive to establish a therapeutic relationship with patients and their families empowering their physical, psychological, sociological and spiritual capabilities through providing preventative, curative and rehabilitative interventions (WFCCN, 2005).

To provide patient-centred critical care, critical care nurses draw upon a variety of knowledge and skills (Critical Care Network National Nurse Leads [CC3N], 2015). The critical care nurse is responsible for assessing complex patient's needs, planning, implementing and evaluating care. They not only provide information, knowledge and management, but must also demonstrate effective clinical leadership and decision-making skills. As a pivotal member of the critical care team, the nurse must also demonstrate effective communication skills not only with the patient and family but with the broader interprofessional team (CC3N, 2015).

Through the Comprehensive Critical Care policy (DH, 2000) the role of the critical care nurse now extends beyond the confines of the CCU, with critical care nurses providing care on the acute care wards though nurse-led critical care outreach teams who care for the deteriorating patient (NICE 2009; Pattison and Eastham 2012). Critical care nurses also facilitate post-hospital care through nurse-led critical care follow-up services, which are responsible for rehabilitation and recovery planning (Odell 2000; Coombes and Dillon 2002; NICE 2009; Pattison and Eastham 2012; CC3N, 2015). Consequently, with such a key role in the provision of critical care and in the context of the increasing numbers of patients surviving critical care, for reasons presented on page 17 below, it is essential that these nurses develop an understanding of how their role and the care provided can contribute to patients' memories of critical care and subsequent survivorship.

1.1.3.1 The art and science of nursing

Nursing is underpinned by 'the art and science of nursing' (Masterson and Robb, 2016). The art of nursing extends as far back as Florence Nightingale who was quoted to have said:

> *"Nursing is an art: and if it is to be made an art, it requires an exclusive devotion as hard a preparation as any painter's or sculptor's work; for what is the having to do with dead canvas or dead marble, compared with having to do with the living body, the temple of God's spirit? It is one of the Fine Arts: I had almost said, the finest of Fine Arts."*
>
> (Nightingale, 1871)

Today, the art of nursing relates to the fundamental clinical skills alongside aspects of clinical practice, including care, compassion and clinical judgement (Masterson and Robb, 2016). Additionally, the art of critical care nursing has been reported to involve: 1) perpetual presence, 2) knowing each other, 3) intimacy and agony. 4) deep detail and 5) honouring the body (Gramling, 2005).

Over recent years in the drive to develop the 'science' of nursing through the expansion of evidence based nursing practice (Straus et al, 2010), the art of nursing has become overshadowed (Biley et al, 2005). Consequently, there is a new drive to refocus nursing on both the art and science of the profession, with the recognition that nursing can perform a therapeutic role in its own right through simply being with the patient in authentic engagement which actively has the person at the forefront of the nurses' priorities with the aim of facilitating human development (Biley et al. 2005).

Additionally, this is being achieved through new clinical academic roles within critical care nursing – clinical professors of critical care nursing who are joint appointments between a university, and NHS organisation or health board have recently been appointed (Masterson and Robb, 2016). The responsibility of these new roles is to undertake clinical research and to disseminate the findings to encourage the adoption and implementation of research evidence to promote good practice in patient care (Florence Nightingale Foundation, 2018).

1.1.4 Models of Care

Throughout this research there is reference to the generic models of care employed throughout critical care practice. These are the:1) medical model (also known as the biomedical model) and 2) biopsychosocial model.

1.1.4.1 The medical model of care

The term 'medical model' is widely used throughout the literature, yet it is difficult to identify a clear definition (Fawcett, 2017). *Medicine* uses specific knowledge of disciplines such as biochemistry and pathology to prevent disease (Fawcett 2017; Venes 2009), whilst *medical* relates to caring for those who are ill (Fawcett 2017; Venes 2009). A useful definition is the '*allopathic medical model*' (Lowenberg,1989. p78) which proposes that human beings are objects consisting of categorial systems such as the respiratory system, and the cardiovascular system. Lowenberg (1989) proposes that the 'medical model' involves a hierarchical patient – doctor relationship developing where the doctor makes decisions regarding the management of these systems, for a passive patient when they are ill (Lowenberg, 1989).

At times nursing practice can be underpinned by the medical model (Biley et al. 2005). Nursing can be seen to respond to patients' needs which have arisen from medical diagnoses and management. In these instances, nurses monitor the physical state of the patient, they administer medication related to the prescribed treatment of a medical disorder and nursing care is regarded to be mechanical according to patients' acuity (Biley et al. 2015).Indeed, it could be argued that this is all in the domain of the critical care nurse who are responsible for:

> *'Understanding and supporting technical medical care, including diagnosis, treatment, care planning, and priority setting'* (Brilli et al. 2001 p.2011).

1.1.4.2 The biopsychosocial model of care

Engel (1977) proposed a generic biopsychosocial model of illness to address what he considered to be the shortcomings of the biomedical model. The biopsychosocial model is underpinned by the philosophy that illness and health are the result of the reaction between biological, psychological and social factors. Wade and Halligan, (2017) adopted Engel's model to develop a biopsychosocial model of critical care. Figure 1.2 presents how the biological, psychological and social factors interact together to inform the provision of holistic critical care practice.

The biological component of this model relates to the medical model of care focusing on physical illness, however overall the biopsychosocial model adopts a person-centred philosophy (Wade and Halligan, 2017). Whilst each individual occupies a body which is made up of organs, the person has a personal context consisting of their personality, experiences, attitudes and expectations. They have a temporal context which reflects the stage of their life and illness. The individual interacts with things and people in the physical environment through a goal-directed approach which relates to their behaviour. Within the social context, the individual and those observing their behaviour will attribute roles being undertaken at that specific time. The individual then exercises choices in relation to their actions and can reflect on their quality of life against their own measures (Wade and Halligan, 2017).

The psychological and social aspects of the model can be defined as social and behavioural factors which can influence an individuals' thoughts and behaviours (Oxford English Dictionary, 2018). In practice, the psychological and social aspects of care relate to the interpretations, affective state, behaviour and coping resources, which in turn can influence social issues such as the ability to work or socialise or other contextual demands life may place (Weiner, 2008).

The model is person centred. Each individual occupies a body which is made up of organs. The person has a personal context consisting of their personality, experiences, attitudes and expectations. They have a temporal context which reflects the stage of their life and illness. The individual interacts with things and people in the physical environment through a goal-directed approach which relates to their behaviour. Within the social context, the individual and those observing their behaviour will attribute roles being undertaken at that specific time. The individual then exercises choices in relation to their actions and can reflect on their quality of life against their own measures (Wade and Halligan, 2017).

Whilst a patient remains an individual, they are also often a member of a wider family unit. The family members of patients receiving critical care also require emotional and social support (Davidson et al, 2016). This leads to a family-centred model of critical care co-existing and supporting the biopsychosocial model of critical care.

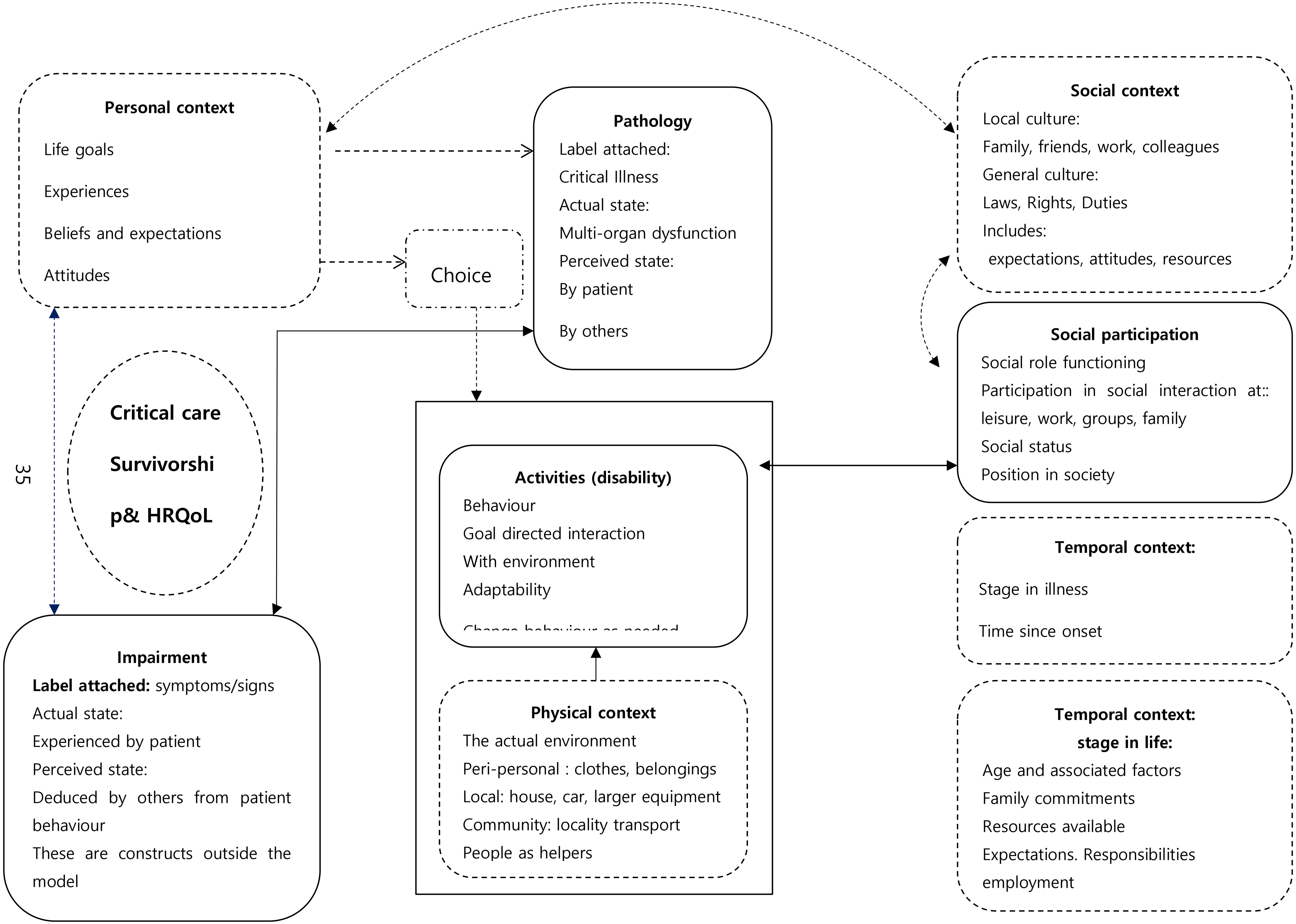


Figure 1.2: The biopsychosocial model of critical care (adapted from Wade and Halligan 2017)

1.1.4.3 The family-centred model of critical care

Family-centred care is defined as:

> *'An approach to health care that is respectful and responsive to individual families' needs and values.'* (Davidson et al. 2016. p.105).

Family-centred critical care focuses on information provision to families (Ladak et al, 2013), family involvement in non-technical care (Garrouste-Orgeas et al, 2010), flexible visiting (Giannini et al, 2014) and simple behaviours such as effective greetings from nurses and determining their relationship to the patient (Latour and Coombes, 2017). Mitchell et al.'s (2016) integrative review found family-centred approaches in critical care to be diverse and limited to the CCU setting, with few researchers providing a multi-dimensional approach to this throughout the entire critical care pathway. However, whilst Mitchell et al's (2016) review included 42 papers, there remains an identifiable lack of research on family-centred care within adult critical care (Latour and Coombes, 2017). Davidson et al. (2017) have reported the outcomes of an international multidisciplinary team scoping review into family-centred critical care. This provides the current model for family-centred critical care and is presented in Figure 1.3.

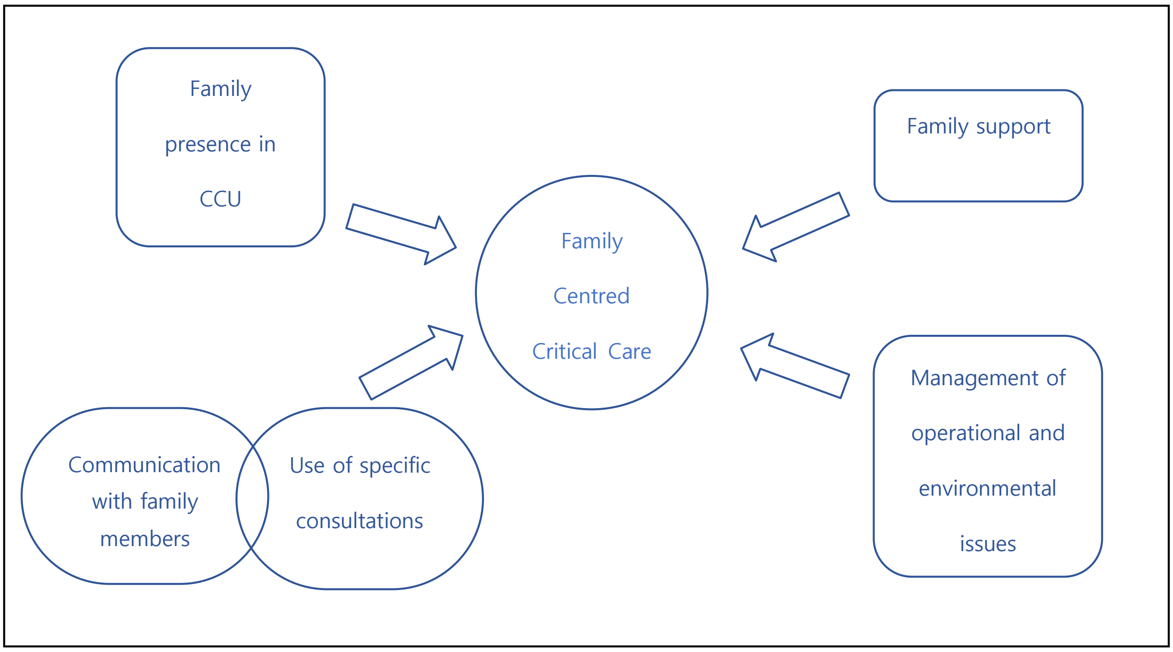


Figure 1.3: A model for family-centred critical care (Davidson et al. 2017)

The patient centred biopsychosocial model of critical care and the family-centred model, do not exist in isolation. As patients receiving critical care are often members of family units, the two models of care dovetail with each other to provide the basis of care for both patients and their family members within the critical care setting. Thus family-centred care is inherent for the holistic care of the biopsychosocial model to be achieved (Davidson et al., 2017). The relationship between the two is presented in figure 1.4.

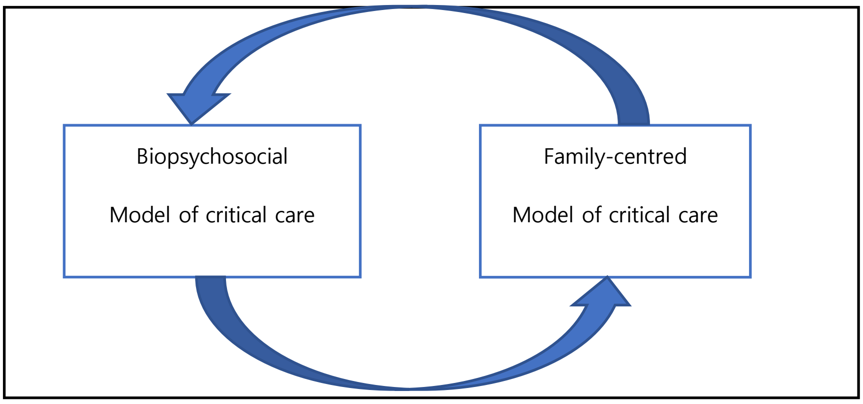


Figure 1.4: The relationship between the biopsychosocial model of critical care and the family-centred model of critical care

1.1.5 Critical care survivorship

Historically, simply surviving critical care was regarded as the main measure of success (Ridley, 2002). Today the focus of research and practice is shifting towards critical care survivorship (Lasiter et al. 2016; Page 2016; Kean et al. 2017). Survivorship is associated with the transitions undertaken by individuals to reclaim their life following a critical illness rather than simply surviving a critical illness and to 'move on' with life (Frank 2002; Kean et al. 2017).

The increase in critical care admissions both nationally (presented in figure 1.1) and internationally is accompanied by an increase in critical care survivorship (Needham et al. 2011; Lasiter et al. 2016). In 2012, the Health and Social Care Information Centre (HSCIC) [now NHS Digital] reported that 144,336 (83%) patients were discharged from critical care in the UK (NHS Digital, 2014). This figure rose to 176,063 (91%) in 2016 (NHS Digital, 2016). These increased survival rates demonstrate it is essential that former critical care patients are best placed physically and mentally to undertake effective rehabilitation following their critical care stay (Kean et al. 2017). However, as the number of critical care survivors increases, so does the reporting of unpleasant dreams, memories and even Post Traumatic Stress Disorder (PTSD) which can influence patients' recovery and survivorship (Samuelson 2011; Chahrouki et al. 2015). It is suggested that former critical care patients' reconstructive memory of critical care develops over time and maybe responsible for some of these unpleasant experiences following discharge from the CCU.

1.1.6 Reconstructive memory

Memory is a hypothetical construct comprising three distinguishable but inter-related phases (Noelen-Hoeksema et al. 2015; Gross, 2015). The first phase is encoding, where sensory information is transformed into a representation that is located within the brain's left hemisphere (Gross, 2015). The second phase involves storing this information within the right hemisphere of the brain, whilst the third stage – retrieval, involves extraction of the information from here (Noelen-Hoeksema et al. 2015; Gross, 2015). Memory is also differentiated as working memory, where small amounts of information are stored for a matter of seconds, in-contrast to long term memory, where large amounts of information are stored for longer periods (Noelen-Hoeksema et al. 2015).

Bartlett (1932) developed the theory of reconstructive memory through studying the effects of the serial reproduction of a story by different individuals. Bartlett found that as the story was reproduced, it became shorter, coherent and included clichés and conventional interpretations. Bartlett thus developed the concept of reconstructive memories. Bartlett proposed that through reconstructive memories individuals reconstruct their past by making it fit into their existing world. Bartlett theorised that these reconstructions that are developed from available information already held by an individual which they draw upon to help them understand a situation referred to as schemata.

According to Butler and McManus, (1998), schemata are simplified, generalised, mental representations which form a framework of encoded trace information within the memory and relate to an individual’s understanding of an event based upon past experiences. When trying to make meaning of an experience, Bartlett proposed individuals draw upon their schemata to construct the missing portions of memories in accordance with their own expectations. Bartlett considered these memories to be selective and interpretive as they are initially constructed and then reconstructed.

Rose (2003) also understood the brain to be an open system which is formed by its own past history through continuous interaction with both the natural and social worlds. Here the brain encodes and retrieves stored information based on its meaning. Each time the information is retrieved, it is worked upon further and the memory is transformed (Rose, 2003). Through this process memories are recreated and developed each time they are retrieved.

The main issue with this however, is that this can produce significant distortions in retrieval and Bartlett’s key argument that reconstructed memories are wholly inaccurate of the event itself, may give rise to false memory syndrome. This is caused by objectively false memories of a traumatic event developing which are strongly believed by the person to be real (Santos and Costa, 2016). These memories will thus correspond to an individual’s psychological reality which may not reflect the objective reality. Irrespective of the objective reality of these reconstructive memories, Bartlett considered they serve individuals well, not through providing a photographic recall of events but through selectively sampling experiences to provide a purpose and meaning to life.

Bartlett's theory has been challenged, specifically the idea that schemata are used to address gaps in memories. Gauld and Stephenson (1967) investigated this through a series of experiments on groups of psychology students. Much like Bartlett's study, Gauld and Stephenson's series of investigations involved participants listening to a story and then being asked to recall what they had heard. In contrast though to Bartlett's findings, Gauld and Stephenson found the ability to remember was not based upon pre-existing schemata, but more: 1) the presence of a 'good memory;' 2) the degree of instruction to remember the story before hearing it and 3) the degree of conscientiousness displayed by the participant and their desire to recall the story accurately. Whilst Gauld and Stephenson's findings go some way to explain the nature of memories, they are difficult to apply to a population of former critically ill patients who are trying to make sense of a stay in critical care. In particular the findings in relation to the presence of a good memory being necessary is also difficult to apply to this population who often have experienced poor tissue perfusion resulting in acute brain failure which may affect the quality of the patient's memory (Smith and Meyfroidt, 2017). Likewise, they were not instructed to remember their experience of critical care before they experienced it.

Earlier research by Northway (1936) explored how age, social background and complexity of the story the partipcants had heard, could influence recall and memories. Northway recruited children from three different schools, a private girl's school, a school in an inner-city slum and school in the country and reported that those in the less socially stable inner-city school modified the story more as they retold it than those from the girls' private school. Northway also found that items of high social meaning tended to be remembered more concluding that memories are interest and meaning-driven and are socially shaped rather than relying on previously held schemata. Again these findings are difficult to apply to a population of former adult critical care patients. Bartlett also argued that such experimental designs may have encouraged participants to produce more accurate results and for them to try harder to remember that they would do in a more naturalistic setting.

Recently, the focus on Bartlett's theory has returned, with Mori (2008) supporting Bartlett's argument that schemata are employed to address gaps in memories. Like Bartlett, Mori found the recollections of a group of undergraduate psychology students in relation to a heard story changed the more they repeated their narrative of the tale. Comparable with Bartlett, Mori attributed this to the 'schemata approach' to memories. Mori also identified that different individuals drew upon different schemata to remember an experience. Mori also agreed with Middleton and Browns' (2005) view that remembering is a process which is influenced by the length of the experience and the present time. Mori found that it was the schemata which contributed to this.

What is striking about the evidence base relating to Bartlett's (1932) theory of reconstructive memories, is that it adopts a positivist approach where experiments on psychology students carried out by psychologists provide the basis of evidence. There are no identifiable studies in the field of nursing, which use Bartlett's (1932) theory of reconstructive memory and the role of schemata as a theoretical lens for a naturalistic, exploratory study into memories of receiving care and the influence this has on patients' longer-term emotional wellbeing. Hence it could be instructive and possibly useful to use the theoretical lens of reconstructive memories in applied health research in general, and nursing research in particular, to assess whether this approach results in meaningful findings that could inform healthcare practice.

Consequently, this exploratory study will use Bartlett's theory of reconstructive memories as a theoretical lens for this research study. Despite the objective reality of reconstructive memories, it is the psychological reality provided through previously held schemata which helps an individual interpret and make sense of an experience, and that arguably influence patients' emotional well-being and survivorship long after their experience of receiving critical care. The present research is thus based on the assumption that reconstructive memories may be a legitimate object of investigation, whether or not an observer would regard them as accurate, as they reflect the patient's current experience of previous events. This will then provide insight as to how these reconstructive memories can influence critical care survivorship.

1.2 The rationale and aim of this research

The increasing rates of critical care survivorship (presented in section 1.1.5) raise new challenges for healthcare professionals (Kean et al. 2017). There is a substantive body of research focusing on patients' experiences of their critical illness, their physical recovery and the CCU stay (Samuelson 2006; Egerod and Christensen 2009; Vincent 2010; Cutler et al. 2013; Page 2016), despite for many, the CCU stay being a brief sojourn within their entire critical care experience (Iwashyna, 2012). Research has demonstrated that following hospital discharge, significant numbers of patients remain physically and –/– or cognitively disabled by frightening nightmares, anxiety and PTSD (Samuelson, 2011; Chahraoui et al. 2015; Elliott et al. 2016). As patients often cannot speak and communicate throughout their critical care stay, it is suggested that nurses often fail to hear about these experiences (White, 2016).

A former critical care patient, author Catherine White reported that because she was unable to communicate when on the CCU she was neither able to contribute to her care nor express her wishes. White (2106) strongly advocated that patients be given a voice through research to describe their critical care experiences. The James Lind Alliance has also highlighted the importance of research into critical care patients' experiences as one of the top ten research priorities for the speciality (Arulkumaran, 2016). In relation to this context, this research is both timely and relevant as it provides former critical care patients with a voice to discuss their reconstructive memories of receiving critical care.

Research relating to patients' memories of critical care is evident within the literature (Adamson et al. 2004; Zetterlund et al. 2012) however these studies relate to patients' experiences of critical illness rather than critical care. These studies acknowledge patients' memories however, they fail to recognise that such memories are reconstructive memories (Bartlett, 1932) and how these can influence an individual's critical care experience. Furthermore, there is no evidence that critical care nurses consider or understand how their care can influence the development of these reconstructive memories, which is particularly important as these can significantly contribute to an individual's critical care survivorship (Adamson et al. 2004). Consequently, to enhance patients' experiences of critical care and their subsequent survivorship, it is important to address this gap in the evidence base.

Section 1.1 of this chapter demonstrated that contemporary professional nursing practice is underpinned by the 10 commitments to nursing detailed in the policy

Leading Change, Adding Value (NHS, 2016). Commitment number seven urges nurses to *'lead and drive research to evidence [sic] what we do'* (NHS, 2016). A further rationale for this research comes from a professional nursing position to uphold this commitment. Through exploring former critical care patients' reconstructive memories of receiving critical care and comparing them with nurses' understanding of these, evidence will be provided as to how nursing practice can influence patients' experiences, reconstructive memories and survivorship of critical care. Additionally, the Leading Change Adding Value policy (NHS, 2016) proposes that nurses must demonstrate the unique contribution they make to patient care. A further rationale for this study was to support critical care nurses to understand their contribution to patients' reconstructive memories of critical care and how this can play a role in their survivorship.

Overall, the rationale for this research was to explore opportunities to foster a greater understanding of patients' reconstructive memories of receiving critical care, with a view to informing nursing practice and enriching patients' experience of critical care. Hence the aim of this research was:

1. *To explore patients' reconstructive memories and subsequent survivorship of critical care.*
2. *To develop an understanding of how nursing practice can contribute to patients' reconstructive memories and experience of critical care*
3. *To identify similarities and differences between patients' reconstructive memories of critical care and nurses' understandings of these, and make recommendations for nursing practice, research and education.*

1.3 The research questions

The aim of the research was addressed through the following questions:

1. *What are former critical care patients' reconstructive memories of critical care?*
2. *How do critical care nurses understand and respond to the patients' reconstructive memories of critical care?*
3. *How do former critical care patients' reconstructive memories of receiving critical care converge with and diverge from critical care nurses' understanding of these?*

The research questions were addressed through a qualitative, exploratory sequential research design (presented in Chapter Three). Question one was addressed through phase one of the design and phase two addressed question two. The third research question was addressed in Chapter Six where the findings from phases one and two were compared and contrasted.

1.4 The structure of the thesis

This thesis is presented in seven chapters. The thesis has the following structure:

1.4.1 Chapter Two: a mixed studies review into patients' experiences of critical care

Chapter Two presents a mixed studies review of primary quantitative, qualitative and mixed-methods research into patients' experiences of critical care. The literature is critically reviewed to identify any gaps in knowledge and sets the scene for the research design, and methods detailed in Chapter Three.

1.4.2 Chapter Three: research design and methods

Chapter Three presents the research design and methods. The qualitative, exploratory sequential design is detailed and strategies to ensure methodological rigour are described. The data collection methods utilised, face-to-face interviews with former critical care patients and focus groups with registered nurses currently practising in critical care are explained. The constant comparative analysis (CCA) method of data analysis is described whilst my reflexivity throughout the study is considered. The chapter concludes with a description of the ethical approval process and ethical considerations for this research.

1.4.3 Chapter Four: findings from the qualitative interview with the patients

Chapter Four presents the findings from interviews with former critical care patients. Verbatim extracts illustrate the findings. How these were subsequently used to develop the topic guide for the focus groups with the critical care nurses is then explained.

1.4.4 Chapter Five: findings from the focus groups with critical care nurses

The findings derived from the focus groups with critical care nurses are presented in Chapter Five. This addresses the second research question presented in section 1.3. Again, verbatim extracts illustrate the findings.

1.4.5 Chapter Six: findings across phases one and two

Chapter Six address the third and final research question presented in section 1.3. It presents the findings from the CCA across the findings from the patient interviews and the focus groups and demonstrates the divergence and convergence in findings between the two

1.4.6 Chapter Seven: discussion and conclusions

Chapter Seven critically discusses the research findings from the patient interviews and the focus groups within the context of the wider literature discussed in Chapter Two. The original contribution this research makes to contemporary critical care nursing practice is also reported in Chapter Seven. The strengths and limitations of the research are considered, and recommendations are made for future nursing practice, education and research.

1.5 Chapter conclusion

This chapter has provided the background and context for the research presented in this thesis. The rationale for conducting this study has been addressed along with the aims and the research questions.

It has been demonstrated that, coupled with the annual increase in critical care admissions, critical care survivorship is increasing nationally year on year (Lasiter et al. 2016). This increase in survivorship is accompanied by patients struggling to recover, rehabilitate and reclaim their life following their critical illness (Frank, 2002; Kean et al. 2017). Potentially exacerbating these issues are patients' reconstructive memories of receiving critical care. Consequently, it is necessary to compare former critical care patients' reconstructive memories of receiving critical care with critical care nurses' understanding of how the care they provide can influence these and patients' experiences of survivorship. The following chapter presents a mixed studies review of current literature exploring patients' experiences of receiving critical care.

Chapter Two: A mixed studies review of critically ill patients’ experiences of receiving critical care

This chapter presents a mixed studies review (MSR) of published papers that report critically ill patients’ experiences of receiving critical care in a variety of settings. In recent years the numbers of patients surviving critical care has proliferated (NHS Digital, 2017). As presented in Chapter One (section 1.1.5), this is associated with growing numbers of physical and psychological sequalae in critical care survivors (Kean et al. 2017). Additionally, nurses are driven to provide competent and effective compassionate care through policies such as Compassion in Practice (Cummings and Bennett, 2012). To help achieve this aspiration, critical care nurses need to develop an understanding of patients’ experiences of critical care and how their care may contribute to the issue’s patients face following a critical care stay (Cutler et al. 2013). Consequently, the rationale for this MSR was to present a critical review of the primary research relating to patients’ experiences of critical care.

2.1 The mixed studies review design

An MSR is a literature review where qualitative, quantitative and mixed method research (MMR) studies are concomitantly reviewed (Johnson et al. 2007; Pluye et al. 2009; Kastner 2016). Through synthesising qualitative and quantitative findings from primary research, the MSR combines the strengths of both types of study and provides a breadth and depth of understanding and corroboration of knowledge based upon all types of empirical research (Johnson et al. 2007; Pluye et al. 2009; Kastner 2016). The design is helpful as qualitative research provides in-depth descriptions of complex, context-specific phenomena, whilst quantitative research provides observations or causal relationships which may be transferable to other contexts (Pluye et al. 2009).

This exploratory MSR aimed to synthesise the primary research base concerning the most significant factors relating to critically ill patients' experiences of receiving critical care in a variety of settings. Through exploring individual perceptions and experiences from a range of designs, MSRs produce a rich, detailed, theoretical and practical understanding of complex heath interventions (Pluye et al. 2009; Pluye et al. 2011; Kastner et al. 2016). Critical care is a 'complex health intervention' (Faculty of Intensive Care Medicine [FICM] and ICS, 2015), consequently, the MSR was considered the best design for this review.

2.2 Methods

This review used an iterative approach to data analysis, spiralling back and forth between the different types of evidence (Mendlinger and Cwikel, 2008). Through this process, mixed evidence was produced as the findings of the qualitative papers and the qualitative component of MMR were synthesised with the findings of the quantitative papers and the quantitative component of the MMR (Hacking, 1999; Pluye et al. 2009).

Whilst there are a variety of ways to integrate the qualitative and quantitative findings (Greene 2006; Johnson et al. 2007; Creswell and Plano Clark 2011) convergence and divergence stances to integration were adopted for this review (Tashakkori and Teddlie, 2003). The method for this is presented in section 2.3.8. This MSR followed the seven systematic review steps (Pluye et al. 2014) presented in Figure 2.1.

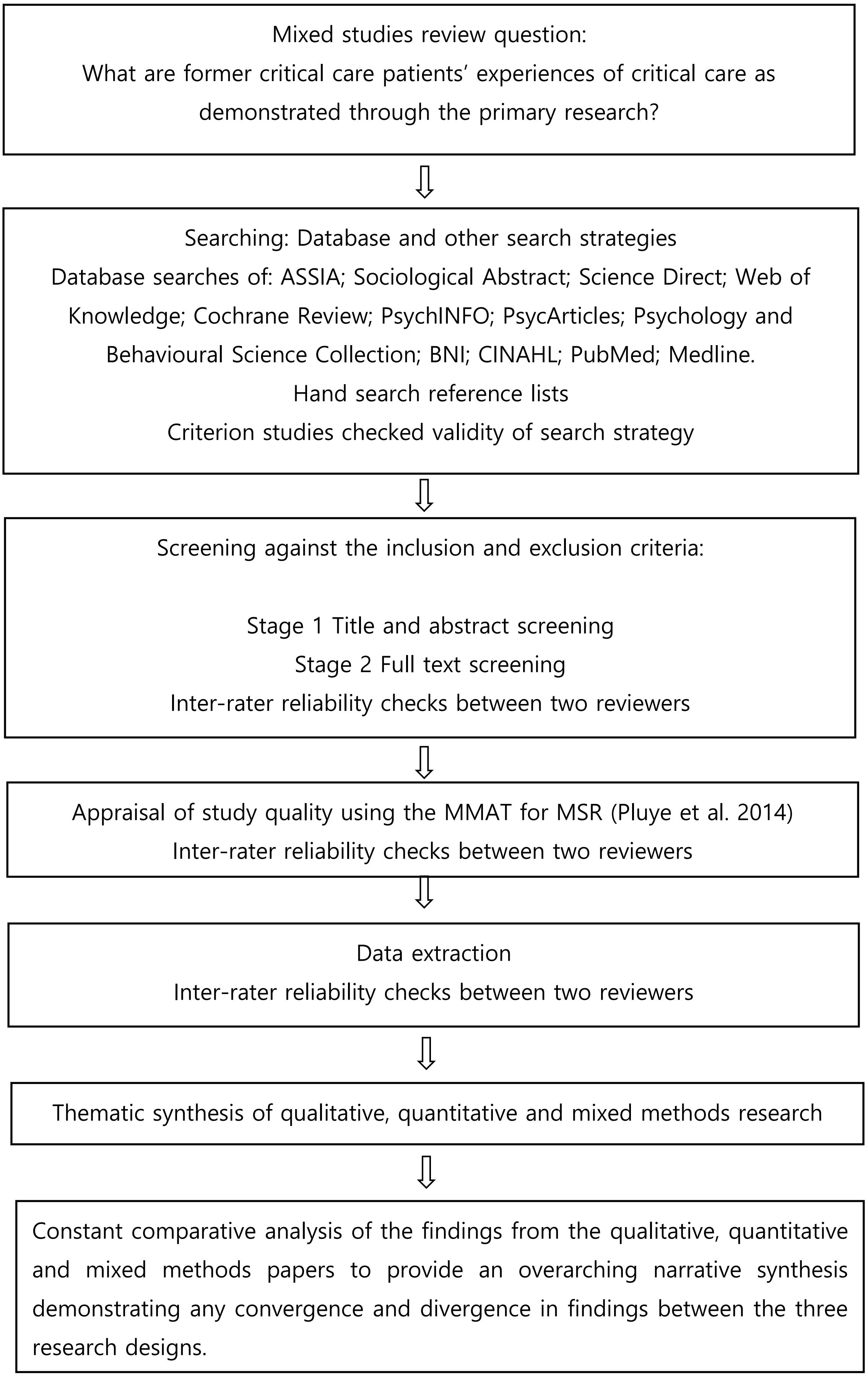
2.2.1 The review question

A well-constructed review question consists of four elements depending upon its focus (Flemming, 1998). Reviews based upon intervention studies are guided by the **P**opulation, **I**ntervention, **C**omparative Intervention and **O**utcome method to formulate the question (PICO) (Booth, 2004). In contrast, qualitatively focused reviews into patients' experiences adopt the **P**opulation, **E**xposure, **O**utcome and **T**ype (PEOT) method to structure the review question (Khan et al. 2003; Bettany-Saltikov and McSherry 2016).

As this was an MSR into patients' experiences of critical care, the review question was framed using the PEOT method (Khan et al. 2003). To ensure it related to and identified the correct research design for inclusion, Khan et al. (2003) included 'T' so that the *types* of research to be included were identified – in this case qualitative, quantitative and MMR designs (Pluye and Hong, 2014). To ensure all elements of the PEOT method were addressed when formulating the question, it was separated into its component parts (Flemming, 1998) which is presented in Table 2.1.

Table 2.1 Development of the review question using the PEOT method

Population	Exposure	Outcome	Type
Former critical care patients	To critical care services	The patients' views of their experiences	Descriptive non- experimental quantitative research Randomised controlled trials Quasi-experimental Phenomenology Grounded theory Descriptive thematic analysis Mixed method research



Mixed studies review question:
What are former critical care patients' experiences of critical care as demonstrated through the primary research?

Searching: Database and other search strategies
Database searches of: ASSIA; Sociological Abstract; Science Direct; Web of Knowledge; Cochrane Review; PsychINFO; PsycArticles; Psychology and Behavioural Science Collection; BNI; CINAHL; PubMed; Medline.
Hand search reference lists
Criterion studies checked validity of search strategy

Screening against the inclusion and exclusion criteria:

Stage 1 Title and abstract screening
Stage 2 Full text screening
Inter-rater reliability checks between two reviewers

Appraisal of study quality using the MMAT for MSR (Pluye et al. 2014)
Inter-rater reliability checks between two reviewers

Data extraction
Inter-rater reliability checks between two reviewers

Thematic synthesis of qualitative, quantitative and mixed methods research

Constant comparative analysis of the findings from the qualitative, quantitative and mixed methods papers to provide an overarching narrative synthesis demonstrating any convergence and divergence in findings between the three research designs.

Figure 2.1 Mixed studies review method (Pluye et al. 2014)

The following review question was formulated for this MSR:

What are former critical care patients' experiences of critical care as demonstrated through existing primary research?

2.2.2 The search strategy

A systematic search strategy was applied to 11 electronic databases: Applied Social Sciences Index and Abstract (ASSIA) (1973 to September 2016); Sociological Abstract (1973 to March 2015); SCOPUS (1995 to September 2016); Science Direct (1995 to September 2016); PsycINFO (1880s to September 2016); PsycArticles (1894 to September 2016); Psychology and Behavioural Science collection (1965 to September 2016); British Nursing Index (BNI) (1985 to September 2016); Cumulative Index to Nursing & Allied Health Literature (CINAHL) (1982 to September 2016); PubMed (1996 to September 2016); Medline(1946 to September 2016).

Key-word searches are the most common way to identify the literature (Ely and Scott, 2007) and because this review was exploring patients' experiences, the key word search was this time framed around PEO (Khan et al. 2003; Bettany-Saltikov and McSherry 2016). The key words and their synonyms, which were combined using the Boolean operators AND along with OR (Bettany-Saltikov and McSherry, 2016) are presented in Table 2.2. The MSR focused on the findings of primary research only and so a filter was applied to remove secondary research including integrative reviews, systematic reviews or MSRs from the search. The AND operator combined across the PEO elements focused the search, whilst the OR operator combined the population and exposure columns to identified papers featuring either term (Bettany-Saltikov and McSherry, 2016). To verify the search further a search proximity was applied using patient* N/3 critical* care and patient* W/3 critical* care, which searched for these words near or within three of each other. The search was limited to papers published since 1st July 2000. A hand search of the eligible papers' reference lists also ensured no relevant papers were missed. The reliability of the search strategy was assessed through a criterion paper check and members of the supervisory team also blind screened a 10% sample of papers. Filters were also applied to the search. These are presented in Appendix 2.1. The search was updated annually and last updated in January 2018.

Table 2.2 Search keywords and Boolean Operators

	STRING 1 POPULATION (P)	**STRING 2 EXPOSURE (E)**	**STRING 3 OUTCOME (0)**
Boolean Operators		AND	AND
	'critically ill patient*'	'intensive care unit'	'patient* experience*'
OR	'critically sick patient*'	ICU	memor*
OR	'ICU patient*'	ITU	outcome*
OR	'ITU patient*'	CCU	'continuity of care'
OR	'intensive care patient*'	'critical care unit'	
OR	'critical care patient*'	'intensive treatment unit'	
OR		'intensive therapy unit'	
OR		'follow-up'	
OR		'follow-up clinic'	
OR		discharg*	
OR		'transition*care' 'critical care' 'critical care follow-up clinic'	

2.2.3 Inclusion and exclusion criteria

The inclusion and exclusion criteria for papers also followed the PEOT method (Khan et al. 2003). They are presented in Table 2.3. A number of filters were applied to the search – as presented in Appendix 2.1.

The substantial body of literature relating to patient diaries was excluded from the MSR. The rationale for this was that despite this literature being referred to as 'patient diaries' they are completed on behalf on the patient by either members of critical care staff or family members (Aitken et al, 2013). Patient diaries are often addressed to the patient, written prospectively and provide a summary of the patient's' need for admission to CCU, the daily interventions which have taken place and a summary of the transfer from CCU to the ward (Egerod et al, 2007). This literature provides an important understanding of CCU care, but from the perspective of staff and family members' experiences rather than patients' first-hand experiences. As the review question was *What are former critical care patients' experiences of critical care as demonstrated through existing primary research?* it was considered that this literature does not directly address the review question and was therefore excluded from this review.

2.2.4 Screening papers against inclusion and exclusion criteria

One reviewer (SM) initially screened the title and abstract of each paper against the inclusion and exclusion criteria. To strengthen the validity of this screen, a second reviewer (supervisor JF) independently repeated this on a 10% random sample of identified papers (Petticrew and Roberts, 2006). Any differences between results were discussed between the reviewers until a consensus was reached. The full text of those papers not excluded at this stage, were then screened against the inclusion criteria, with another 10% sample being blind screened by a second reviewer (supervisor JJ). Differences between reviewers' screening were again discussed until a consensus was achieved.

2.2.5 Quality appraisal of the literature

The quality appraisal of the included papers was completed using the mixed method appraisal tool (MMAT) (Pluye et al. 2011). This is presented in Appendix 2.2. This tool was developed to facilitate the critical appraisal of the methodological quality of the qualitative, quantitative and MMR papers within an MSR and to assign a quality assessment score (Pace et al. 2012) and as such was considered to be the most appropriate appraisal tool for this MSR. A full critique of the tool is also presented in Appendix 2.2. Two reviewers (SM and JF) independently used the tool and met to discuss any differences until a consensus was achieved.

Table 2.3 Inclusion and exclusion criteria formulated through the PEOT method

PEOT Element	**Inclusion Criteria**	**Exclusion Criteria**
Population (P) Former critical care patients	Adult patients > 18 years who have received critical care	Neonates, children < 18 years who have received intensive care. Relatives, family, visitors Healthcare professionals
Exposure (E) To critical care	Hospital Intensive care unit/ critical care/critical care unit /CCU/ ICU /ITU/ intensive treatment unit/ intensive therapy unit Transitional care, discharge to the general ward Critical care follow-up	Neonatal intensive care unit (NICU) Paediatric intensive care unit (PICU) Clinical assessments and treatments Specialist Critical Care Not having received critical care Patient diaries Clinical condition Developing research, evaluation tools and guidelines End of life care
Outcome (O) Patients' experiences, perceptions and memories.	Experiences of receiving critical care Memories of receiving critical care	Delirium Not reporting patients' experience Socioeconomic outcomes

	Health related quality of life outcomes relating to receiving critical care: nightmares; hallucinations; pain; sleep; anxiety	Health related quality of life outcomes relating to critical illness: critical illness myopathy; reduced mobility; poor cognition
Types of study (T): *Qualitative*	Grounded theory; Phenomenology; Ethnography; Case study; Descriptive; Narrative; Constant comparative analysis; Thematic analysis	
Types of study (T): *Quantitative*	Case control studies Randomised controlled trials Cross-sectional surveys Quasi-experimental studies	
Types of study (T): *Mixed method*	Mixed methods research	
		Secondary research which is not primary research including: Anecdotal reviews and comment papers Mixed studies reviews Integrative literature reviews Meta-synthesis of qualitative research Meta- analysis of quantitative research Systematic literature review

A sensitivity analysis was then conducted to identify the possible effect of bias arising from differences in quality on the review (Dixon-Woods et al. 2006). Two reviewers (SM and JF) examined the relative contribution of all the included papers to the final identified themes and overall recommendations (Thomas and Harden, 2008). First, all papers were included in the synthesis (as described below) and findings were noted. Second, weaker papers (with a quality score of either 0% or 25%) were removed to ascertain whether this would make any difference to the synthesis (Dixon-Woods et al. 2006).

2.2.6 Data extraction and management (study characteristics)

A customised tool was used to extract data from the papers (presented in Appendix 2.3). This included: bibliographic details (author, title, publication year), journal reference, stated aims and objectives, sampling strategy (sampling sample number, age, gender, ethnicity, and country), study design, data collection method (setting and timing of data collection) and the study's main findings.

2.2.7 The thematic synthesis

A three-stage thematic synthesis of the findings was then conducted and is presented in Table 2.4. (Thomas and Harden, 2008). Thematic synthesis translates the stages of thematic analysis (often used as method of analysis for qualitative research) and integrates the findings from multiple papers in a systematic review (Thomas and Harden, 2008). NVivo 11™ the computer assisted qualitative data analysis software (CAQDAS) was used to manage the data (Woolf and Silver, 2017).

Table 2.4 The thematic synthesis method (Thomas and Harden, 2008).

Stage	**Method**
Stage one	Inductive line-by-line coding of the findings from the primary papers into 'free codes.'
Stage two	Organising the 'free codes' into related areas to form 'descriptive themes.'
Stage three	Moving beyond the descriptive themes to develop 'analytical themes' in response to addressing the review question

First, thematic synthesis of the qualitative and then MMR findings took place. Any convergence or divergence between the results was identified. Thematic synthesis of quantitative findings was then conducted and any convergence or divergence with the other designs was identified. To complete the synthesis, the findings from all approaches were integrated using the complementary and divergent stances to integration method (Tashakkori and Teddlie, 2003). This involved treating the findings from each design separately except when the qualitative findings contributed to the quantitative and vice-versa (Tashakkori and Teddlie, 2003). The divergent stance identified the discrepancy in findings between the three research designs (Tashakkori and Teddlie, 2003). Again, this was managed using NVivo 11™.

2.3 Findings

Section 2.3.1 below presents the findings from the literature search. This is followed by the findings of the thematic synthesis.

2.3.1. Identification of papers

The initial search identified 6,203 records with a hand search identifying a further 25. After duplicates were removed by hand (Refworks™ the data management system proved unreliable for this), 5,265 records were screened for inclusion. 4,992 records were then removed following screening the titles and abstracts against the inclusion and exclusion criteria. A further 155 records were excluded after screening the full text against the criteria. Finally, 116 records were included in the review. Details are presented in the PRISMA diagram in Figure 2.2. Whilst not specifically screening for secondary research, the search demonstrated that there was no MSR into patients' experiences of critical care.

2.3.2 Results of screening

Following screening, the 10% of papers for which consensus was not achieved were taken to the next stage where the full text of these papers were screened against the inclusion criteria. Differences between reviewers were discussed until a consensus was achieved. As the sensitivity analysis indicated that they would not bias the review, those papers which were appraised as weak with a score of 25% were included in the MSR. The final number of papers for inclusion was 116. This is presented in Figure 2.2.

2.3.3. The included papers

Table 2.5 presents the number of papers and participants included for each research design. A total of 6,133 individuals participated. The sample sizes ranged from one participant (Tordres et al. 2000) to 464 participants (Granja et al. 2004).

Table 2.5 Number of included papers for each research design

Research design	**Number of included papers**	**Number of participants**
Qualitative design	63	863
Quantitative design	40	4776
Mixed methods design	13	478
Total	116	6,133

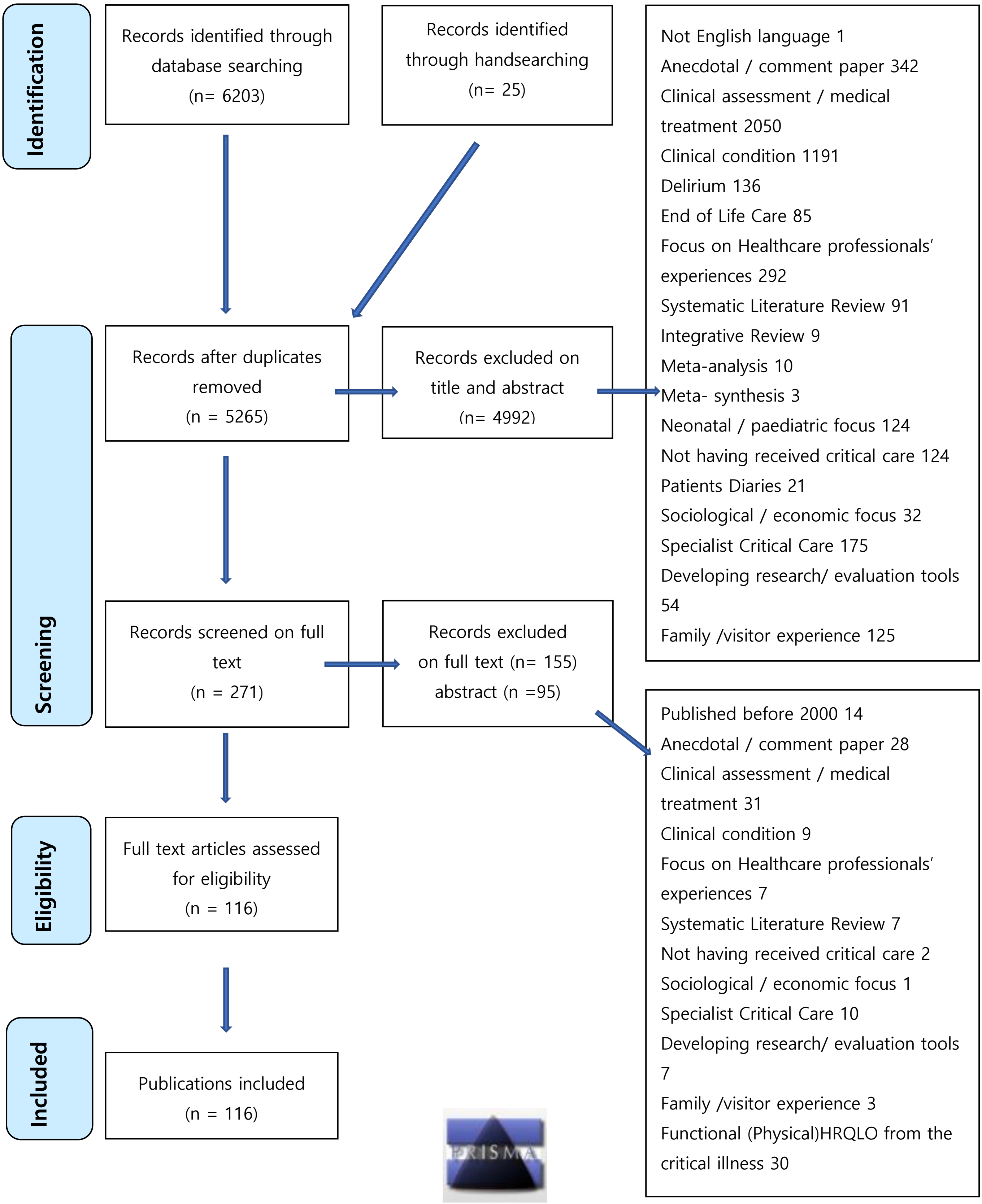


Figure 2.2 PRISMA diagram showing results

2.3.4 The quality appraisal

A quality appraisal score for each paper was assessed through the MMAT (Pluye et al, 2011; presented in Appendix 2.2). The full report on the results of the quality appraisal is presented in Appendix 2.4. The overall risk of bias for the included papers is presented in Table 2.6. The qualitative papers gained the greatest proportion of higher MMAT quality scores with 29% scoring 75% and 23% scoring 100%. This was followed by the descriptive non-experimental quantitative papers where 16% scored 75% and 5% scored 100% score.

Table 2.6 The overall quality scores of the risk of bias for the papers appraised by the MMAT (Pluye et al. 2011).

Total MMAT Score for the MSR		**% of the total sample**
0% = Very weak (No criterion met)	0	0
25% = Weak (One criterion met)	2	2
50% = Fair (Two criteria met)	12	10
75% = Good (Three criteria met)	66	57
100% = Excellent (Four criteria met)	36	31
Total	116	100%

2.3.5 Characteristics of studies

The characteristics of studies are presented in Appendix 2.5. Figure 2.3 shows that the most frequently reported design was qualitative (54%). An exploratory/descriptive approach was reported by 31 papers whilst 27 described phenomenology and two grounded theory. Interviews were the most frequently reported method and thematic analysis the most reported method of analysis.

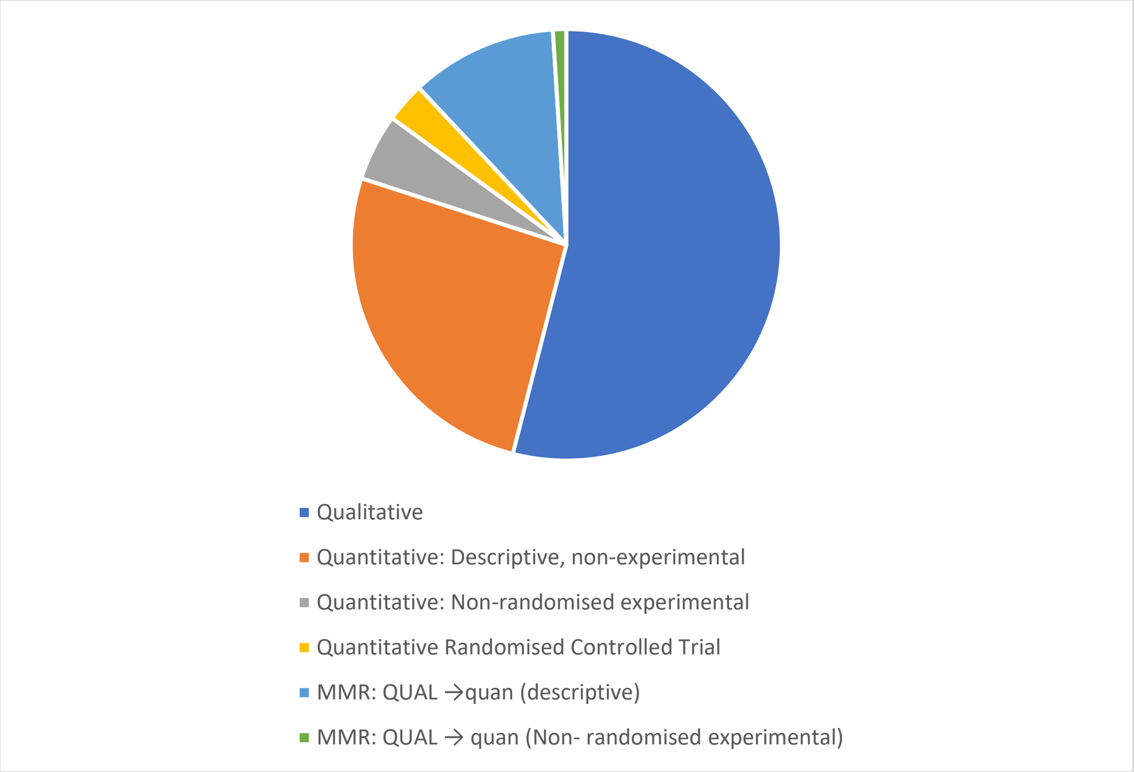


Figure 2.3 Research design of the included studies

The MMR papers included both quantitative and qualitative data however the qualitative findings provided the focus of reporting for this review. The MMR papers used measurement tools including the Hospital Anxiety and Depression Scale (HADS), Impact of Events Scale (IES), ICU Experience Questionnaire (ICEQ) and ICU Memory Tool (ICUM) along with qualitative findings from interviews, to report on Health Related Quality of Life outcomes (HRQoLO) .

Thirty quantitative papers reported a descriptive, non-experimental design. In addition, there were eight quasi-experimental studies and one randomised controlled trial. These reported similar measurement tools as detailed in the MMR papers.

2.3.6. Regions of data collection

Figure 2.4 demonstrates the distribution of region of data collection. The Nordic region published most papers (38%). A number of these were published by the same authors (namely Bergbom, Engstrom, Eriksson, Samuelson) often on the same subjects as part of their doctoral studies. In contrast 10% were from the UK and there was one multi-national study on rehabilitation involving 35 sites (Deacon, 2012).

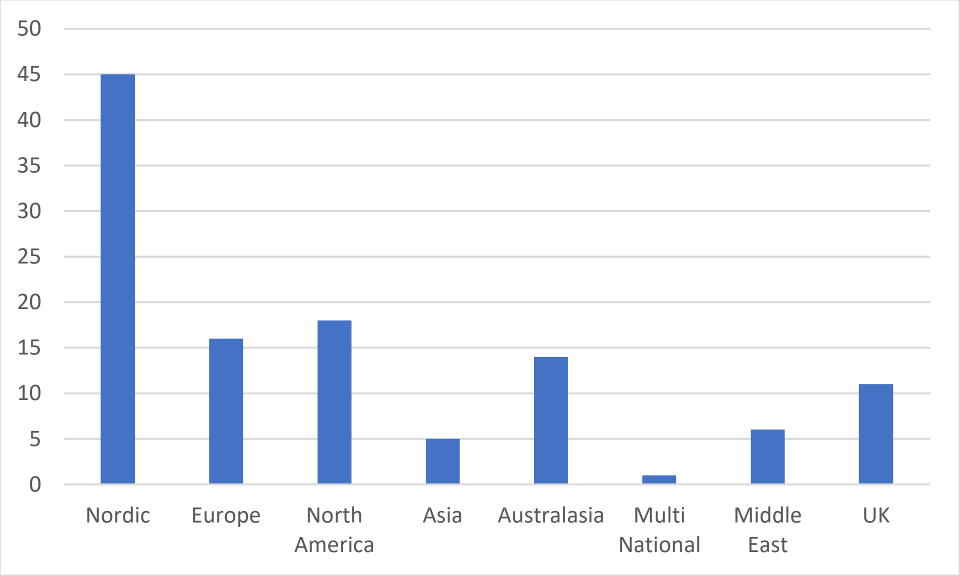


Figure 2.4 Region of data collection

2.3.7 Year of publication

Figure 2.5 presents the distribution of the year of publication. There was a spike in publications in 2008, which reflected an increased output from the Nordic region. A further spike in 2015 was associated with an increase in MMR papers, which aimed to augment findings from earlier papers which adopted a single design (Fink et al. 2015; Guttormson, et al. 2015).

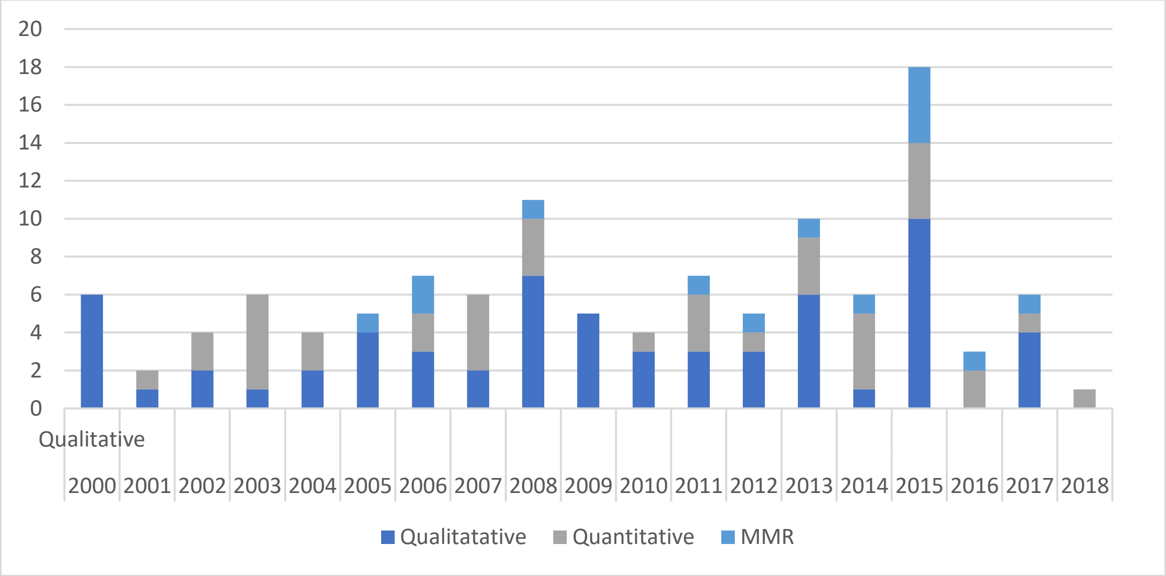


Figure 2.5 Years of publication of the included studies

2.3.8 Gender and mean age distribution

The reported gender distribution of participants was 56% male. This matches the UK national critical care gender distribution which was 147,240 male patients in 2014-2015 (57% of the critical care population) (NHS Digital, 2017). The reported mean age range of participants was 60-70 years old, with 37% of papers including participants from this age group. This is in line with the UK national critical care demographics where the majority of critical care patients between April 2014 and March 2015 were aged 65-69 years old (n=32,600) (NHS Digital, 2017).

2.3.9 The focus of the studies

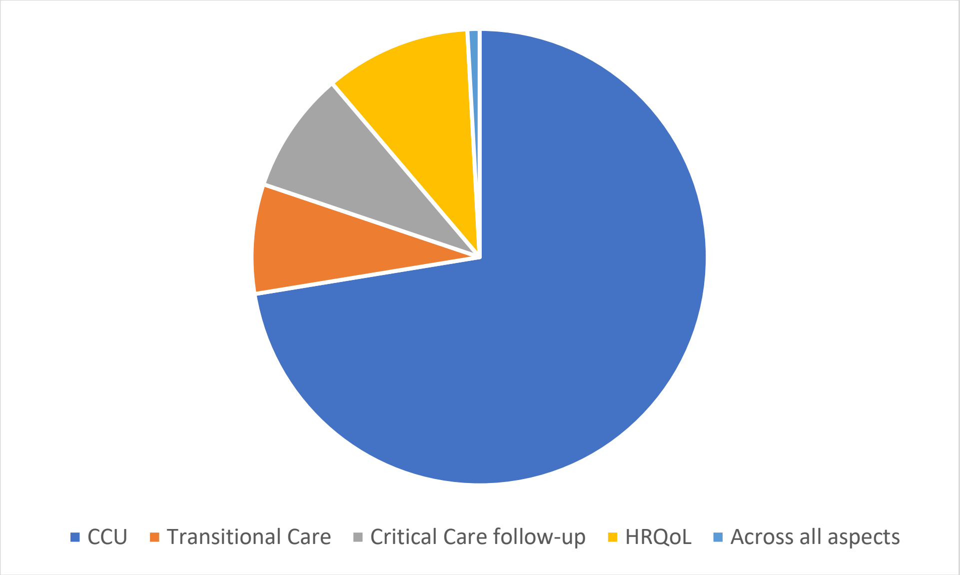


Figure 2.6 the focus of the studies

Figure 2,6 demonstrates that the majority of papers focused on the CCU stay. Just one paper explored patients' experience across all stages of critical care.

2.3.10 Thematic synthesis of the qualitative papers

The thematic synthesis of the qualitative papers identified four analytical themes. These were*: 1) patients' experiences of remembering critical care; 2) discomfort; 30 patients' hope to survive during critical care; and 4) returning to a life after critical care.*

2.3.10.1 Patients' experiences of remembering critical care

Four different aspects of patients' experiences of remembering critical care were identified. These are presented in Figure 2.7.

Thirteen papers specifically studied patients' memories of critical care and these all focused on memories associated with the CCU stay (Adamson et al. 2004; Carryer and Minton 2005; Granja et al. 2004; Guttormson 2014; Löf et al. 2006; Magarey and McCutcheon 2005; Merilainen et al. 2013; Ringdal et al. 2008; Samuelson et al. 2006;

Samuelson et al. 2007; Samuelson 2011; Storli et al. 2008; van de Leur et al. 2004). The studies reported on either factual memories which, despite no paper defining what a factual memory was, seemed to relate to recollections of discomfort caused by pain or the presence of the ETT (Samuelson et al. 2007; van de Leur et al. 2004) or delusional memories associated with surreal or unreal experiences, dreams and hallucinations (Magarey and McCutcheon, 2005).

The literature demonstrated that patients have a poor recollection of critical care (Adamson et al. 2004; Ballard et al. 2006; Carryer and Minton 2005; Cluckey et al. 2014; Engstrom et al. 2013; Foster 2010; Holm and Dreyer 2015; Löf et al. 2006; Löf et al. 2008; Maddox et al. 2001; Odell 2000; Ringdal et al. 2008; Wahlin et al. 2006). Most papers focused on memories of CCU, whilst three reported patients' memories of becoming ill (Löf et al. 2006; Löf et al. 2008; Ringdal et al. 2008) and waking up in a strange frightening place, not understanding what had happened (Deacon 2012; Flinterud and Andershed 2015; Löf et al. 2008; Odell 2000; Ringdal et al. 2008). Consequently, patients reported CCU to be a technologically hostile, chaotic environment full of light and noise (Almerud et al. 2007; Auriemma at al 2015; Ballard et al. 2006; Carryer and Minton 2005; Ding et al. 2017; Erikson et al. 2010; Herbland et al. Laerkner et al. 2017; Olsen et al. 2017 Samuelson 2011; Wang et al. 2008; Zeilani and Seymour, 2010).

As patients' level of consciousness improved, they reported that fragmented memories started to develop of nurses, physiotherapy, relatives, and ventilation (Claesson et al. 2005; Clukey et al. 2014; Deacon 2012; Engstrom et al. 2013 Holm and Dreyer 2015; Löf et al. 2008; Maddox et al. 2001). They also reported gaps in these memories emerging (Carryer and Minton, 2005). Patients reported the need to fill these, so they could understand their experience (Carryer and Minton 2005; Engstrom et al. 2013; Haraldsson et al. 2015; Hupcey 2000; Löf et al. 2006; McKinley et al. 2002; Storli et al. 2008). One strategy was to ask relatives what had happened (Carryer and Minton 2005; Haraldsson et al. 2015; Odell 2000; Olsen et al. 2017), which proved helpful for some, but unhelpful for others who felt isolated and suspicious that family members were withholding information to protect them (Olsen et al. 2009).

Free codes	**Descriptive code**	**Analytical theme**
Lack of recall	Recalling critical care	**Patients' experiences of remembering critical care**
Filling the gaps		
Unpleasant/ pleasant memories		
Powerlessness		
One-to-one care	Feeling safe and secure	
Trust and Distrust		
Technology providing Safety		
Healthcare professionals approach to care	The care provision in CCU	
Patient centred care		
Dignity and respect		
The CCU room	The critical care environment	
A technologically rich environment		
fear and trust of technology		

Figure 2.7 Analytical theme: patients' experiences of remembering critical care

A formal approach to addressing the memory gaps reported by a number of papers was a critical care follow-up clinic where patients explored their memories and experiences with practitioners (Deacon 2012; Engstrom et al. 2013; Haraldsson et al. 2015; Löf et al. 2008; Maddox et al. 2001; Storli and Lind 2008). Unpleasant memories were widely reported within the literature, with pain being the main issue (Carryer and Minton 2005; Engstrom et al. 2008; Löf et al. 2006; McKinley et al. 2002; Olausson et al. 2013; Ringdal et al. 2006; Samuelson 2011; Wang et al. 2008; Zeilani and Seymour 2010). Physiotherapy, mouthcare, injections, physical examinations, depression, sadness and isolation also contributed to patients' negative recollections (Samuelson 2011; Wang et al. 2008). In contrast, memories also included pleasant recollections of CCU like the relief of analgesia working or being able to speak when extubated (Samuelson, 2011).

Through the one-to-one care from CCU staff, patients remembered feeling safe with the nurse who was in sight, but also feeling uncared for if they moved away (Adamson et al. 2004; Almerud et al. 2007; Engstrom et al. 2013; Erikson et al. 2010; Johnson 2004; Karlsson and Forsberg, 2008; Laerkner et al. 2017; Locsin and Kongsuwan 2013; Löf et al. 2008; McKinley et al. 2002; Olausson et al. 2013; Olsen et al. 2017; Samuleson 2011). Others reported their privacy had been invaded and felt uncomfortable being watched (Forsberg et al. 2011; Olausson et al. 2013). Some reported it restricted the opportunities to communicate with family members and caused them to withdraw into themselves (Karlsson et al. 2012).

Patients reported that technology was a non-negotiable, life-saving 'necessary evil' in CCU, which provided reassurance that any deterioration in their condition would be detected (Lindberg et al. 2015; Locsin and Kongsuwan, 2013; Stayt et al. 2015).

Patients reported the alarms caused stress and the technology was oppressive if it became the focus of attention (Almerud et al. 2007; Auriemma at al 2015; Ding et al. 2017; Erikson et al. 2010; Laerkner et al. 2017; Olausson et al. 2013; Olsen et al. 2017 Samuelson, 2011 Wang et al. 2008; Stayt et al. 2015; Zeilani and Seymour, 2010).

Patients reported difficulties with communication due to the endotracheal tube (ETT) (Flinterud and Andershed 2015; Foster 2010; Holm and Dreyer 2015; Karlsson et al. 2012; Laerkner et al. 2017; Moen and Naden 2015; Olsen et al. 2017; Tordres et al. 2000). Being unable to express how frightened they were, patients reported feeling vulnerable, with low self-esteem and frustration (Almerud et al. 2007; Flinterud and Andershed 2015; Karlsson et al. 2012; Karlsson et al. 2012; Lindberg et al. 2015; McKinley et al. 2002; Maddox et al. 2001; Moen and Naden 2015; Tordres et al. 2000). They felt invisible as staff knew *how* they were but not *who* they were (Almerud et al. 2007; Karlsson et al. 2012 Laerkner et al. 2017; Lindberg et al. 2015; McKinley et al. 2002; Stayt et al. 2015; Tordres et al. 2000). Patients also described a lack of information which made them feel helpless and apathetic (Lykkegaard and Delmar, 2013). Consequently, they felt powerless receiving critical care (Almerud et al. 2007; Ballard et al. 2006; Eriksson et al. 2010; Karlsson et al. 2012; Löf et al. 2008; Lykkegaard and Delmar2013; Wang et al. 2008).

None of the included studies exploring patients' memories of critical care considered reconstructive memories may address the gap in memories which can persist following critical care. Consequently there is limited understanding of implications of reconstructive memories of critical care for patients and consequently nursing practice.

2.3.10.2 Patients' experiences of discomfort

Six different aspects of patients' experiences of discomfort were identified. These are presented in Figure 2.8..

Free codes	Descriptive code	Analytical theme
Breathlessness Thirst Uncomfortable Being conscious	Experiencing physical discomfort	**Patients' experiences of discomfort**
Negative emotions Not understanding what had happened	Experiencing emotional discomfort	
Powerlessness Voiceless Using aids	Experiencing difficulty with communication	
Putting life into the Hands of others Feeling invisible Loss of control Dreams	Experiencing powerlessness	
Nightmares Hallucinations	Surreal experiences	
Abandonment and neglect Handing over the power	Moving from the CCU to the ward	

Figure 2.8. Analytic theme: patients' experiences of discomfort

Patients stated they were powerless over decisions like eating, toileting, levels of sedation or receiving visitors (Almerud et al. 2007; Eriksson et al. 2010; Flinterud and Andershed 2015; Hupcey 2000; Karlsson et al. 2012; Lykkegaard and Delmar2013).

Consequently, they reported this led to discomfort as they felt frightened and trapped in uncomfortable bodies (Almerud et al. 2007 Eriksson et al. 2010; Lykkegaard and Delmar 2013).

Some reported this powerlessness lessened if they were conscious and could communicate (Karlsson et al. 2012; Laerkner et al. 2017). However, patients reported that using communication aids left them physically and emotionally exhausted and at times unable to cope (Flinterud and Andershed 2015; Foster, 2010; Karlsson et al. 2012; Laerkner et al. 2017; Moen and Naden 2015; McKinley et al. 2002; Samuelson 2011).

Patients recalled physical discomfort such as pain, dyspnoea and paralysis whilst on CCU (Adamson et al. 2004; Samuelson 2011; Stayt et al. 2015; Wang et al. 2008; Wong and Arthur 2000). The ETT resulted in overwhelming thirst as they could not drink (Engstrom et al. 2013; Holm and Dreyer 2015). The physical discomfort was so bad some considered dying (Löf et al. 2006; Lykkegaard and Delmar 2013; Locsin and Kongsuwan, 2013).

Patients described fear about their own mortality as they vacillated between death and life (Almerud et al. 2007; Alpers et al. 2012; Ballard et al. 2006; Carryer and Minton 2005; Engstrom et al. 2013; Löf et al. 2008; Olausson et al. 2013; Ringdal et al. 2008; Tembo et al. 2013; Tordres et al. 2000). Some felt the unit resembled a post-mortem room and they were surrounded by misery and death (Engstrom et al. 2013). Other were shocked to learn of their proximity to death as they recovered (Almerud et al. 2007; Carryer and Minton, 2005).

Patients' experiences of dreams, nightmares and hallucinations were widely reported with insomnia, difficulty communicating, and sedation reported as contributory factors (Adamson et al. 2004; Ballard et al. 2006; Carryer and Minton 2005; Claesson et al. 2005; Engstrom et al. 2008; Karlsson and Forsberg 2008; Karlsson et al. 2012; Locsin and Kongsuwan2013; Löf et al. 2006; Maddox et al. 2001; Olausson et al. 2013; Olsen et al. 2017; Ringdal et al. 2006; Samuelson 2011; Tembo et al. 2013). Patients reported that as reality and dreams became interwoven, they existed in a world seated between reality and unreality. This added to their anxiety, sadness and anger (Auriemma et al. 2015; Engstrom et al. 2013; Herbland et al. 2017; Olausson et al. 2013; Ringdal et al. 2008; Samuelson 2011). Others reported these dreams to be full of colour and recovery, a place of retreat from the overwhelming reality of CCU (Claesson et al. 2005; Holm and Dreyer 2006; Karlsson and Forsberg 2008; Löf et al. 2006; Samuelson 2011).

In contrast, the nightmares and hallucinations were reported to be traumatic, vivid and terrifying and could persist up to six months following discharge to home (Carryer and Minton 2005; Engstrom et al. 2008; Locsin and Kongsuwan, 2013; Olsen et al. 2017; Löf et al. 2006; Tembo et al. 2013). Some patients reported the hallucinations made them aggressive and difficult which became the focus of their care and they felt marginalised further (Eriksson et al. 2010; Hupcey and Zimmerman 2000; Löf et al. 2006).

Patients recalled moving from CCU to the ward to be distressing (Carryer and Minton 2005; Field et al. 2008; Olsen et al. 2017; Strahan and Brown 2004). They reported that staff managed the transfer process and patients' feelings that they themselves did not feel ready to leave CCU became irrelevant (Forsberg et al. 2011; McKinney and Deeny 2002; Odell, 2000 Ramsay et al. 2013).Once on the ward, they reported feeling abandoned, isolated, helpless and depressed (Chaboyer et al. 2005; Field et al. 2008; McKinney and Deeny, 2002; Odell 2000; Ringdal et al. 2006; Strahan and Brown, 2004). They were frightened that should their condition deteriorate it would go unnoticed by the ward staff (Chaboyer et al. 2005; Forsberg et al. 2011; Strahan and Brown 2004).

2.3.10.3 Patients’ experiences of hope to survive during critical care

Two different aspects of patients’ experiences of hope to survive critical care were identified. These are presented in Figure 2.9.

Free codes	Descriptive code	Analytical theme
Developing a positive Attitude	Experiencing the will to live	**Patients’ experiences of hope to survive during critical care**
Being motivated to get better		
Finding an inner strength		
The role of spirituality		
Providing support and encouragement	Experiencing family providing hope	
The presence of the next of kin		

Figure 2.9. Analytical theme: patients’ experiences of hope to survive critical care

Patients reported that by focusing on the world beyond CCU, they developed a will to live (Locsin and Kongsuwan 2013; Wahlin et al. 2009). They stated that having loved ones close by provided hope and a sense of responsibility to survive (Karlsson and Forsberg 2008; Locsin and Kongsuwan 2013). Through an optimistic, strong, self-positive attitude patients drew upon their inner strength to continue living (Wahlin et al. 2006; Wahlin et al. 2009; Wang et al. 2008). As their level of consciousness improved and the efforts made to support them with technology and high staff ratios, patients reported hope for their recovery (Karlsson et al. 2012; Stayt et al. 2015). Some patients also reported that prayer provided hope for survival (Arslanian-Engeron et al. 2003; Hupcey 2000; Zeilani and Seymour, 2010).

The importance of the presence of family members for patients was highlighted in the literature, with patients reporting they would have given up without their families (Arslanian-Engeron et al. 2003; Bergbom and Askwall 2000; Wong and Arthur 2000; Zeilani and Seymour 2010) and that their presence provided a life-line to regain their life as they could see they were loved and needed (Bergbom and Askwall 2000; Olausson et al. 2013; Olsen et al. 2009; Zeilani and Seymour 2010). Patients reported their next-of-kin to be a calming distraction who provided hope and reduced feelings of abandonment and death (McKinley et al. 2002).

Patients reported their families continued to care for them at home (Maddox et al. 2001; Ringdal et al. 2008). Some recognised this enhanced their relationships (Maddox et al. 2001), whilst others reported they were a burden on their family which led to tension especially if they relied on elderly family members for support who could not always cope but were unwilling to ask for help (Maddox et al. 2001; Ringdal et al. 2008).

2.3.10.4 Patients’ experiences of returning to a life after critical care

Four aspects of patients’ experiences of returning to a life after critical care were identified. These are presented in Figure 2.10.

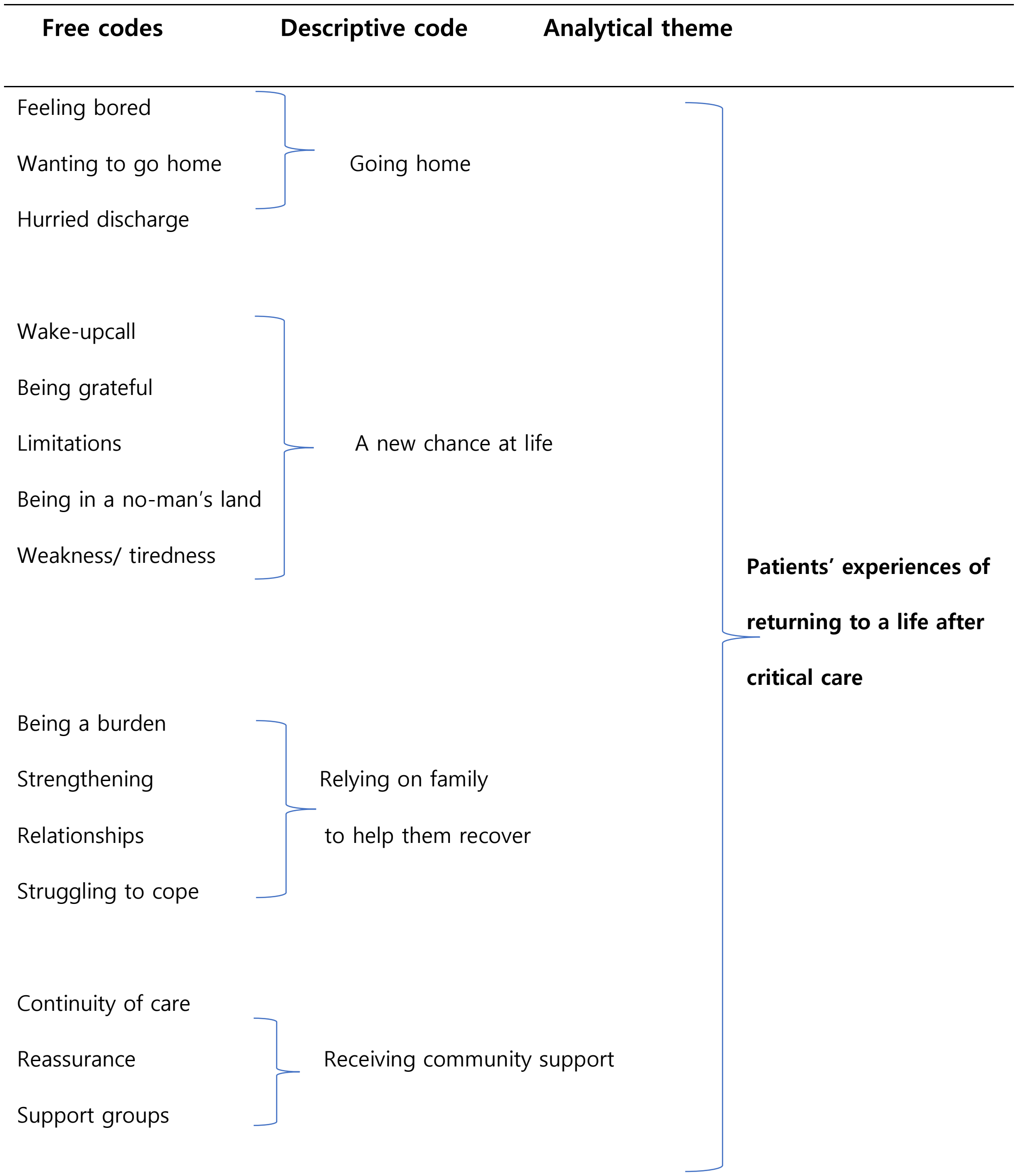


Figure 2.10. Analytical theme: patients' experiences of returning to a life after critical care

Following critical care, patients reported being grateful to be alive and having another chance at life (Herbland et al. 2017). Some perceived critical care had been a 'wake-up' call at how precious life is (Cypress, 2011). Others were humbled by the experience and learnt not to take things for granted (Ringdal et al. 2008).

Patients reported difficulty adapting to new routines following critical care (Karlsson et al. 2015; Ringdal et al. 2008), as they failed to complete daily chores. To cope they postponed doing those things which impacted on their quality of life (Karlsson et al. 2015). The fatigue experiences caused distress for some patients who reported nightmares about how weak they were (Carryer and Minton, 2005). Being too fatigued to socialise, patients talked about feeling marginalised and forgotten with no place in society (Ringdal et al. 2008). Others reported being determined to concentrate on the future and get their normal life back (Olsen et al. 2009; Ramsay et al. 2013).

Patients reported that their general practitioners and community nurses provided support for their physical recovery (Maddox et al. 2001; Prinjha et al. 2009). Others reported feeling abandoned and relied on family members to help them recover (Ringdal et al. 2008). Feelings about support groups were mixed, with some reporting it would help to meet with those with similar experiences (Ringdal et al. 2008), whilst others felt it would not be helpful (Maddox et al. 2001).

2.3.11 Thematic synthesis of the mixed methods research (MMR) papers

The thematic synthesis of the MMR papers identified three analytical themes. These were: *1) patients' experiences of remembering critical care; 2) discomfort and 3) returning to a life after critical care.*

2.3.11.1 Patients' experiences of remembering critical care

Within this theme four descriptive codes represented different aspects of recalling critical care. These are presented in Figure 2.11..

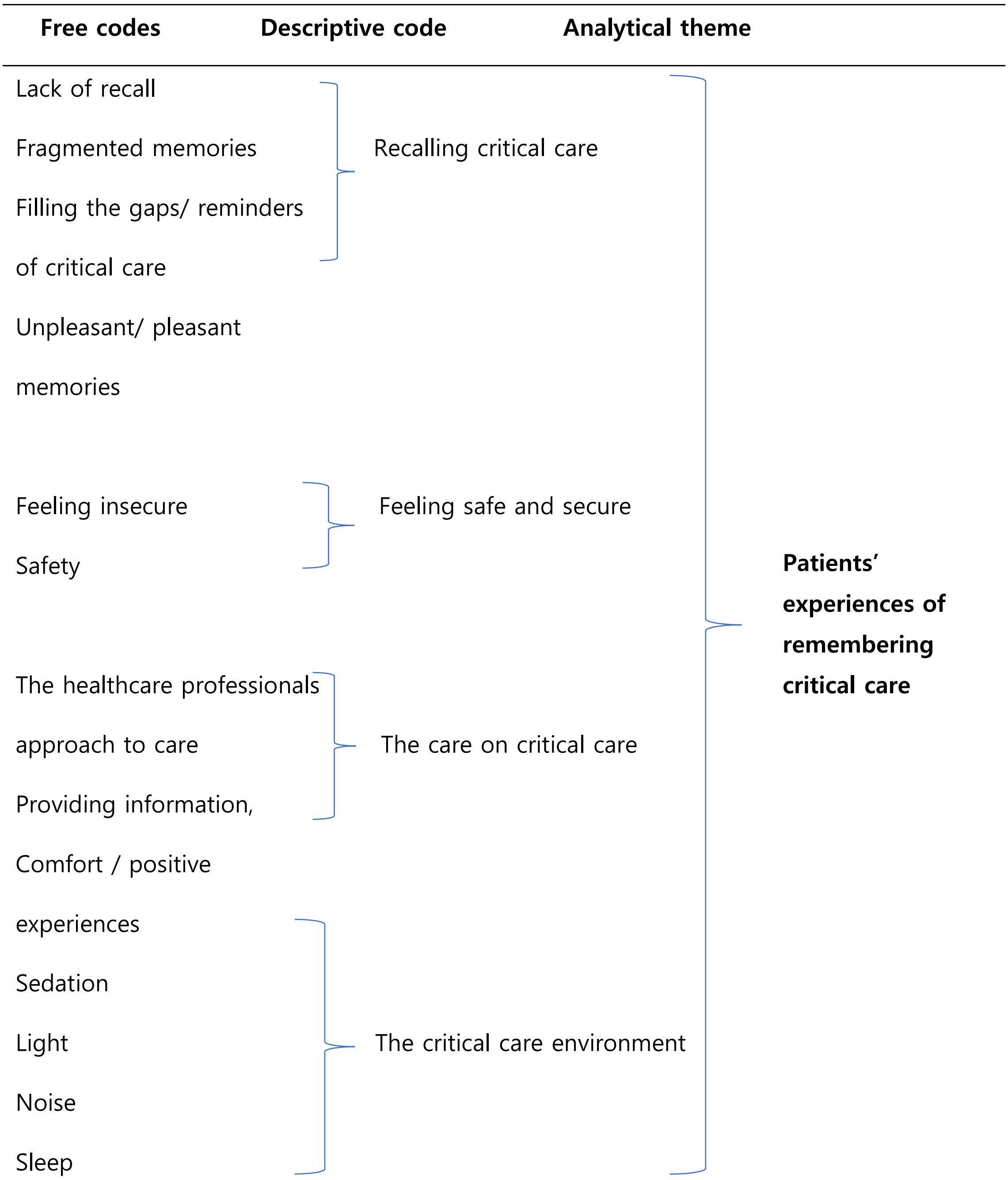


Figure 2.11. Analytical theme: patients' experiences of remembering critical care

Patients continued to report poor recall of critical care, relying on family members to fill in the gaps (Chahraoui et al. 2015; Magarey and McCutcheon 2005; Talisayon et al. 2011). However, between four and nine of participants from a sample of 20 remembered feeling anxiety, thirst, pain, insomnia, fear, feeling abandoned and not understanding why they were in critical care (Chahraoui et al. 2015). They also reported feeling that death was imminent (Chahraoui et al. 2015; Magarey and

McCutcheon 2005). Others remembered a bustling critical care environment, full of equipment (Merilainen et al.2013) and felt safe if they could hear nurses' voices (Johansson et al. 2012). Others reported that even with people in the room they felt inhuman, alone and unsafe, perceiving them to be passive by-standers (Haugdahl et al. 2017). Others recognised that whilst the nurses' expertise was important, it was their compassionate care which provided security and reduced their fear (Hofhuis et al. 2008). If nurses appeared angry, patients reported being unconfident and frightened to request help (Hofhuis et al. 2008).

Patients reported memories of disturbed sleep from alarms, pumps and ventilators (Engwall et al. 2015; Johansson et al.2012). They recalled drifting in and out of consciousness whilst sedated (Magarey and McCutcheon, 2005). Others reported feeling happier in a room where natural light helped them distinguish between day and night (Engwall et al. 2015).

2.3.11.2 Patients' experiences of discomfort

Within this theme four descriptive codes represented different aspects of patients' experiences of discomfort. These are presented in Figure 2.12.

Patients reported physical discomfort in relation to pain, breathlessness and withdrawal from tobacco or caffeine (Fink et al. 2015; Guttormson et al. 2015; Haugdahl et al. 2017; Magarey and McCutcheon, 2005; Merilainen et al. 2013; Prime et al. 2016). They recalled that nurses who took time to communicate helped reduce such discomfort (Hofhuis et al. 2008). Therapeutic touch was also seen to provide comfort and hope for patients receiving critical care (Henricson, et al. 2009).

Free codes	**Descriptive code**	**Analytical theme**
Pain Dyspnoea Exhaustion	Experiencing physical discomfort on the CCU	**Patients’ experiences of discomfort**
Death Fear Frustration Loneliness Feeling trapped	Experiencing psychological distress on the CCU	
Feeling unsafe Frustration at not being able to communicate Communication aids Feeling helpless	Experiences with communication	
Dreams Nightmares Hallucinations	Surreal experiences	

Figure 2.12. Analytical theme: patients’ experiences of discomfort

Patients described psychological distress from feeling anxious as they stood on the threshold between life and death (Fink et al. 2015; Haugdahl et al. 2017). They recalled feeling lonely, bored and trapped in a worthless body (Haugdahl et al. 2017; Prime et al. 2016). Patients reported barriers to communication such as increased levels of sedation which interfered with their ability to interpret information, and respiratory support contributed to this distress (Fink et al. 2015; Guttormson et al. 2015; Haugdahl et al. 2017; Magarey and McCutcheon 2005; Magnus and Turkington 2006; Merilainen et al. 2013; Patak et al. 2006; Prime et al. 2016).

Seven out of eight patients reported receiving no advice on communication in critical care (Magnus and Turkington 2006). Others remembered that attempts to help them communicate included alphabet boards, pictures, writing, non-verbal gestures, help from family and continuity of staff (Guttormson et al. 2015; Hofhuis et al. 2008; Magnus and Turkington 2006; Patak et al. 2006; Prime et al. 2016). Patients reported if effective, these strategies to support their communication relieved stress (Hofhuis et al. 2008; Prime et al. 2016) but caused frustration if they were not (Guttormson et al. 2015).

As patients drifted in and out of consciousness they recalled surreal experiences as they moved from reality to unreality (Fink et al. 2015; Johansson et al. 2012; Magarey and McCutcheon, 2005). One patient remembered the sounds of the CCU infiltrating her dreams (Johansson et al. 2012). Others reported seemingly real, scary and distressing hallucinations which related to death (Haugdahl et al. 2017; Guttormson 2014; Hofhuis et al. 2008; Magarey and McCutcheon 2005).As they participated in interviews for research, some participants reported relief at sharing their dreams with their interviewer (Guttormson 2014), whilst others found them difficult to discuss (Haugdahl et al. 2017). They reported a need to be supported to connect with reality and to process their memories to understand their experiences (Guttormson, 2014).

2.3.11.3 Patients' experiences of returning to a life after critical care

Within this theme two descriptive codes represented different aspects of patients' experiences of returning to life after critical care. These are presented in Figure 2.13.

Free codes	Descriptive code	Analytical theme
Getting better Life at home Surviving critical care	Getting on with life	**Patients' experiences of returning to a life after critical care**
PTSD Depression	Psychosocial experiences of life	

Figure 2.13. Analytical theme: patients' experiences of returning to a life after critical care

Some patients reported the joy of surviving critical care (Haugdahl et al. 2017). Others described how their coping strategies helped them adopt a positive outlook on life, accept what had happened and helped them move on with some even returning to work (Chahraoui et al. 2015; Talisayon et al. 2011). However, those less able to cope reported psychological and social issues which were related to social and behavioural factors influencing individuals' thoughts, mind and behaviour (Oxford English Dictionary, 2018). For some patients their psychological and social experiences of critical care related to feelings of anxiety and depression, which resulted in social withdrawal once they were back home (Chahraoui et al. 2015; Talisayon et al. 2011). In contrast though, some reported that the experience had strengthened their relationships, whilst others seized the opportunity to re-evaluate these and some fragile relationships did not survive (Talisayon et al. 2011).

In the study by Talisayon et al.(2011), 37% of 97 patients were reported to have PTSD following their discharge home, with another study reporting patients having flashbacks to their time in critical care, with unpleasant memories, recurring nightmares and difficulty sleeping (Chahraoui et al. 2015). Whilst PTSD was associated with a higher HADS score (Chahraoui, et al. 2015), Talisayon et al.'s (2011) findings could not determine a particular profile for those at risk of developing PTSD.

2.3.12 Thematic synthesis of the quantitative papers

The thematic synthesis of the quantitative research resulted in identification of three analytical themes. These were: *1) patients experiences of remembering critical care; 2) psychological distress of critical care and 3) life after critical care.*

2.3.12.1 Patients' experiences of remembering critical care

Within this theme three descriptive codes represented different aspects of patients' experiences of remembering critical care. These are presented in Figure 2.14.

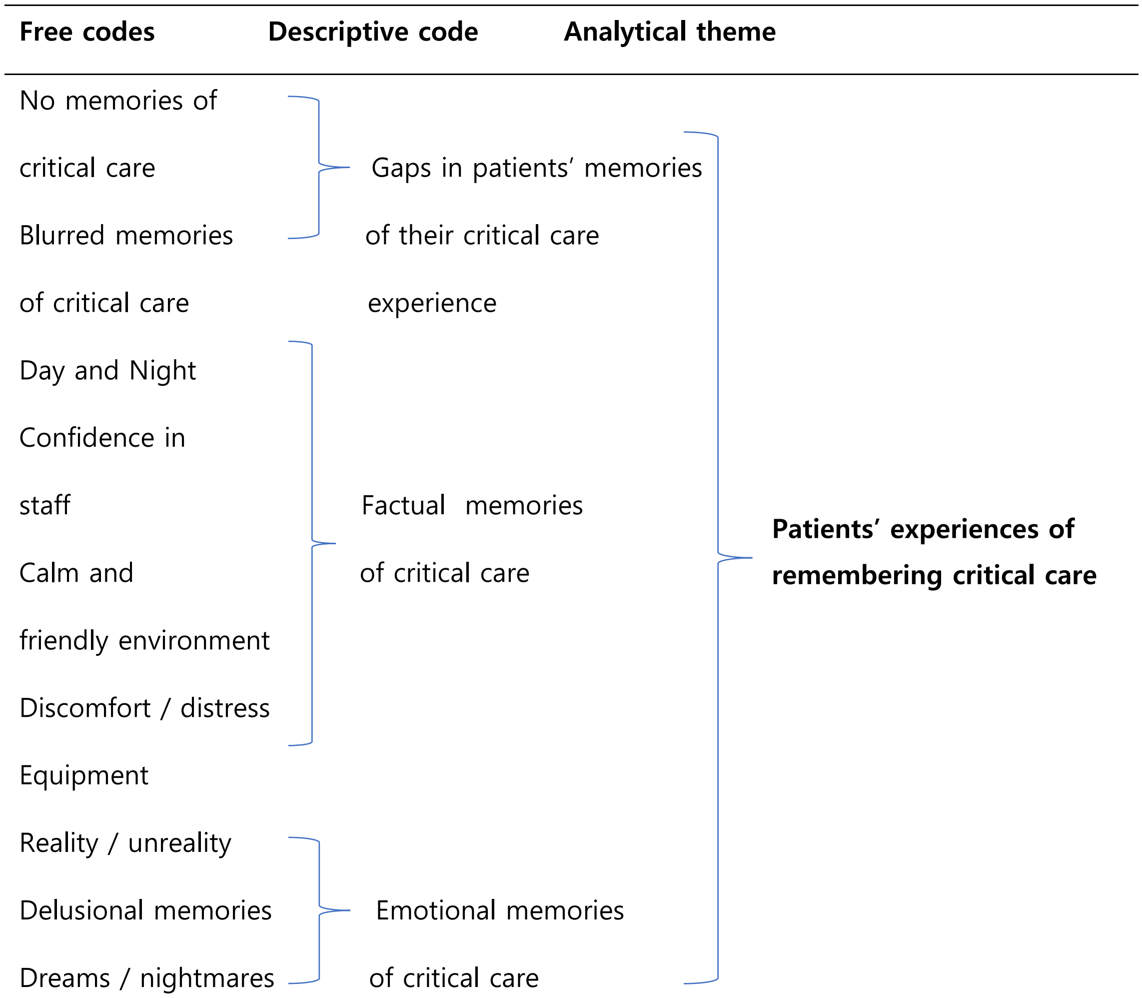


Figure 2.14 Analytical theme: patients' recall of their critical care experience

Patients reported a poor recall of critical care (Jones et al. 2007; Samuelson et al. 2006; Samuelson et al. 2007; Schandl et al. 2011; Jeitziner et al. 2015), which was reported to reduce HRQoL post critical care (Granja et al. 2005). Those patients less likely to remember being in critical care had the characteristics of being retired, sicker on admission, had an increased length of stay and received more sedation (Capuzzo et al. 2001; Elliott et al. 2013; Granja et al. 2005; Rundshagen et al. 2001; Samuelson et al. 2006; Samuelson et al. 2007).

Few patients remembered CCU to be a calm and safe place (Granja et al. 2005). More remembered the discomfort of the ETT, pain, bleeding, dyspnoea, thirst, the inability to speak, other patients, hallucinations and care (Alasad et al. 2015; Capuzzo et al. 2001; Dziadzko et al. 2017; Elliott et al. 2016; Rotondi et al. 2007; Rundshagen et al. 2001; Samuelson et al. 2007; van de Leur 2004). Such discomfort affected their sleep which in turn was seen to affect their psychological recovery (McKinley et al. 2012; Rotondi et al. 2007). One paper reported that a tracheostomy did not reduce discomfort (Breckenridge et al. 2014).

Emotional memories of CCU focused on nightmares and hallucinations with patients reporting difficulty distinguishing reality (Elliott et al. 2016; Granja et al. 2005; Rundshagen et al. 2001; Samuelson et al. 2007). Contributory factors were: length of stay, severity of illness on admission; an increased HADS score; female; older; sedation and corticosteroids (Capuzzo et al. 2001; Elliott et al. 2016; Granja et al. 2005; Rundshagen et al. 2001; Samuelson et al. 2006).

2.3.12.2 Patients' experiences of the psychological distress of critical care

Three descriptive codes were identified from the findings reported by the quantitative studies which described the different aspects of the patients' experiences of critical care. These are presented in Figure 2.15.

Free codes	Descriptive codes	Analytical theme
Anger Anxiety Fear Pain Stress	Emotions experienced on the CCU	**Patients’ experiences of the psychological distress of critical care**
PTSD Depression	Longer lasting emotional experiences of a CCU stay	
Critical care follow-up Family	Experiencing emotional support during critical care	

Figure 2.15 Analytical theme: patients’ experiences of the psychological distress of critical care

Anxiety, pain, stress and frustration at not being able to speak were found to be causes of psychological distress on CCUs (Castillo et al. 2016; Fleischer et al. 2014; Jeitziner et al. 2015; Granja et al. 2005; Hweidi 2007; Jones et al. 2007 Khalaila et al. 2011; McKinley et al. 2012; Rotondi et al. 2007). Fear of death, complications, pain and suffocating were reported as other contributory factors (Castillo et al. 2016; Dziadzko et al. 2017; Pang and Suen, 2007), whilst those anxious by nature –referred to as trait anxiety (Castillo et al. 2016) or with a previous psychiatric history were particularly susceptible to anxiety on CCU – state anxiety (Castillo et al. 2016; McKinley et al. 2012; Paparrigopoulos et al. 2014). Smoking, length of CCU stay and sedation were also reported as contributory factors (Castillo et al. 2016). Castillo et al. (2016)

could find no relationship between gender and state anxiety, in contrast McKinley et al. (2012) identified those to be at greatest risk of a reduced psychological recovery following critical care were younger females with stress and sleep issues (McKinley et al. 2012). What both studies demonstrate is that having identified such predisposing and contributory factors, it is possible to develop an increased sensitivity of those at greater risk from state anxiety whilst on the CCU and as such interventions can be undertaken to minimise the incidence of state anxiety whilst patients are receiving critical care (Castillo et al. 2016; McKinley et al. 2012).

As patients were moved from CCU to the ward 48% of a sample of 100 patients reported transfer anxiety (Brodsky-Israeli and Ganz 2011) which could last from the time patients were informed of the move, four hours following the move and then one night after the move (Gustad et al. 2008). As with the state anxiety findings from McKinley et al. (2012), females were once again reported to be most susceptible to anxiety at this point demonstrating statistically significant higher anxiety scores than men (Brodsky-Israeli and Ganz 2011). A transfer at night also raised anxiety with seven out of a sample of 11 participants (64%) reporting transfer anxiety at this time (McCairn and Jones, 2013).

The reported levels of pain in patients receiving critical care ranged between 40% and 77% of patients (Capuzzo et al. 2001; Castillo et al. 2016; Darawad et al. 2015; Elliott et al. 2013; Hweidi, 2007; Li and Puntillo 2006; Jeitziner et al. 2015; Jones et al. 2007). However, reports of memories of pain on CCU were inconsistent, with some recalling the pain at three months post CCU and others not (Jones et al. 2007). Six to 12 months post CCU, among older patients who had received an information programme whilst on the CCU, reports of pain were low, however this research only included patients aged 65 years of age or over (Jeitziner et al. 2015).

Out of a sample of 222 former critical care patients, 13% reported PTSD symptoms at 6 months post ICU discharge (Elliott et al. 2016). Similarly, out of a sample of 120 former critical care patients, 15% reported experiencing PTSD up to one year post CCU discharge, (Davydow et al. 2013). Out of these, 71% attributed this to memories of CCU (Davydow et al. 2013) including frightening experiences of CCU, pain and insomnia which raise stress levels. It was also found that such memories also contributed to depression (Elliott et al. 2016; Jones et al. 2007). Younger patients, in receipt of disability benefit, with a reduced ward stay or experiences of fear and delusional memories after critical care, or those with a pre-existing psychiatric condition were reported to be at a greater risk of PTSD (Davydow et al. 2013; Elliott et al. 2016; Garcia Lizana 2003; Jonasdottir et al. 2018; Jones et al. 2007; Paparrigopoulos et al. 2014; Samuelson 2007).

Current research demonstrates there is little evidence that a structured nurse-led critical care follow-up actually improves PTSD rates following a critical care stay (Jonasdottir et al. 2018; Schandl et al. 2011). However, one study of 61 former critical care patients with no previous psychiatric history, found that critical care follow-up is valuable at identifying PTSD and enabling referral to specialist services (Schandl et al. 2011). In contrast, one study undertaken in one North American CCU compared the outcomes of a group of 18 participants who received a daily sedation interruption (DSI) with 14 participants who did not (Kress et al. 2003). This study reported that none of the participants who had received a DSI experienced PTSD in contrast to 4 of those who had not received a DSI. (Kress et al. 2003).

A study of 198 former critical care patients in Scandinavia demonstrated no difference in length of CCU stay nor morbidity rates between those who received visitors and those who did not (Eriksson and Bergbom, 2007). However, one study from two American CCUs explored through a structured interview, 50 patients' experiences of acute psychological trauma (Dziadzko et al.2017). Forty-three participants reported that family presence reduced the fear and hallucinations they experienced as well as helping them to communicate whilst they were on CCU (Dziadzko et al.2017). A further study from Norway of six participants identified that the presence of their family was positive as it provided affirmation, however it was also a negative experience as the patients'' developed concern for their family member (Fredriksen and Svensson, 2010).

Whilst the presence of healthcare professionals also provided reassurance (Dziadzko et al.2017), a randomised controlled trial across three CCUs in Germany on 211 partipcants examined the effect of a structured information programme on CCU on patients' anxiety rates amongst those receiving critical care (Fleischer et al. 2014). This study reported no demonstratable benefit of this for the 104 participants who received the information programme in contrast to the 107 who received unstructured communication (Fleischer et al. 2014).

2.3.12.3 Patients' experiences of a life after critical care

Two descriptive codes were identified from the findings reported by the quantitative research which identify the different aspects of the patients' experiences of life after critical care. These are presented in Figure 2.16.

A prospective study across 10 Portuguese CCUs studying 464 participants reported by Granja et al. (2005), found 57% reported fatigue and 40% reported sleep disturbances that persisted at six months following a critical care stay. Furthermore, 14% of patients with nightmares on CCU continued to experience these at home and reported difficulty concentrating and remembering (Granja et al. 2005). This study also found that participants who remembered their critical care stay (62% of the sample) reported an improved quality of life and were more independent once back home, in comparison to those who had no recollection of their stay (Granja et al. 2005).

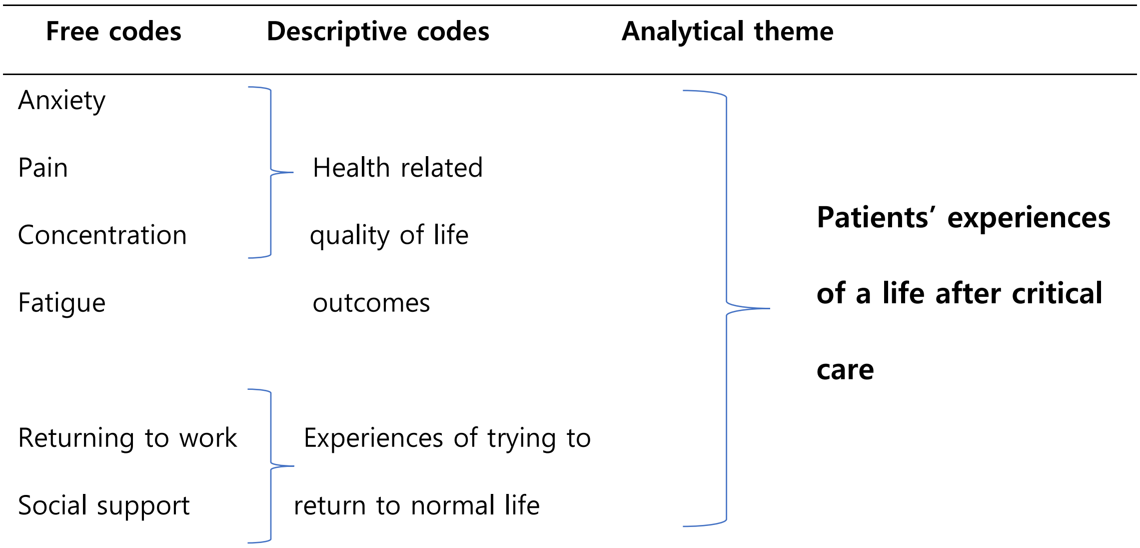


Figure 2.16 Analytical theme: patients' experiences of life after critical care

Another prospective observational study examined long-term outcomes in 96 critical care patients and found they reported issues relating to poor mobility (23%), reduced autonomy (16%) and loss of ability to care for themselves (25%) (Garcia Lizana et al. 2003). Pain (44%) and anxiety –/– depression (30%) were also reported (Garcia Lizana et al. 2003). By 18 months post-discharge, whilst 28% of patients reported they had returned to work, 54% reported they had failed to return to their previous level of activity (Granja et al. 2005). A further prospective, longitudinal observational study in one CCU examined the change in quality of life at one year and six years following a critical care stay (Kaarlola et al. 2003) for 169 participants. This found at six years post-discharge, 15 participants were still reporting pain and an HRQoL worse than that prior to critical care (Kaarlola et al. 2003).A cross sectional survey on 88 former critical care patients, surveyed the influence of social support on individuals' quality of life following a CCU stay on a 35 bedded CCU in the Netherlands. They found 70 participants preferred to receive social support from family members to help them return to a normal life in contrast to friends, healthcare professionals or fellow CCU patients (Tilburgs et al. 2015).

Finally, a quasi-experimental study which compared the effect of a nurse-led follow-up clinic on patients' psychological recovery with 'usual' after-care (however they did not explain what the 'usual care' involved), found no evidence that the clinics improved patients' psychological recovery following a critical care stay (Jonasdottir et al. 2018). Another descriptive study also found that these clinics did not improve psychological recovery *per-se* but identified that such clinics are effective at identifying underlying physical and psychological problems in patients enabling them to be referred for specialist support (Schandl et al. 2011). A study on 96 former critical care patients found many enjoyed the opportunity to attend a nurse-led follow-up clinic. However others reported being unable to attend because they were physically too weak to travel (Glimelius et al. 2011). This study concluded for follow-up to be effective, it needed to be adjusted to the individual needs of the patient. (Glimelius et al. 2011). To complement these findings, a randomised controlled trial on 126 participants in the UK into the effectiveness of a self-help rehabilitation manual found this to be helpful (Jones et al. 2003). However for those experiencing greater psychological distress following critical care, additional psychological care alongside the manual maybe beneficial (Jones et al. 2003).

2.3.13 Comparison of findings between the qualitative, quantitative and MMR papers

The findings of these three types of research designs were examined for convergence and divergence (Tashakkori and Teddlie, 2003). Four analytical themes relating to convergence and divergence of the findings are presented in Table 2.7.

Studies from all three types of design reported that patients had difficulty recalling their critical care experience. The quantitative papers focused on the causes for this memory loss such as the level of sedation (Samuelson et al. 2007) and used the ICUM to measure patients' recall of critical care. In contrast, the qualitative papers focused on the experience these memory gaps had on patients. This difference in focus is unsurprising because qualitative research inductively explores rich and deep understanding of experiences whilst quantitative research deductively measures the relationship between variables (Bowling, 2014).

Patients' fear of death and dying was identified across all types of studies. Anxiety exacerbated by environmental stressors was also reported by all three types of design (Capuzzo et al. 2001; Granja et al. 2005; Haugdahl et al. 2017; Heidi 2007; Khalaila et al. 2011; Rotondi et al. 2007; Rundshagen et al. 2001; Samuelson et al. 2006; van de Leur 2004).

With the ICU Environmental Stressor Questionnaire (ICUESQ) some quantitative studies rated the influence of stressors on patients' experiences (Cornock, 1998). This tool demonstrated that in all but one paper, the ETT was the most significant stressor for critical care patients (Granja et al. 2005; Hweidi 2007; Khalaila et al. 2011) with pain reported as the most significant stressor by Soh et al. (2008). The MMR papers considered strategies to manage anxiety and discussed the benefits of effective communication by nurses (Hofhuis et al. 2008).

Both the qualitative and MMR papers presented findings on patients' experiences of care (Lykkegaard and Delmar 2015; Moen and Naden 2015). Experiences of care were not scrutinised by the quantitative research studies, which focused more on measurable causes and outcomes.

In relation to safety, the qualitative papers reported extensively that patients felt safe on CCU due to the one-to-one care received (Adamson et al. 2004; Almerud et al. 2007; Engstrom et al. 2013; Erikson et al. 2010; Locsin and Kongsuwan 2013; Löf et al. 2008; McKinley et al. 2002).One MMR reported on how communication affected patient safety (Guttormson et al. 2015). In contrast, no quantitative studies reported on feelings of safety whilst on CCU.

The qualitative studies reported extensively on the powerlessness patients experienced in CCU and how this led to feelings of psychological discomfort (Almerud et al. 2007; Ballard et al. 2006; Eriksson et al. 2010; Karlsson et al. 2012; Löf et al. 2008; Lykkegaard and Delmar2013; Wang et al. 2008). The quantitative papers did not investigate nor report on powerlessness, whilst some MMR studies reported that managing communication was found to be a contributing factor to patients' feelings of powerlessness (Guttormson et al. 2015; Hofhuis et al. 2008; Magnus and Turkington 2006; Patak et al. 2006; Prime et al. 2016).

Table 2.7 The comparison of findings from the qualitative, quantitative and MMR research.

Descriptive Code	Qualitative	MMR	Quantitative
	Experiences of remembering critical care		
Gaps in memories	x	x	x
Factual / emotional memories	x	x	x
The care provision	x	x	x
Feeling safe and secure	x	x	x
	Experiences of discomfort		
The critical care environment	x	x	
The technology	x	x	
Sleep, light and noise	x	x	x
Difficulties speaking and communicating	x	x	x
Presence of the ETT	x	x	x
Feeling powerless a6nd vulnerable	x		
Dreams/ nightmares and hallucinations	x	x	x
Transitional care to the wards	x	x	x
Psychological and social HRQoL outcomes		x	x
	Experiences of hope		
The will to live	x		
The importance of family	x	x	
	Experiences of returning to a life after critical care		
Social support	x	x	
Critical care follow-up	x	x	x

Through measurement tools such as the ICUESQ, IES and HADS, the quantitative studies were able to identify trends and develop profiles of individuals who were more susceptible to stress (Hweidi, 2007). In contrast, the qualitative studies focused on the lived experience of stress (Auriemma et al. 2015; Herbland et al. 2017; Olausson et al. 2013; Ringdal et al. 2008; Samuelson 2011).

All three types of studies explored the influence of sleep deprivation on the patients' experience. The qualitative studies identified the contributing factors of poor sleep, whilst the quantitative studies measured the quality of sleep on CCU (Frisk and Nordstrom, 2003). The MMR papers reported the influence of sleep deprivation on the development of psychological outcomes such as PTSD (Chahraoui et al. 2015; Talisayon et al. 2011).

All forms of studies reported that patients struggled to differentiate between real and unreal events because of dreams and hallucinations and that this had long-term consequences for the patients. (Adamson et al. 2004; Ballard et al. 2006; Carryer and Minton 2005; Claesson et al. 2005; Engstrom et al. 2008; Fink et al. 2015; Guttormson, 2014; Johansson et al. 2012; Karlsson and Forsberg 2008; Karlsson et al. 2012; Locsin and Kongsuwan2013; Löf et al. 2006; Maddox et al. 2001; Magarey and McCutcheon 2005; Olausson et al. 2013; Olsen et al. 2017; Ringdal et al. 2006; Samuelson 2011; Tembo et al. 2013).

The qualitative and MMR studies identified that patients' will to live motivated them to get better and the important role of the family in supporting this motivation (Haugdahl et al. 2017; Locsin and Kongsuwan, 2013). Again because they focused more on the measurable outcomes of critical care, the quantitative studies did not explore the will to live.

The qualitative research studies reported how the patients felt abandoned once they had been discharged to the ward (Chaboyer et al. 2005; Field et al. 2008; Odell 2000). Just one quantitative study measured anxiety throughout the transition in care (Brodsky-Israeli and DeKeyser Ganz, 2010) whilst no MMR paper approached this area of investigation.

Finally, both the quantitative and MMR studies investigated the HRQoL outcomes following a stay in critical care reporting on the prevalence of PTSD (Chahraoui et al. 2015; Davydow et al. 2013; Elliott et al. 2016; Talisayon et al. 2011). The qualitative research did not focus on the prevalence of specific HRQoL outcomes; however one study did discuss how experiences within critical care may contribute to the emergence of PTSD at home (Samuelson et al. 2007).

The qualitative papers highlighted the importance of the family to the patients' experience of critical care (Bergbom and Askwall 2000; Wong and Arthur 2000; Zeilani and Seymour 2010) and how family members helped to care for them once home (Maddox et al. 2001; Ringdal et al. 2008). The quantitative research reported that the presence of family members on CCU was a positive experience which helped patients' recovery (Dziadzko et al.2017). There was also consensus from the MMR that their' families gave the patients a sense of will to survive (Haugdahl et al. 2017).

Just one quantitative study reported on the types of social support patients experience following critical care stating it to be either instrumental, informative or emotional support (Tilburgs et al. 2015). Two qualitative studies identified the types of support the patients required once they had been discharged into the community including the role of community services and follow-up (Maddox et al. 2001; Prinjha et al. 2009).

Studies of all designs investigated the impact of critical care follow-up clinics. The qualitative papers reported on patients' experiences of the different models of critical care follow-up (Deacon 2012; Haraldsson et al. 2015; Löf et al. 2008; Maddox et al. 2001; Ramsay et al. 2013). In contrast, one quantitative study reported that critical care follow-up has no influence over HRQoL outcomes (Jonasdottir et al. 2018), whist another found they facilitate early referral to specialist services when required (Schandl et al. 2011). The MMR did not examine critical care follow-up services.

2.3.14 Summary of the thematic synthesis

In line with the thematic synthesis method (Thomas and Harden, 2008) described in section 2.2.7, four analytical themes relating to patients' experiences of critical care as reported in primary, peer-reviewed research papers were identified. These are presented in Figure 2.17.

Studies of all three types of research designs reported on issues patients had recalling their CCU stay, which was exacerbated by difficulties differentiating between real and unreal experiences. Studies from all the designs reported on patients' experiences of physical and psychological discomfort associated with critical care. The longer lasting experiences associated with a critical care stay were also explored across the designs. Whilst the qualitative papers adopted methods which focused on patients' experience and motivations to recover, the quantitative papers identified trends for those at risk of psychological distress following their CCU stay.

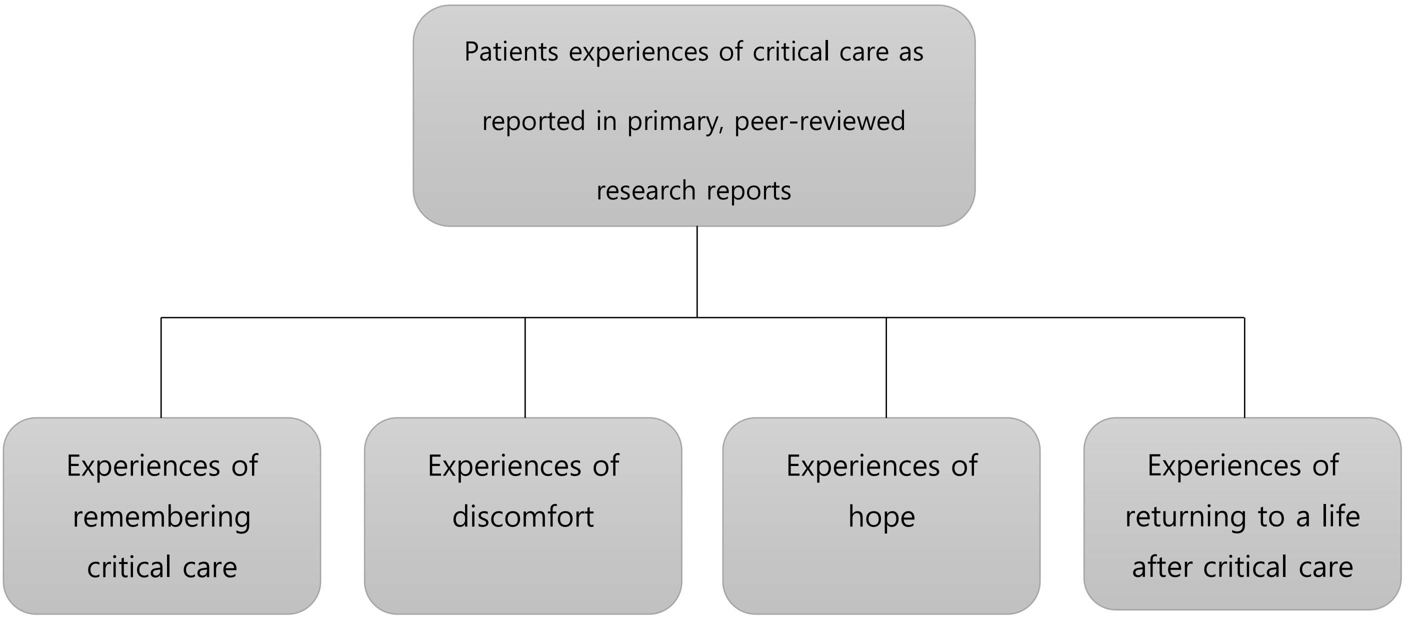


Figure 2.17 Analytical themes relating to patients' experiences of critical care as reported in primary, peer-reviewed research reports

2.4 Discussion

This MSR addressed the question, what are former critical care patients' experiences of critical care as demonstrated through the primary published research? The principal findings from this MSR are detailed below:

- There has been extensive research on a variety of aspects of patients' experiences of critical care using a range of research designs, but this has largely focused on the CCU stay in isolation from the longer-term experiences of people who have been critically ill.
- Research has taken place into patients' memories of critical care; however these relate to specific aspects of critical care in isolation and focus on factual or delusional memories of critical care. There are no identifiable research studies into patients' reconstructive memories of critical care and the implications of these for patients and subsequent nursing practice.
- The research into patients' memories of critical care report that they demonstrate a poor recall of their CCU stay.
- A contributory factor for this is that patients have a mixture of factual and delusional memories of their time on the CCU. The delusional memories are where memories of real events merge with those of unreal events in the form of hallucinations and dreams.
- These memories mean that patients have difficulty making sense of their CCU stay because they cannot differentiate between aspects that were real and unreal.
- Those patients who do remember their critical care stay have better HRQoL outcomes in contrast to those who do not remember the experience.

- The presence of the ETT is reported to be a significant stressor. However, the key issues patients reported in relation to this tube differs across research approaches. The qualitative studies reported that patients felt marginalised and powerless by the presence of the tube. In contrast the quantitative studies focus on measurable experiences associated with the presence of the tube such as pain, breathlessness, thirst and a feeling of being choked.
- Patients perceived the technology as a necessary evil.
- There is limited evidence within the literature regarding the effectiveness of critical care follow-up. Two quantitative studies report that these clinics fail to improve HRQoL outcomes in relation to PTSD.
- The quantitative research focused on the causes of anxiety and reported that patients who are anxious prior to critical care are more likely to experience anxiety on the unit. These studies use tools such as the HADS and IES and also identified PTSD in some patients.
- The qualitative research reported that family members play a central role to patients' experience providing patients with a will to survive. Family members also provided social support on discharge home.
- The qualitative research reported findings on transitional care. On transfer from the CCU to the ward, many patients felt abandoned and being one amongst many patients. The quantitative research focused instead on measurable factors such as the best time for discharge.

2.4.1 Strengths and limitations of this review

The strength of this review is the systematic approach taken to searching, appraising and synthesising primary research with different research designs relating to patients' experiences of critical care across a variety of critical care settings and not just the CCU. Therefore, the review reflects the 'critical care without walls' ethos which underpins contemporary critical care practice within the UK. Due to the broad focus of this review, the recommendations are based on patients' entire critical care experience and not just that isolated to a CCU stay. This has highlighted the influence of patients' experiences at particular moments of their critical care stay and of significance is how this has continued (or not) after discharge from critical care as patients continue their recovery on the ward and then at home.

A potential limitation to this review is that it is difficult to disentangle patients' experiences of critical care with their experiences of critical illness. However, there are times when the papers clearly reported patients' experiences of critical care – for example, being conscious but being unable to speak because the patient is intubated and receiving ventilatory support. A further limitation is that approximately 10 papers were excluded as – specialist critical care settings were excluded from the review. However, this does make the findings of the review more generalisable to general adult critical care settings.

2.4.2 Comparison of findings with other reviews into patients' experiences of critical care

Over recent years there have been a limited number of reviews (six) exploring different aspects of patients' experiences of critical care. A meta-synthesis of patients' experiences of being mechanically ventilated found that patients experienced vulnerability, anxiety, fear and loneliness whilst receiving mechanical ventilation (Baumgarten and Poulson, 2014). Caruthers et al. are currently undertaking a meta-synthesis exploring the patient experience of mechanical ventilation; however this is yet to be published. A literature review by Cutler et al. (2013) examined the qualitative research on patients' experiences of critical care and reported broadly on experiences of the CCU stay and commented there was a paucity of research on patients' experiences outside the CCU. In contrast, through adopting an MSR design, this review has been able to include studies which reported patients' experiences of receiving critical care in a variety of settings using a variety of research designs.

Page (2014) published an integrative review of patients' experiences of the critical illness trajectory. The focus of this review was patients' experiences of critical illness rather than critical care and the impact this has on critical care survivorship. A key finding related to the difference in experiences of the nurses and the patients' family members during a period of critical illness. Consistent though with the findings of this current review, Page (2014) recommended that open visiting enabling more contact with family and friends would enhance patients' emotional well-being on CCU.

A meta-synthesis into patients' experiences of transitional care by Bench et al. (2010) reported physical and psychological problems for patients following discharge from CCU to the ward along with patients' desire to have greater control over their CCU discharge. They also reported patients' needs to feel safe and secure with this resulting in a dependence on healthcare professionals (Bench et al. 2010). As with Bench et al.'s (2010) findings, this current review identified the physical weakness and fatigue that patients experience as they move out of CCU. Whilst Bench et al. (2010) highlighted that critical care patients feel unimportant on the ward; this current review identifies more feelings of abandonment patients experience as 'one amongst many.'

One of the most contentious areas of critical care identified in this review was the effectiveness of critical care follow-up services. The PRaCTICAL study (Cuthbertson et al.2009) found there was no evidence that nurse-led follow-up clinics enhanced HRQoL outcomes. This study was not included in the review because it was investigating HRQoL outcomes in relation to a manual-based physical rehabilitation programme and was not investigating patients' experiences of critical care follow-up.

The findings from the PRaCTICAL study (Cuthbertson et al.2009) are consistent with the findings from this review in so much as there is currently no evidence that critical care follow-up enhanced HRQoL outcomes. However, it is important to note that whilst frequently cited within the literature, caution should be applied when generalising the PRaCTICAL study findings to all critical care follow-up services.

Finally, despite the fact that the MMR papers reported both quantitative and qualitative findings the quantitative findings were usually reported in isolation, generally through frequency statistics, followed by a narrative presenting the qualitative findings. At no point in these papers were the quantitative and qualitative findings integrated to demonstrate how they fit together which is considered a methodological limitation of these particular studies.

2.4.3 Recommendations for practice

Taken together, these review findings suggest that patients may benefit from changes to healthcare practice:

- Critical care practitioners should be aware that older patients who were sicker on admission and had an increased length of CCU stay are more susceptible to psychological distress on discharge home, as are those with a pre-disposition to depression or anxiety.
- The HADS tool provides a reliable measure for anxiety and depression in CCU and should be used to assess those patients who may be at risk of psychological distress. Measures can then be taken on CCU to help alleviate such distress.
- Critical care nurses should aim to promote pleasant memories of critical care for patients who are awake on the CCU, through providing information on care, effective communication and approachable body language.
- To reduce feelings of isolation due to difficulties with speaking, speech and language therapists should be encouraged to work more within CCU to facilitate patients' ability to use communication aids effectively whilst intubated.

- The importance of family members to critical care patients' emotional well-being cannot be underestimated. Critical care units should facilitate open visiting to facilitate patients' access to their family.
- Transfers from CCU to the ward should be planned carefully with prior preparation for patients and their families where possible and occur during the day.
- Critical care follow-up should be used to identify physical and psychological issues in former critical care patients thus facilitating a timely referral to specialist services.

2.4.4 Recommendations for future research

- The contribution of critical care follow-up services to patients' psychological recovery following a CCU stay remains unclear. As there is no evidence of a systematic review into critical care follow-up being registered on PROSPERO (checked 30th September 2018) an MSR is recommended into the effectiveness of critical care follow-up clinics on patients' psychological recovery following critical care.
- Future MMR into patients' experiences of critical care should report the integration of the quantitative and qualitative findings and how they fit together to provide a rich, deep and measurable analysis of patients' experiences of critical care.
- There is no identifiable research exploring patients' *reconstructive* memories of critical care. It would be helpful to address this gap and to explore this to help identify how patients reconstruct memories of their time in CCU and how this affects their ability to move on with their life.

2.5 Chapter conclusion

This MSR has explored patients' experiences of critical care as reported by primary, published peer-reviewed research. The findings identify the difficulties that patients experience in remembering critical care, which is exacerbated by the difficulty they have in differentiating between factual and delusional memories. Many patients reported physical and psychological distress throughout their critical care stay, with patients reporting difficulty moving on with their life after critical care because they are physically weak and socially isolated. There is currently no empirical evidence to show whether critical care follow-up services enhance HRQoL outcomes following critical care.

What this review does highlight is the gap in the evidence base regarding patients' reconstructive memories of receiving critical care and nurses' understanding of these and the implications of this for both patients and nursing practice. The review also highlights the need to integrate the findings from different research designs to provide a rich, deep and measurable analysis of patients' experiences of critical care.

The two recommendations made above are addressed in the following chapters which, drawing upon recommendations of Creswell and Plano Clark (2011), present an exploratory sequential qualitative study into former critical care patients' reconstructive memories of critical care and nurses' understanding and response to these. The following chapter presents the research design and methods for this study.

Chapter Three: research design and methods

This chapter discusses the rationale for adopting a qualitative research design to address the research questions presented in Chapter One (and reported below)*.* The rationale for using an exploratory sequential qualitative design, based upon the recommendations of Creswell and Plano Clark (2011), is presented. The qualitative research methods adopted – interviews and focus groups are explained. The Constant Comparative method of Analysis (CCA) used to analyse data from both the interviews and focus groups is described. The importance of memo keeping and reflexivity throughout the research process is also considered.

3.1 The rationale for adopting a qualitative design

Qualitative research is the naturalistic enquiry of individuals in their natural world, which focuses on the meaning's participants attach to their social world (Bowling, 2014). Through a qualitative design, researchers can explore how participants make sense of their social world and how they experience events (Neuman, 2011). This is pertinent for this research, as it explores how former critical care patients' reconstructive memories assist them to make sense of the world of critical care and the care they received there.

The purpose of a qualitative research design is to gain an understanding of a phenomenon from an individual's perspective as it enables them to describe and unravel their own experiences (Neuman, 2011). The research question also helps uncover a 'plurality of truths' (Fraser 2004, p.181) where different perspectives are sought regarding the same phenomenon (Fraser 2004; Moriarty 2010). Consequently, this research explored not only what former patients' reconstructive memories of receiving critical care are, but also what understanding of these memories the nurses who provide the care hold. This exploratory sequential qualitative design, with two different qualitative methods has enabled an exploration of the convergence and divergence between the two perspectives of patients and nurses.

Through exploring the processes which have contributed to different participants' experiences and by documenting their explanations of these, qualitative research helps to explain the causal relationship between interventions and events and the related outcomes (Moriarty, 2010). By empowering individuals to tell their story, the data generated through a qualitative design is detailed, extensive and information-rich (Moriarty, 2010). With the aim of exploring what is being studied from the individual's perspective and to apply the findings to the context of time and place under exploration, qualitative research requires significant time to collect and analyse data (Given, 2008). For this research, the event was the critical care stay and the outcome was the individual's reconstructive memories of this experience.

Qualitative research enables researchers to explore complex and sensitive issues by introducing a topic in a sensitive and personalised way (Neuman, 2011; Bowling 2014). Consequently, participants are more likely to 'open up' and be willing to explore their personal experiences (Neuman, 2011). To facilitate this, the effective communication skills and compassion presented in the Compassion in Practice policy (Cummings and Bennett, 2012) were drawn upon as data was collected from former critical care patients. These skills were pertinent here, as former critical care patients who often remain vulnerable and emotionally sensitive following a critical care stay (Jones and Lyon, 2003) were being asked to revisit potentially difficult and emotional reconstructive memories for them regarding the complex and personal nature of the care they received throughout their critical care stay. Thus, a qualitative design is useful as it provides the flexibility other designs do not which enables participants to tell their own story Neuman 2011; Bowling 2014).

A qualitative design helps to explore issues about which there is little pre-existing knowledge (Bowling, 2014). As the MSR presented in chapter two demonstrated, there is a gap in the evidence base regarding patients' reconstructive memories of receiving critical care and nurses' understanding of these. Through an exploratory, sequential qualitative design, this research aimed to address this deficit.

3.1.1 The exploratory sequential qualitative design

This qualitative research adopted an exploratory sequential design with separate phases (Creswell and Plano Clark, 2011) which are presented in figure 3.1. The research involved a two-phase design in which qualitative data was collected and analysed in the first phase (Creswell and Plano Clark, 2011) to answer the first research question:

> *What are former critical care patients' reconstructive memories of critical care?*

This involved interviews with former critical care patients. A second phase was designed based on the findings from phase one and consisted of focus groups with critical care nurses. The second phase aimed to scrutinise and explore the implications of the findings from phase one (Creswell and Plano Clark, 2011) and to answer the second research question:

> *How do critical care nurses understand and respond to the patients' reconstructive memories of critical care?*

Finally, convergence and divergence between patients' reconstructive memories of receiving critical care and the understanding of these memories by the nurses who delivered the care was explored to answer research question three:

> *How do former critical care patients' reconstructive memories of receiving critical care converge with and diverge from critical care nurses' understanding of these?*

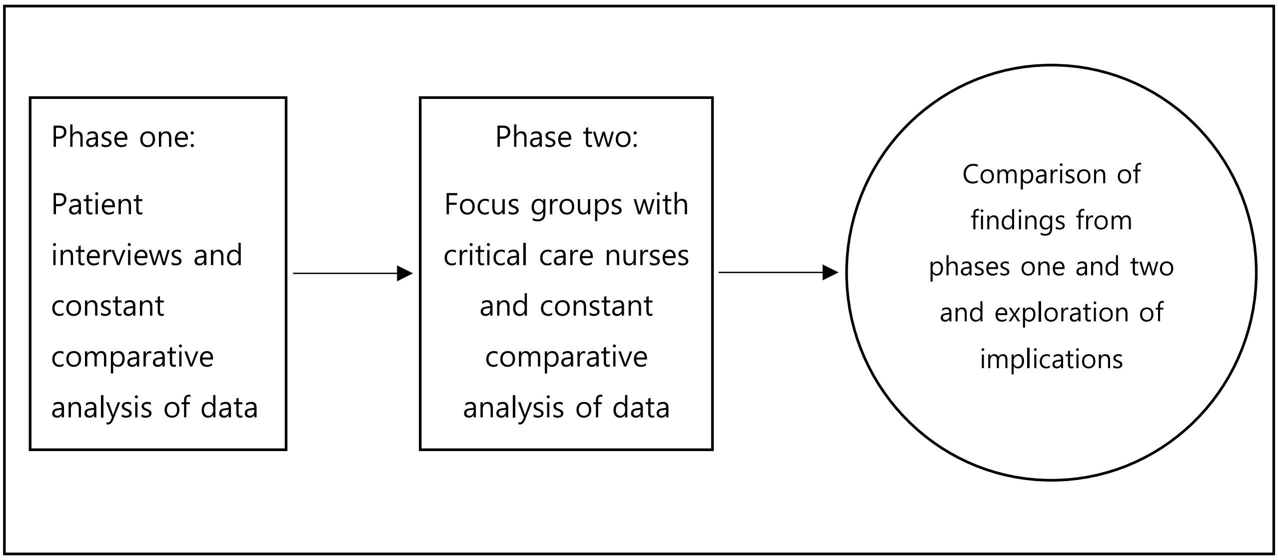


Figure 3.1 The exploratory sequential qualitative design (Creswell and Plano Clark, 2011)

For this type of mixed method qualitative design, sequential timing occurs when the collection and analysis of data from one phase and method follows the collection and analysis of data using a different method (Creswell and Plano Clark 2011; Morse 2017). For this research, this is abbreviated to QUAL→ qual (Morse, 2017). The first study is abbreviated to 'QUAL' (with capital letters) which not only denotes the qualitative nature of phase one – but identifies this as the core study and consequently the primary source of data (O'Byrne 2007; Morse 2017). In contrast the 'qual' represents the qualitative nature of phase two, referred to as the supplementary component which consists of a research strategy from a second qualitative method, using separate data, derived from a different method to phase one (O'Byrne 2007; Morse 2017). The arrow denotes the sequential timing (O'Byrne 2007; Morse 2017). Thus, the design reflected two interdependent phases with phase two based on findings from phase one (Creswell and Plano Clark, 2011). The findings from the patient interviews in phase one informed the topic guide and stimulus material for phase two, the focus groups with critical care nurses.

A further reason for adopting this sequential design relates to the rationale presented in chapter one section 1.2 with the desire to explore how critical care nurses hear the patient's voice and understand and respond to their recall of critical care. By interviewing former patients first, I explored their reconstructive memories of critical care. These findings were then used as a prompt for group discussion with the nurses during the focus groups. This design enabled an exploration of the similarities and differences in understanding of patients' reconstructive memories between former critical care patients and critical care nurses. This design was adopted to not only address the gap in the literature relating to critical care patients' reconstructive memories of their care and nurses understanding of these, but to also gain a deeper understanding of the complexity of patients' reconstructive memories of care through exploring these different perspectives and understandings (Given, 2008). The aim here was to provide a 'thick description' of the multifaceted complexities of patients' reconstructive memories and the nurses' understanding of and response to these (Given, 2008).

3.2 Methods

This section describes the two qualitative methods adopted for phases one and two: the interviews and focus groups.

3.2.1 The interview method

An interview is an interactional event, which can be conducted face-to-face or through a medium such as the telephone (Bowling, 2014), Skype™ (Oates, 2014) or email (Pattison et al. 2011). Interviews may be the only method of data collection in a study, or they can be used in combination with other methods, as is the case in this research.

Interviews are used to explore an individual's perspective of their world whilst uncovering the meanings people attribute to their own lived experiences (Kvale, 1996). Through interaction, interviews collect qualitative data which is used to construct knowledge which is both contextual and situated (Kvale, 1996). Such interaction can become a source of data itself (Edwards and Holland, 2013). Interviews are deemed to be an appropriate method when investigating new areas of study (Kvale, 1996). They can also be used to engage marginalised voices from groups in society who in other circumstances may not be given a voice (Braun and Clarke,2013).

There are different forms of interview according to the structure used: the main types being structured, semi-structured and unstructured (Bowling, 2014). The degree of structure is linked to both the depth of the response sought and the level of flexibility required to move between topics and questions within the interview topic guide. The interview topic guide is generated from the literature and early ideas (Morgan and Kruger, 1998). It moves from general to specific areas involving opening questions, transition questions, key questions and ending questions (Morgan and Kruger, 1998).

Phase one used semi-structured interviews. The rationale for the choice of this method was that it provided a structured yet flexible guide that allowed for spontaneous probing questions and sub-questions (Ritchie and Lewis, 2003) which engaged former critical care patients in a discussion focused on their perspective on their reconstructive memories of receiving critical care (Bowling, 2014). As a qualitative method, the interview is well suited to collecting data on sensitive topics (Elmir et al. 2011; Richards and Schwartz, 2002) and it was considered that this area of research could be sensitive for some of the participants, as they might be remembering experiences that were distressing at the time and also when discussing at a later time. A further rationale was that interviews are an appropriate method to gain insight into patients' reconstructive memories and this is pertinent for phase one of this research (Ziebland et al. 2004; Kinmouth 1995; Hewitt 2007). After phase one was complete, phase two was designed.

3.2.2 The focus group method

Focus groups are a widely used qualitative data collection method aimed at developing comprehensive knowledge concerning the attitudes, perceptions and opinions of individuals in a group context regarding a specific topic (Then et al. 2014). They involve a pre-arranged meeting of a group of individuals, selected and bought together by a researcher to discuss their collective personal experience of the research topic (Powell and Single, 1996) with the aim of generating new ideas and solutions through a focused discussion (Kitzinger 1994; Powell and Single 1996; Cronin 2016). As with interviews, focus groups can provide data which is augmented by the group dynamic, as when participants are drawn together to discuss a topic their contributions and understandings can be enhanced (Krueger and Casey 2000; Freeman 2006; Cousin 2009; Then et al. 2014). The group processes can help individual participants to explore and clarify their views and attitudes whilst also encouraging participation from those who feel they have less to contribute (Kitzinger 1995; Freeman 2006; Cronin 2016). The interaction within a focus group is viewed by some as *the* central analytical resource which should be considered during the data analysis stage (Kitzinger, 1994) and field notes relating to group dynamics and interactions are considered essential for this to occur (Then et al. 2014). In this research, the focus group was facilitated by a moderator who understood the topic under exploration. An assistant took notes whilst the moderator facilitated the flow and focus of the meeting (Morgan and Kruger 1998; Shaha et al. 2011; Then et al. 2014).

Focus groups can be used in a variety of scenarios, including researching group norms, meanings and processes (Bloor et al. 2001). Different experiences and attitudes within the group can also become evident and be discussed (Ritchie and Lewis, 2003). Such differences can be useful and are used to either strengthen the researcher's understanding or guides them to develop new ones, and it is this which enriches the findings of the study (Krueger and Casey 2000; Then et al. 2014). It is pertinent to the research presented here that focus groups can be used in combination with other methods to clarify, challenge or extend the findings from other methods (Then et al. 2014). The focus groups with critical care nurses were held following the analysis of the patient interview data. This was so that the focus groups could verify, clarify and extend the findings from the patients' data, thus enhancing the knowledge gained through this research (Krueger and Casey 2000; Creswell and Plano Clark 2011; Then et al. 2014).

The purpose of the sequential timing in running the focus groups after the patient interviews was to explore whether the nurses recognised and –/– or understood patients' reconstructive memories of their critical care. Extracts from the patients' data were used as stimulus material for the focus groups. This helped to identify possible differences regarding critical care nurses' perceptions and understanding of patients' reconstructive memories compared to those of patients. This identified the divergence and convergence between the nurses' understanding of the patients' actual reconstructive memories of receiving critical care. Having described the two methods used for this study, each phase of this sequential exploratory design will now be presented.

3.2.3 The constant comparative method of analysis

The data analysis for both methods was the constant comparative method (CCA). CCA was developed by Glaser and Strauss (1967) and involves a number of systematic stages to analysing qualitative data and which enables comparisons to be made at each stage of the analysis (Charmaz, 2014). Whilst historically synonymous with Grounded Theory, CCA is gaining popularity as a useful data analysis method of other qualitative approaches (Boeije 2002; O'Connor et al. 2008; Fram 2013; Charmaz 2014). A key strength of CCA is that it provides a rigorous method to analyse qualitative data and of particular significance to this research that it provides a framework to enable qualitative data to be systematically compared and contrasted within and across data sets (O'Connor et al. 2008).

The rationale for adopting CCA for this research drew on a number of reasons. Primarily, CCA systematically organises qualitative data through coding and analysing the data at the same time and identifies patterns within data sets which are then compared (Taylor and Bogdan, 1998). This was beneficial for this study as there were two data sets to be compared – the interviews with patients and focus groups with critical care nurses. Furthermore, this systematic method of analysis increased the internal validity of the findings by ensuring that no data were disregarded or overlooked thus adding to the richness and depth of the findings (O'Connor et al. 2008; Fram 2013). CCA also helped the PI to describe and conceptualise the diversity of data provided through comparison of data provided by former critical care patients and critical care nurses. As Boeije (2012) found, CCA enabled the PI to identify a variety of findings relating to the convergence and divergence in behaviour, attitudes, and understanding of the two groups. This systematic and in-depth approach to data analysis helped enhance the external validity and transferability of the findings to the wider adult critical care population (Charmaz, 2014). Consequently, the external validity enhanced the generalisability of the concepts and the relationships identified so that they could be applied to the wider critical care population (Boeije, 2002; Bickman and Rog 2008).

The CCA used for this research followed Boeije's (2002) and Frams' (2013) precedent of using CCA outside a grounded theory study. To assist the process of analysis, Charmaz's (2014) approach to coding data was adopted. The rationale for this was that Charmaz (2014) comes from a constructivist philosophical stance and reconstructive memories (Bartlett, 1932) are regarded as sitting within this philosophical position. Constructivism recognises that participants use cognition to engage with and understand their social world (Crotty, 1998). Constructivism is a transactional epistemology aimed at shaping a reconstructive understanding of the social world based upon social interaction with others and from personal history

(Crotty, 1998; Lincoln and Guber 2013). What individuals know of themselves, the world and the objects of that world are constructed through the systems of meanings and discourse that people experience (Lincoln and Guber, 2013).

The data from the interviews and the focus groups were each coded following Charmaz's (2014) two step coding approach: 1) initial coding and 2) focused coding. Categories were then identified through analysis of the focused codes. Data from both phases were coded chronologically starting with the first interview through to the last and similarly for the focus groups.

Once the CCA of the interviews and the focus groups were complete, the combined findings from both phases then underwent further CCA. Here I utilised a three-step CCA approach [adapted from a five-step approach by Boeije (2002)] for the exploratory sequential design which is explained below in section 3.2.3.1.

3.2.3.1 Step one: initial coding

For the initial coding of both the interview and the focus group transcripts I studied words, lines, segments or incidents from the data in-order to define what was happening and its analytic significance (Charmaz, 2014). During this step, the segments of data were labelled with a code which summarised and categorised them (Charmaz, 2014).

To move beyond the simple statements within the data and to take the analysis to a deeper level, I then developed an "interpretive rendering" (Charmaz, 2014 p.111). To do this, and to gain the depth of analysis and interpretation I desired, I asked analytical questions of the data which merged the subjective with the objective in order to understand the world under investigation; in this case patients' reconstructive memories of receiving critical care and the critical care nurses' understanding of what patients' experience and recall as a result of their care. I applied this "interpretive rendering" through considering what meaning I had gained from the coded data (Charmaz, 2014). Through this whole approach to analysis I followed Charmaz's (2014) code for coding as presented in Figure 3.2. An example of the initial coding can be seen in Figure 3.3 for the code 'nursing assessment'.

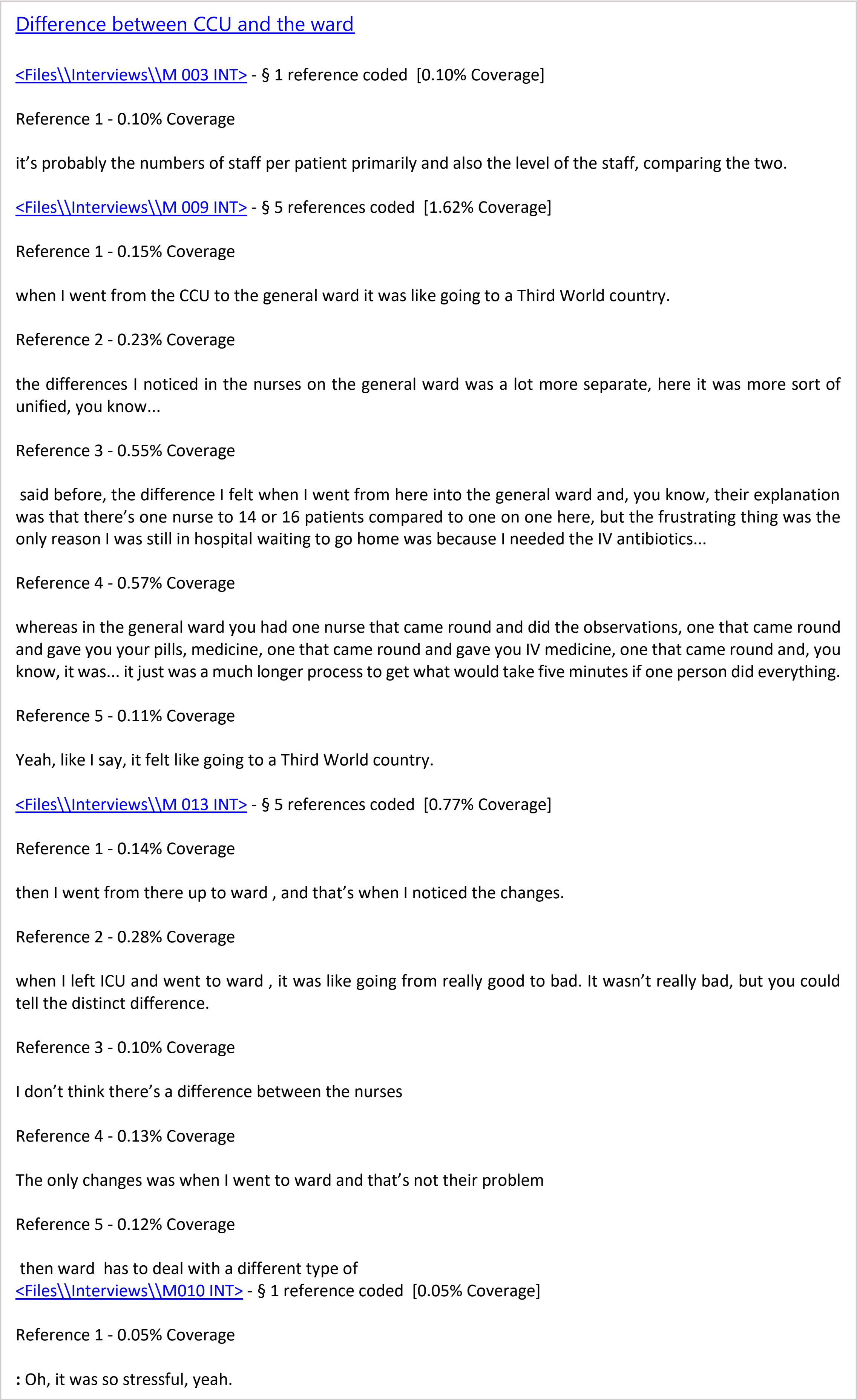
Remain open

Stay close to the data

Keep your code short and precise

Construct short codes

Figure 3.2 Coding framework (Charmaz, 2014)



Difference between CCU and the ward

<Files\\Interviews\\M 003 INT> - § 1 reference coded [0.10% Coverage]

Reference 1 - 0.10% Coverage

it's probably the numbers of staff per patient primarily and also the level of the staff, comparing the two.

<Files\\Interviews\\M 009 INT> - § 5 references coded [1.62% Coverage]

Reference 1 - 0.15% Coverage

when I went from the CCU to the general ward it was like going to a Third World country.

Reference 2 - 0.23% Coverage

the differences I noticed in the nurses on the general ward was a lot more separate, here it was more sort of unified, you know...

Reference 3 - 0.55% Coverage

said before, the difference I felt when I went from here into the general ward and, you know, their explanation was that there's one nurse to 14 or 16 patients compared to one on one here, but the frustrating thing was the only reason I was still in hospital waiting to go home was because I needed the IV antibiotics...

Reference 4 - 0.57% Coverage

whereas in the general ward you had one nurse that came round and did the observations, one that came round and gave you your pills, medicine, one that came round and gave you IV medicine, one that came round and, you know, it was... it just was a much longer process to get what would take five minutes if one person did everything.

Reference 5 - 0.11% Coverage

Yeah, like I say, it felt like going to a Third World country.

<Files\\Interviews\\M 013 INT> - § 5 references coded [0.77% Coverage]

Reference 1 - 0.14% Coverage

then I went from there up to ward , and that's when I noticed the changes.

Reference 2 - 0.28% Coverage

when I left ICU and went to ward , it was like going from really good to bad. It wasn't really bad, but you could tell the distinct difference.

Reference 3 - 0.10% Coverage

I don't think there's a difference between the nurses

Reference 4 - 0.13% Coverage

The only changes was when I went to ward and that's not their problem

Reference 5 - 0.12% Coverage

then ward has to deal with a different type of
<Files\\Interviews\\M010 INT> - § 1 reference coded [0.05% Coverage]

Reference 1 - 0.05% Coverage

: Oh, it was so stressful, yeah.

Figure 3.3: An example of initial coding for difference between CCU and the ward

3.2.3.2 Step 2: focused coding and categories

As previously explained, the coding and interpretation of data was conducted concurrently and as such there was an iterative transition from initial to focused coding. I had already begun to identify the most frequent and –/– or significant codes as well as codes that subsumed many initial codes. I had also begun to compare the codes within the interviews as I initially coded. Focused coding involved me studying, assessing and reassessing the initial codes (Charmaz, 2014). I had to consider what the codes said and what they implied and revealed (Charmaz, 2014). To help with this I asked several questions of the initial codes. These are presented in Figure 3.4.

What do I find when I compared the initial codes?

In which ways do the initial codes reveal patterns?

Which of the codes best account for the data?

Figure 3.4 Defining the focused codes (Charmaz, 2014)

The purpose of the focused coding was to identify categories. A category develops as certain codes are identified as having an overriding significance or can be developed into an analytical concept (Strauss and Corbin 1997; Charmaz 2014). The categories identified from this analysis are presented in detail in Chapters Four and Five.

Having identified the categories, I revisited the data and described the properties of each of the categories by comparing data with data of the same kind of experience the participants were reporting. Then I coded for the 'if, when, how and why' that participants reported. It was at this point that my analysis moved from the descriptive (as in the initial coding) to a more abstract and theoretical level. I used the map function on NVivo 11™ to help organise the data at this point. An example of this is presented in Appendix 3.6.

Through the focused coding, the direction of my analysis became apparent. I was able to identify the key categories for phase one – former critical care patients' reconstructive memories of receiving critical care. These were the categories which explained the memories of receiving care most clearly. They are presented in Chapter Five.

The categories from phase one provided the stimulus material and focus for phase two (focus groups with critical care nurses). The data from the focus groups then underwent the same CCA as during phase one and in the same chronological order as the focus groups had been conducted.

Having completed the CCA of both phases using Charmaz's (2014) method, I proceeded to undertake further CCA across the findings from both phases. This was to answer research question three:

> *How do former critical care patients' reconstructive memories of receiving critical care converge with and diverge from critical care nurses' understanding of these?*

To do this, I adapted Boeije's (2002) approach to CCA for an exploratory, sequential design. This is described in the following section.

3.2.3.3 The Constant Comparative Analysis of findings from phases one and two

The study by Boeije (2002) provided guidance as to how the analysis of phases one and two could be brought together; Boeije (2002) used CCA to analyse data from a sequential exploratory research study of patients' and spouses' lived experience of multiple sclerosis. Boeije (2002) used CCA sequentially to firstly compare data from the patients' interviews with each other, secondly to compare the data from the spouses' interviews with each other and then thirdly to compare and contrast the data from both the patient's and spouse's interviews with each other to identify the convergence and divergence between the two perspectives. Accordingly, I followed a three-step CCA approach (presented in Figure 3.5) adapted from Boeije's (2002) five-step method, to provide a systematic approach for the final stage of CCA between the patients' interviews and the nurses' focus groups necessary to answer research question three. I adapted Boeije's (2002) framework to three rather than five steps because the final two steps used by Boeije (2002) related to the CCA of data from husband and wife dyads and then overall between couples within his study which was not necessary for this research study.

1. Comparison within a single interview
2. Comparison between interviews within the same group
3. Comparison of data from different groups

Figure 3.5 The three-step analysis CCA method adapted from Boeije (2002).

Step one involved comparison within a single interview. This was the initial and focused coding undertaken on the data from each interview and focus group.

For step two the findings from the focused coding for phases one and two were then analysed to establish which codes had an overriding significance (Boeije 2002; Charmaz 2014). At this point I combined similar categories. This was an iterative method of comparison (Birks and Mills, 2011). It was this comparison which provided the conceptualised and abstract categories (Birks and Mills, 2011).

3.2.3.4 Step 3 : comparison of data from different groups

The findings from patients' interviews were compared and contrasted with those from the focus groups with nurses. This level of analysis brought the findings from the patient interviews and focus groups with nurses even closer together (Boeije, 2002). This level of comparison identified the convergence and divergence in understanding relating to patients' reconstructive memories of receiving critical care between the patients and critical care nurses and provided the answer to research question three. These finding will be presented in Chapter Five.

Whilst the CCA is described as a linear process, the steps at all stages of this analysis continuously moved backwards and forwards between the data and the codes. This provided the heavily cyclical and iterative nature of this research. That said, the simpler comparisons associated with steps one and three were carried out more extensively at the start of the analysis, whilst the more complicated steps two and four were extended later at the more abstract analytical stage.

As I conducted the interviews and focus groups, I not only heard the participants' accounts, but also viewed the setting, watched their interactions, examined their non-verbal communication and heard their voices. These were recorded in my research memos which supplemented the CCA, as described in section 3.5.

3.3 Phase one: interviews with former critical care patients

This section explains the data collection and analysis methods undertaken for phase one. This phase was designed to answer the following research question:

> *What are former critical care patients' reconstructive memories of critical care?*

3.3.1 Method

The method of data collection was semi-structured interviews. These were conducted with 15 former critical care patients.

3.3.1.1 The research setting

The research setting was a CCU within a medium-sized district general hospital (DGH) located in the South East of England, with 517 hospital beds. The Trust serves a population of 252,000 in an area with a deprivation score of 192 out of 326 local authorities. Life expectancy for men and women is slightly below the national average at 82.9 years for females in 2013-2015 and 79.1 years for males during the same period (Host Organisation, 2017). These figures are slightly below the England average of 83.1 years for females, and 79.5 years for males (Public Health England, 2017). The 2011 UK national census reported that 26.1% of the local population were from an ethnic group with 5.2% being Black African and 5.1% white other (Office for National Statistics, 2011). The census reported that the number of residents born outside the UK had doubled in 10 years from 20,500 in 2001 to 46,100 (18.5% of the population) in 2011 which is significantly higher than the UK national average at 13.8% (Office for National Statistics, 2011)

The CCU comprised nine adult critical care beds with bed occupancy around the UK national average of 85% (NHS England, 2017). A matron had overall responsibility for the nursing staff, supported by band seven senior sisters and an advanced nurse practitioner. An unknown number of nurses recruited from overseas worked on the CCU for whom English was not their first language. The unit operated visiting hours between 1030 and 2000 with a rest period for patients between 1330 and 1500.

This research setting was chosen because it represented an average general adult CCU in terms of size, patient dependency in contrast to a specialist CCU such as a neurosurgical or cardiothoracic CCU. The site was also chosen as the principle investigator [PI] (SM) had no previous professional connection with the hospital or geographical area having neither nursed nor taught in this NHS Trust.

3.3.1.2 The sampling recruitment procedure

A deliberately non-random method of purposive sampling was used to select participants who were "information rich" (Patton, 2015 p.53) in relation to the phenomenon under investigation (Palinkas et al. 2015), namely former critical care patients' who had received level three critical care. An acknowledged limitation to the purposive sampling method is that the results may not be generalisable to the wider population (Bowling, 2014).

3.3.1.3 Inclusion and exclusion criteria

Purposive sampling of former level three dependency patients (ICS, 2009) as presented in Table 1.1 on page 16, took place between 15/01/13 and 10/06/14, based upon the inclusion criteria presented in Table 3.1. Based upon the PI's clinical judgement and the majority of qualitative studies (n=21) in the MSR reporting an inclusion criterion of patients who had experienced a critical care stay of three days or more, patients who had stayed in CCU for less than three days were excluded from the sample. The rationale for this was that they would have been exposed to fewer care interventions and did not meet the criteria for critical care follow-up at this particular NHS Trust. Participants were also excluded if they had been discharged from CCU less than six weeks prior to the interview taking place, as the MSR presented in Chapter Two reported that patients recall up to six weeks post critical care can be limited (Chahraoui et al. 2015).

Table 3.1: inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Former level three, general, adult critical care patients	Patients with traumatic brain injury
Having received general, adult critical care for three days or more	Patients who had received specialist critical care such as burns and plastics or neurosurgery
Having been discharged from general, adult critical care longer than six weeks prior to the interview	18 years of age
	Unable to converse or understand English

Patients who had experienced a traumatic brain injury were excluded on the grounds that such injuries can affect an individual's physical, cognitive, emotional, and behavioural functioning (Bosma et al. 2018) and hence memory. Mental capacity was not formally assessed by the PI, but by the follow-up sister for critical care who, with a comprehensive understanding of the participants and their current mental capacity, acted as a gatekeeper in identifying potential participants. The senior sister for follow-up was a band seven nurse with responsibility for leading the critical care follow-up clinic at the Trust, where former patients were invited to meet with herself and the lead consultant for critical care, to discuss their critical care stay and the longer-term effects of their critical illness. The follow-up nurse was responsible for co-ordinating the clinic, listening to patients and their family members and providing information and psychological support (Hanifa et al. 2018). This strategy where follow-up sisters have acted as gatekeepers in selecting participants for qualitative research in critical care critical care has been reported by other research studies involving former CCU patients (Hofhuis et al. 2008).

Previous research has demonstrated it can be difficult to gain access to former critical care patients for research purposes as they are often reluctant to revisit their experiences of critical care through research participation and also report limited recollections of critical care (Burns et al. 2013; Reay et al. 2014). Therefore the support of the senior sister for the critical care follow-up services at the NHS Trust was gained to help with the recruitment of participants for this study. This was considered an ethical and practical strategy because she was already known to and had good rapport with the patients. However, due to this recruitment strategy with the sister undertaking the initial approach to potential participants, data pertaining to excluded participants (deemed to be unsuitable for participation) and those who declined to participate, was unfortunately not captured. This is clearly a limitation of recruitment via a gatekeeper, in this case the senior sister.

The sister for the critical care follow-up service approached prospective participants, in person either at the follow-up clinic or the “ICUsteps” support group at anytime between three months and two years after their discharge from hospital. “ICUsteps” is a charity and self-support group founded by ex-patients, their relatives and CCU staff to support patients and their families through the recovery from critical illness. The time frame following discharge was based on the availability of participants. One participant had been discharged three months earlier whilst another from the ICUsteps group had been discharged two years before. Letters of invitation and the participant information sheet were distributed by hand by the sister and, if the participants wished to participate, a time for the interview was arranged by her. All the interview participants read the participant information sheet (presented in Appendix 3.2) and provided written, informed consent (presented in Appendix 3.3) prior to the interviews. A condition of ethical approval was that the sister remained in the building when the research interviews took place.

3.3.1.4 Materials

A topic guide developed from the initial literature review and the PI's clinical experience (presented in Appendix 3.4) provided both structure and flexibility for the interviews (Bowling 2014; Mason 2002). Each interview opened with demographic questions which identified participants' characteristics including age and gender. The guide then moved on to an experiential question aimed at eliciting the participant's reconstructive memories of receiving critical care such as, "Tell me about what you recall the nurses doing for you on the critical care unit?" 'Feeling' questions followed such as: "How did this make you feel?" These identified the aspects of care that participants had found helpful or difficult. They also elicited the emotional recall participants had of receiving care. Owing to the semi-structured nature of the interview, probes were applied to responses enabling a more complete narrative to be drawn from the participants. These probes involved reflecting back to the participant followed by an open question such as, 'You said … are you able to expand on this further?' This helped the PI explore participants' responses further and provided additional depth and clarity (Qu and Dumay, 2011).

3.3.1.5 Ethical approval

Ethical approval was awarded through the Integrated Research Application System (IRAS) by the National Research Ethics Committee Service (NRES) committee, London Camberwell St Giles, REC reference 11/LO/0631 (See Appendix 3.4). Prior to data collection the PI attended research governance training at a Health NHS Trust in London. The PI assured the participants of anonymity and confidentiality at all times. The digital recordings were kept in a double-locked cupboard in a locked office at the PI's place of work, the university where the data analysis took place. All data were coded to ensure anonymisation. In the information sheet and during the interviews, participants were reminded that should they disclose issues relating to poor professional nursing practice, I was bound as a registered nurse, by the NMC Code (NMC, 2015), to disclose these to the necessary authorities. I am pleased to say this was not necessary.

Following receiving NRES ethical approval, approval at the research site was sought. This required a site specific information (SSI) form which was submitted to the research and development committee at the Trust where the research was to take place. Once approval had been gained from the research and development department based upon the SSI, access was ultimately gained to the research site through a research passport (See Appendix 3.1). As part of the research passport process the PI attended research governance training. The research was discussed with the relevant nursing staff on the CCU prior to commencing data collection and access was granted.

3.3.1.6 Procedure

The Principal Investigator (PI), who was the interviewer, conducted semi-structured interviews with 15 former critical care patients to explore their reconstructive memories of receiving critical care. The interviews took place in an office by the front door of the CCU (so that the partipcants did not have to walk through the CCU itself and see other ventilated patients), or in a room in a local community centre where the "ICUsteps" support group meeting was held. The interviews ranged from 17 minutes to 68 minutes.

Once the participants were settled into the room and had been offered refreshments, the interview opened with the PI introducing herself as a researcher exploring patients' memories of their experiences of receiving critical care. Written consent was then obtained by the PI from the participants. All the interviews opened with the first question on the topic guide (presented in Appendix 3.5):

> "Tell me about your experience of critical care?"

As this was an open-ended question, the participants were given time to respond to this question. To enhance the quality of the narratives provided by the participants, the PI took the opportunity to respond to the key issues they raised along with general non-verbal cues they demonstrated. It became clear that through simply asking the initial open-ended question, the participants became engrossed in the unfolding narrative as their memories of their experience of receiving critical care returned (Price, 2002).

To enhance the clarity of some of the responses, the interviewer made use of verbal and non-verbal probes. The application of probes throughout the interviews assisted participants to recall and reflect upon their experience whilst enabling contextual details to also be explored by the PI. The use of probes helped the participants to provide truthful and authentic responses. The use of probes also enhanced the interaction between the interviewer and the participants and supported the development for engagement to take place between the two. Care was taken by the interviewer to ensure probing was not excessive to ensure the participant didn't feel under pressure to respond or be anxious to provide the "right answer."

Each interview was drawn to a conclusion with the interviewer asking the participant if they had anything else they wanted to discuss? The participant was then thanked for their contribution by the interviewer and shown to the exit.

The digitally-recorded audio data collected from the patients' interviews was then transcribed verbatim into Word™ transcripts. This allowed for the analysis of this data using the CCA. Before this commenced, every transcript was reviewed for accuracy and to remove any information that might identify patients, family or staff members. To assist with this, the PI received training on the NVivo11™ Computer Assisted Qualitative Data Analysis Software (CAQDAS). NVivo 11™ is a data management system which systematically organised the results of CCA (Silver and Lewins, 2014). The PI sought permission to record each interview at the start and provided each participant with information on the maintenance of confidentiality and how the recordings would be stored and used (Bowling, 2014).

Throughout the interviews the PI drew upon the fundamental nursing skills that she had developed as a former critical care nurse, namely care, compassion and communication (Cummings and Bennett, 2012). These were important because the PI was aware that through being asked to revisit often traumatic and emotional memories the participants might find the interview difficult. The PI aimed to make the participants feel as comfortable as possible by ensuring that the room was the right temperature, enquiring if they wanted the door open or shut and ensuring that they had a drink if they wanted one. The PI tried to make her approach as light as possible, sharing humour with them where appropriate. She also agreed to relatives attending the interview if the participants so wished, however the PI made it clear that the interview was only with the former patient. The role of the 'uninvited participant' is explored further in section 7.4.2.

The fundamental communication skill the PI used was to maintain eye contact with participants demonstrating her interest in their story. The PI actively listened to them, using reflecting listening skills to engage with their responses to her questions and to ensure she had understood their meaning (Bramhall, 2014). The PI observed participants' body language, to see the effects of the question on them (Bramhall, 2014). She recorded these observations in memos. At the end of each interview, the PI checked that the participant had discussed all they wanted to by asking them this directly. The interview was closed by the PI thanking participants for their time and contribution. She also offered to the senior sister for follow-up to return to the unit to present the findings of the research.

3.4 Phase two: focus groups with critical care nurses

This section describes the focus groups undertaken for phase two. This phase was designed to answer the following research question which developed from the findings of study one:

> *How do critical care nurses understand and respond to the patients' reconstructive memories of critical care?*

3.4.1 Method

The method of data collection was focus groups. These were conducted with critical care nurses.

3.4.1.1 The sampling recruitment procedure

Four focus groups were conducted at a university in the East of England which provides post graduate critical care nurse education. The participants were all critical care nurses who were attending the university for postgraduate training. A common challenge in running focus groups with healthcare practitioners is bringing a group together at the same time, away from their clinical duties (Roxburgh 2006; Shaha et al. 2011). Therefore, this particular group of nurses was chosen to provide a convenient and accessible group of critical care nurses who were free from the clinical practice environment. This particular university site and group of nurses were also selected as, whilst the PI was a critical care nursing lecturer at the same university, she had not been involved with this student cohort either as a teacher or assessor.

The critical care nurses who participated in the focus group were recruited from a group of 33 nurses who were attending a postgraduate certificate course in critical care nursing. The participants came from a range of CCUs, DGH CCUs and tertiary referral centres located in the East of England. The focus groups were conducted between March and April 2018.

This sample of critical care nurses was selected through convenience sampling. This recruitment strategy was adopted as it provide participants who had the required clinical experience but for practical purposes were easy to recruit, accessible and more likely to respond and attend the focus group as they were already free from their clinical responsibilities whilst attending university on the day of the focus groups.

Letters of invitation and the participant information sheet (presented in Appendix 3.2) were distributed individually to the students at the beginning of the course by the module leader. The module leader asked for expressions of interest from those willing to participate in the study. The PI arranged to meet the individuals who had expressed an interest in participating as a group to discuss the research and to explain that they were under no pressure to participate. She highlighted that even though she was employed by the university as a critical care nursing lecturer, she would not be teaching them nor assessing their work and therefore there would be no conflict of interest. After reading the participant information sheet, participants provided written, informed consent using the consent form (presented in Appendix 3.3) prior to the focus groups commencing. Participants then completed the participant demographic information form at the start of the focus group interview (presented in Appendix 3.9).

3.4.1.2 Ethical approval

Ethical approval was obtained from City, University of London (Ref: PhD 16-17/07). Out of courtesy the PI informed the university where the focus groups were conducted Faculty Research Ethics Panel about the research as it would take place in their facilities and with their students and they responded that they were happy for the research to take place. The focus group discussions were digitally recorded. These recordings were stored in a double-locked room at the PI's university of employment.

3.4.1.3 Materials

Two sets of materials were used in the focus group: 1) a topic guide and 2) stimulus material involving anonymised quotations from the interview transcripts from phase one presented as PowerPoint slides.

The topic guide (presented in Appendix 3.7) was developed prior to the focus groups meeting, based upon the findings from phase one. This aimed to facilitate a semi-structured interview approach to the focus group (Then et al. 2014). The guide included three sections: engagement questions, exploration questions (which address the topic) and exit questions (Then et al. 2014). Exit questions enabled me to check if what I had understood was correct and if there was anything else that needed to be included. The topic guide was very much a guide rather than being "set in stone" (Cronin, 2016 p.307). This was to allow spontaneity and to facilitate discussion amongst the members of the group. Consequently, the questions developed were broad, and as the moderator it was my role to ensure the group remained focused throughout the session (Morgan and Krueger 1998; Then et al. 2014).

Once the first set of questions in the topic guide had been concluded, stimulus material was shown to the group in the form of anonymised quotations from the interview transcripts from phase one being presented as PowerPoint slides. These are presented in Appendix 3.8.

The rationale for adopting this staged approach to the focus group was that firstly the PI wanted to elicit what critical care nurses understood of patients' reconstructive memories of receiving critical care as a baseline measure. Secondly, drawing upon White's (2016) recommendations, the PI wanted the nurses to 'hear' the patients' voices in relation to their reconstructive memories of receiving critical care and to explore the nurses' reactions.

3.4.1.4 Procedure

To gain confidence in facilitating a focus group, the PI undertook focus group training at the University of Surrey and through a Qualitative Research Summer School at King's College, London where she acquired practical and theoretical insight into facilitation (Shaha et al. 2011). This training encouraged her to use reflective listening so that she could share with the participants what she understood had been said (Then et al. 2014). The PI did this through clarifying, paraphrasing, reflecting feelings and summarising. The PI used this strategy to gather a rich and deep understanding from each participant (Then et al. 2014). Reflective listening also helped her redirect the group if she considered the conversation was drifting off topic (Shaha et al. 2011). The PI ensured all participants had the opportunity to contribute by drawing further upon her communication skills to facilitate group interactions and encouraging the quieter participants to engage in the discussion (Cronin, 2016).

Four focus groups of between six to eight critical care nurse participants were convened. This number of participants ensured the group was small enough for everyone to contribute, yet large enough to elicit diverse opinions across the group (Freeman, 2006). The discussion concentrated on the nurses' understandings of patients' reconstructive memories of receiving critical care. Importantly, the focus groups took place before the group received a lecture on patients' experiences to prevent the content of the module the participants were undertaking priming them (the module did have a lecture on patients' experiences of being critically ill – particularly in relation to delirium later in the module).

Each focus group was designed to last for one hour and took place at lunchtime, with lunch provided, in a classroom at the university. The PI acted as the moderator supported by an assistant who took notes regarding the group discussion to support the accuracy of the transcriptions and analysis throughout the discussion. These included a log of speaker changes to assist with transcription (Shaha et al. 2011). The notes were also used throughout the analysis to help the PI to recall specifics of the group (Shaha et al. 2011).

Seating was arranged in a semi-circle (presented in Figure 3.6) and the PI sat at the front. Here she could fully engage with and observe the participants' non-verbal cues (Cronin, 2016). Arranging the seating in this way also discouraged participants from hiding in the back row (Then et al. 2014). The assistant was seated slightly back from the semi-circle to avoid imposing on the discussion (Then et al. 2014).

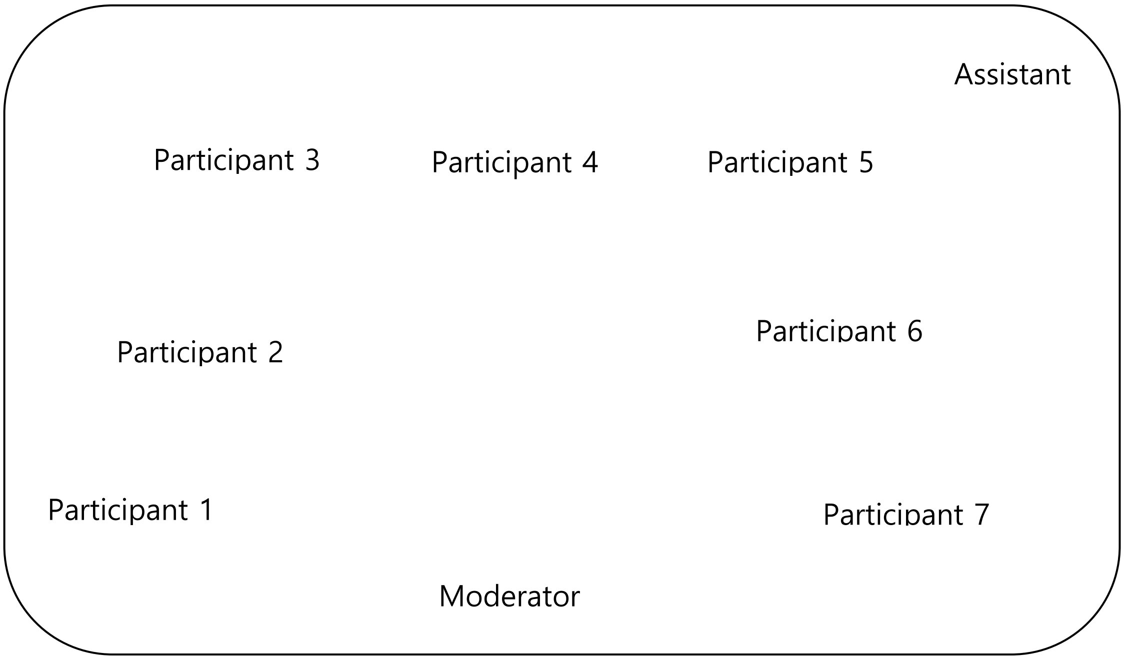


Figure 3.6 The focus group seating plan

As the moderator, the PI once again drew upon her nursing skills of care, compassion and communication (Cummings and Bennett, 2012) to develop an environment in which clear understandings from the nurses' discussions could be explored (Doody et al. 2013). Drawing upon recommendations from Grover et al. (2007) she reminded the group that the potential for coercion and conflict of interest would be reduced as she did not know the participants. She did this by explaining to them that she welcomed their participation and contributions and that she hoped they would be able to say things knowing they would be kept confidential. The PI explained that she was there to moderate the discussion and hoped that they would feel able to speak freely.

The assistant was a colleague who recorded verbal and non-verbal cues, behaviour, eye contact and group interactions and dynamics in a set of notes. At the end of each group discussion the PI and assistant held a debriefing where they discussed the notes, identifying what had happened in the group and what themes were being identified, whilst also planning what they needed to do next (Shaha et al. 2011; Then et al. 2014).

Participants were informally welcomed on arrival to the focus group and formally welcomed at the start of the group discussion. The PI then provided verbal and written information (via the information sheet) about the research. She reiterated details from the information sheet that whilst anything discussed by the group would remain confidential, should any areas of either unsafe or unprofessional nursing practice be discussed within the group, then in view of her own professional responsibilities as a registered nurse with the Nursing and Midwifery Council (NMC, 2015) she would have to break this confidentiality and raise the issue with the module leader. The PI then outlined the expected format and structure of the group and discussed timings and how long the group would take. She proceeded to gain permission to digitally record the session to ensure that parts of the conversation were not missed (Morgan and Krueger, 1998) and obtained written consent for participation from the participants (Then et al. 2014). Finally, she highlighted the need for confidentiality once the group had finished and that discussions should not continue outside the group. Each focus group then set their own additional ground rules (Morgan and Krueger, 1998).

After the PI had set the scene and explained the ground rules, each participant introduced themselves to the group using their number. This identified the different voices to the transcriber and acted as an icebreaker (Then et al. 2011; Cronin 2016). The PI then asked the group questions from the topic guide (presented in Appendix

3.7). She added comments and asked probing questions to focus the group as they responded. The PI acknowledged comments from individuals and through reflective listening and reflecting back what she understood was being said to the group to validate her understanding (Then et al. 2011; Cronin 2016).

The PI then presented the stimulus materials on PowerPoint slides (which are presented in Appendix 3.8), these enabled her to probe the group further for their thoughts and understandings on what patients had reported. After this discussion, the PI closed the groups by asking if there was anything else they wished to cover, summarised the discussion and concluded by thanking them for their time and contribution (Stewart et al. 2007).

3.4.1.3 Analysis

Each recording was transcribed verbatim into a Word™ document and each transcript was checked for accuracy. These were edited to remove any information that might identify participants, as were the notes written by the assistant (Cronin, 2016). The focus group data were analysed using the same CCA as the interviews presented in section 3.2.3.

3.5 Memo writing

Memo writing is a core tenet of qualitative research (Birks and Mills, 2011). Memos are defined as:

> *'If data are the building blocks of the developing theory, memos are the mortar.'*
>
> (Stern, 2007 p.118).

This description helped the PI to appreciate fully the role memos played in this research. The rationale for memo writing within qualitative research can be outlined using the following mnemonic:

- M – mapping research activities
- E – extracting meaning from data
- M – maintaining momentum
- O – opening communication

(Birks and Mills, 2011)

3.6 Reflexivity

Throughout the data collection and analysis, the PI undertook reflexivity. This is defined as the:

> *"Critical self-reflection on how the researcher's background, assumptions, positioning, and behaviour impact on the research process"*
>
> (Finlay and Gough, 2008 p.9).

Reflexivity involves being transparent about the decisions made throughout the research design (Engward and Davis, 2015). This is achieved through the researcher acknowledging that:

> *'We are always on the corner somewhere.'*
>
> (Richardson, 1992 p.104).

As this research relied upon her interpretation of data from former critical care patients and nurses ,the PI had a duty to acknowledge how a *priori* knowledge as a former critical care nurse and now academic, can benefit yet also bias her thinking, interaction with participants and interpretation of data (Alvesson and Skolberg, 2009). The PII had to maintain conscious awareness of her "insider" perspective throughout this research.

3.6.1The Insider-outsider perspective

The *emic* (insider) stance relates to researchers who have insider knowledge of the group being studied (Burns et al. 2012). In contrast, the *etic* (outsider) stance is where researchers hold no prior knowledge or experience of the group (Burns et al. 2012).

To address potential bias, I adopted an etic stance (in an organisational sense) to the research site, having neither practised nor taught at either the NHS trust or the University site where the interviews and focus groups took place. However, my emic professional identity helped me to gain access to these sites. In the NHS Trust I worked with the critical care follow-up sister who was pivotal in recruiting the participants and enabling me to gain access to the field. In the University I worked with the module leader to gain access to the participants

From an *emic* stance, I acknowledge that I entered the field with insight into, and assumptions around, patients' reconstructive memories of critical care and nurses' understanding of these. I considered this to be beneficial, as it provided me with insider knowledge which would identify areas within the data which might have been missed by an "outsider."

As my position as an "insider" was so important to the research, I adopted a systematic approach to my reflexivity, which was based upon Alvesson and Skolberg's (2009) model of reflexivity (Engward and Davis, 2015). The initial stage explored any social control my insider knowledge had over how participants answered the questions. Throughout the interviews I was careful to listen and reflect back responses, rather than to dominate and ask excessive questions. With this approach, the participants were able to explore their own thoughts and memories without me interrupting and asking the next question. Consequently, the data obtained through the interviews was richer and deeper than it would have been had I stuck rigidly to the interview schedule (Bowling, 2014). I also adopted the role of an empathetic listener, where I aimed to explore the participant's inner world (Qu and Dumay 2011; Roulston 2010). To achieve this, I acknowledged my own role in relation to the participant and the research through my own reflexivity (Koch and Harrington, 1998). I demonstrated this through being open to the interviewee about my interests in the research topic as a former critical care nurse and now as an academic.

Through stage two of the model I considered reflexivity in the analysis of the data (Alvesson and Skolberg, 2009). I was aware that my understanding of critical care jargon could influence the way I coded the data. To address this, a sample of data was coded separately by hand by my supervisor who held an etic stance . We met to discuss any discrepancies and discussed these until a consensus was achieved.

Exposure to rich and deep data challenged me to remain in the etic role. There is evidence that I adopted an emic stance in terms of explaining certain interventions to participants within the transcripts. I acknowledge that adopting an emic role, with the ability to analyse data non-judgementally, was challenging for me as a nurse researcher (Deacon, 2013).

Considering stage three of Alvesson and Skolberg's (2009) model, the political – ideological context, I ultimately chose to adopt the middle ground between emic and etic (Burns et al. 2012). I embraced my emic stance, believing it enhanced my sensitivity to data analysis by enabling me to identify connections between the data. However, this was balanced by my etic role in relation to the field site.

The final stage considered how I communicated my research (Alvesson and Skolberg, 2009). I kept a reflexive diary of memos (Montgomery and Bailey, 2007) throughout the research, which related to my experience at the time. An excerpt from this is presented in Figure 3.10. This prevented a unidimensional approach to data collection, analysis and interpretation and enabled others to challenge my work (Engward and Davis, 2015). These memos also provided an audit trail of my thought processes and their potential influence over the conclusions reached in this study.

Having presented the data collection, analysis methods and procedure for phase one of this exploratory sequential design, the following section now presents the data collection methods and procedure for phase two.

3.7 Chapter conclusion

This chapter – *research design and methods*, has presented a rationale for adopting a qualitative research design to address the research questions presented in Chapter One and confirmed in Chapter Two following the MSR reported there. The rationale for using an exploratory, sequential qualitative design (Creswell and Plano Clark, 2011) has been presented. Definitions and descriptions of the methods used to collect and analyse data have been presented as has the role of memo keeping and personal reflexivity throughout the research period. The following chapters present the findings from phase one and two and then describe how these converge and diverge.

Chapter Four: Findings from the patient interview study

This chapter presents the findings from interviews with 15 former critical care patients which addressed the question:

> *What are former critical care patients' reconstructive memories of critical care?*

The constant comparative analysis as described in Chapter Three identified five categories. These categories provide the focus of this chapter.

In keeping with the rationale (presented in section 1.2) to give the patients a voice to explore their reconstructive memories of receiving critical care, *in vivo* codes taken verbatim from the participants' responses contributed to some of the focused codes as proposed by Charmaz (2014). In contrast, the categories' substantive labelling reflects the reality of the participants' reconstructive memories of receiving critical care whilst also reflecting their reported concerns and actions (Charmaz, 2014).

4.1 Participants' characteristics

The participants' characteristics are presented in Table 4.1. Additionally, a 'pen portrait' of each participant is presented in Table 4.2. These provide a rich and holistic picture of the participants (Howatson-Jones, 2011) describing how they were admitted as emergency admissions to a CCU, their ages, length of stay and the time elapsed following their CCU discharge to when they were interviewed. The location of the interview is depicted and contextual information regarding their life before and following the critical care stay is presented. To maintain anonymity, but to also to help develop the narrative and create a greater humanistic perspective to the research, pseudonyms (participant codes in Table 4.1) have been assigned to each participant (as recommended by Birks and Mills 2011). If participants referred to staff members by name in their responses, these names have also been changed to pseudonyms.

Table 4.1 Characteristics of interview participants

Participant Code	**Male (M)/ Female (F)**	**Age**	**Length of CCU stay (days)**	**Reason for admission**	**Duration since CCU discharge (Months)**	**Location of interview**
Fiona	F	23	14	Emergency: ruptured ectopic	6	Office on the CCU
Colin	M	53	23	Emergency: cardiac arrest	24	ICU steps meeting at a local community centre
Pete	M	41	28	Emergency: cardiac arrest; Acute Respiratory Distress Syndrome (ARDS)	17	ICU steps meeting at a local community centre
Derek	M	63	14	Emergency: Acute Kidney Injury; ARDS	10	ICU steps meeting at a local community centre
Lee	M	43	7	Emergency: cardiac arrest; ARDS	2	ICU steps meeting at a local community centre
Beverley	F	53	22	Emergency: peritonitis	6	Office on the CCU
Diane	F	54	18	Emergency: respiratory failure	14	Office on the CCU
Sean	M	37	23	Emergency: pancreatitis	5	Office on the CCU
Alan	M	49	28	Emergency: Meningococcal septicaemia	18	Office on the CCU
Karen	F	42	28	Emergency: sepsis	8	Office on the CCU
Jeff	M	56	14	Emergency: respiratory failure	6	Office on the CCU
Mike	M	61	21	Emergency: endocarditis	11	Office on the CCU
Janet	F	72	10	Emergency: Sepsis	4	Seminar Room on the CCU
Sheila	F	75	54	Emergency: Guillain Barre Syndrome	7	Office on the CCU
Dave	M	67	28	Emergency: Multiple trauma; RTA	12	Office on the CCU

Table 4.2 Pen Portraits of the participants

Participant	Pen Portrait
Fiona	Fiona was a 23-year-old Scottish female living with her partner. She had been admitted to the CCU for 14 days following a ruptured ectopic pregnancy and severe hypovolaemia. The interview took place six months following her discharge from the CCU. Fiona was reported that day as it was the first time she had driven somewhere on her own since becoming ill. She was embracing the second chance at life her critical care admission had given, to the full and was proud to tell me she was busy applying for jobs. The interview took place in the office by the front door of the CCU.
Colin	Colin was a 53-year-old male who lived and worked locally as a paramedic. Colin had been admitted as a cardiac emergency and had required some time on the cardio thoracic unit at the local cardiothoracic centre for invasive cardiac surgery. He had been transferred back to the CCU at the local DGH once his surgery had taken place. In total he received 23 days of critical care. Unfortunately, Colin experienced multiple complications following discharge home from his original admission which required him to be readmitted as an emergency on two occasions – one of which necessitated further emergency surgery. Colin had not been afforded the opportunity of a follow-up clinic or critical care rehabilitation programme. Colin was still very angry about this. His interview took place in a room at the local ICU Steps support group which he enjoyed attending each month.
Pete	Pete was a 41-year-old male who worked as an IT consultant, who was an emergency admission to the CCU following a cardiac arrest whilst out playing badminton with friends. Following his arrest, Pete had an internal defibrillator fitted to sustain his life. Pete had a tracheostomy whilst on the CCU, but this was removed before he went to the ward. Pete was married to Jess and was a father to two daughters who were aged seven and ten when he was taken ill. Pete was on the CCU for 28 days and then transferred to the cardiology ward at the hospital, which both he and his wife found extremely difficult. Pete’s interview took place in a quiet room at the ICU Steps meeting. Jess his wife was present.

Participant	Pen Portrait
Lee	Lee was a 43-year-old male and admitted following a witnessed cardiac arrest at home. Lee had recently been diagnosed with a hereditary cardiac condition following a myocardial infarction earlier in the year. Lee had only been discharged from the CUU seven weeks earlier, following a seven-day stay on the CCU. Lee was married but did not have any children. Lee was at the ICU Steps meeting for the first time since his discharge. He had turned down the offer to attend a follow- up meeting as he didn't feel ready for that at the time, however he was now keen to arrange this as he wanted more information about what had happened. Lee was still signed off sick from work and was still experiencing unstable angina and still not fit enough to tolerate the surgery for an internal defibrillator. Lee was keen to move on with his life as best he could.
Beverley	Beverley was a 53-year-old female of Afro-Caribbean ethnicity. She was married and a housewife with two grown-up daughters. Beverley had been admitted with peritonitis following a perforated bowel, for which she had an open wound which required frequent revisions in theatres. Whilst she was extubated for some of the time, whenever she went back to theatre she needed to be re-intubated. This had resulted in her having difficulty speaking now that she was discharged, and she had a very husky voice. She had been discharged from the CCU six months earlier. Beverley remained physically disabled from her stay and still walked slowly with a stick. She spoke in a slow and measured way and was clearly very grateful to the staff on the unit for getting her through this. The interview took place in the office by the front door of the CCU. Beverley's husband was present during the interview.
Karen	Karen was a 42-year-old female and admitted to the CCU with sepsis. Karen had been admitted to the CCU for 28 days and discharged eight months earlier. Karen was divorced and had a married son who visited her with his wife. She worked as an administrator locally. Karen experienced profound hallucinations whilst on the CCU making her a bit 'fru fru in the head' which required her son to come in to calm her down. Karen's interview took place in the office by the front door of the CCU.

Participant	Pen Portrait
Sean	Sean was a 37-year-old male originating from Australia who was living with his ex-girlfriend locally. Sean had been admitted with acute pancreatitis and multiple organ failure between Christmas and New Year following a few days of partying in Scotland. By his own admission he was a patient with split personalities; there was the good Sean whom all *'the nurses loved him and then there was another one who was sort of middle of the range and then there was one that had been a little shit to all the nurses.'* (Sean). Sean was on the CCU for 23 days receiving both ventilatory and renal support and had been discharged five months earlier. He did not have a tracheostomy. Sean had two dogs who meant the world to him and had worked locally in IT. Following his illness, he was about to start a new job as he had had to take his previous employer to tribunal as they had terminated his employment in-view of his critical illness. Sean said he remained wiped out from his time in hospital and was not sure how his new job would go. Sean's interview took place in the office by the front door of the CCU.
Alan	Alan was a 49-year-old male who had been discharged from the CCU for 18 months earlier following a 28 day stay for meningococcal septicaemia associated with an inner ear infection. This had left Alan's sight and hearing slightly impaired. Alan had previously led a big corporate life as the CEO of a company in London. The role necessitated him to travel the world and indeed he was taken ill during a conference in Switzerland. He was flown home, met by a car and taken to the hospital where he was immediately admitted for ventilation and renal support on the CCU. Alan had since reassessed the way he lived his life and has only recently started work in a less demanding managerial role in a local company, enjoying the cycle to work each morning. Again, Alan had had issues with his previous employer and his old role in view of his critical illness. Alan provided an incredibly articulate account of not only his time on the CCU but of the follow- up clinic he felt both he and his family had benefited from. Alan's interview took place in the office by the front door of the CCU and his wife was present at the interview.

Participant	Pen Portrait
Jeff	Jeff was a 56 -year-old male who was an office worker who had been admitted with acute respiratory distress syndrome secondary to swine flu. Jeff had been transferred as an emergency to a regional respiratory centre in London to receive a treatment known as ECMO, however fortunately he didn't require this intervention. Jeff had been heavily sedated and ventilated. When he returned to the CCU in the local hospital, Jeff had recovered well and was no longer sedated or ventilated. He was just waiting for a suitable bed to come up for him on the ward and was with them for 14 days. This was six months ago. Jeff relied heavily on his wife Sue who was a health care assistant at the hospital to provide care for him whilst he was on the CCU. He was also a father to three daughters. Jeff had yet to return to work following his illness. His interview took place in the office by the front door of the CCU. Sue was present in the interview.
Mike	Mike was a 61-year-old male and a former soldier turned surveillance officer who had been discharged from the CCU six months earlier, following a CCU stay of 14 days for acute respiratory failure. Mike was a difficult person to interview as a lot of his interview related to his time on surveillance. Mike admitted that the nurses found it difficult to ascertain if he was telling them the truth or hallucinating, however his visitors maintained he was telling the truth! He recalled his brain CT scan showed 75% of his brain had been damaged due to oxygen starvation. Mike was divorced with two grown-up daughters. He was particularly frustrated with the workload organisation on the general ward believing a lot of the nurses' time was wasted on inappropriate tasks. Mike was delighted to have been informed that day he could drive again. He did however show me his fingers which had been severely damaged by the drugs he had received on critical care and had been in the day to ask for them to be amputated. Mike's interview took place in the office by the front door of the CCU.

Participant	Pen Portrait
Janet	Janet was a 72-year-old retired female who was admitted with sepsis just four months earlier. She was on the unit for 10 days and was critically ill, so much so that the Doctors did not think she was going to survive. Janet was married with a daughter who had her baby daughter whom Janet had been providing childcare for before she became unwell. Janet was grateful to be alive stating 'I'm still here.' Janet's interview took place in the seminar room in the CCU. This necessitated Janet walking through the unit to get to the room for the interview. When she arrived in the seminar room there were tears in Janet's eyes.
Sheila	Sheila was a fit and healthy 75-year-old married female who was retired and was without children but heavily involved in local life until she was admitted to the CCU for a total of 54 days with Guillain Barre Syndrome, which involved her being paralysed and unable to breath on her own. Sheila received ventilatory support and had a total reliance on the nurses to carry out all her care. A highly determined lady, Sheila had made a great recovery in the seven months since she was discharged from the CCU and had gained the use of her legs once more. She was looking forward to returning to the swimming pool, the following day with one of her many friends, the first time since her illness. Sheila's interview took place in the office by the front door of the CCU.
Dave	Dave was a 67-year-old male who was retired and was admitted to the CCU from a neighbouring Cities Trauma unit where he had been taken following a serious road traffic accident resulting in him receiving multiple trauma. Dave had been on the local CCU for 28 days and discharged 12 months ago. He was interesting to interview as he seemed to be experiencing episodes of absences throughout the interview. Dave had been banned from driving following his accident due to experiencing epilepsy. Whilst in hospital he had experienced three bereavements – his wife (for whom he had been the main carer), brother and sister. His son had subsequently given up his job and relationship to move back in with Dave to be his main carer. Dave was well known in the hospital being a frequent visitor to the WRVS coffee shop. Dave was a bit unsteady on his feet and refused a walking stick! Dave's interview took place in the office by the front door of the CCU.

Participant	Pen Portrait
Derek	Derek was a 63-year-old male who was a retired lorry driver and was admitted to the CCU in multiple organ failure. He required a lot of sedation as well as ventilatory and renal support during the fourteen days he was on the unit. By Derek's own admission he was a bit of a nightmare patient. He stopped smoking whilst on the CCU and is now also drinking less alcohol. Derek was discharged from CCU 10 months prior to the interview taking place Derek is now loving life to the full having come into some inheritance, he was due to be going on a cruise shortly. Derek's interview took place in a quiet room at the ICU Steps meeting; however he does not attend this.
Diane	Diane was a 54 year-old-female who was admitted to the CCU with acute respiratory failure for which she needed ventilatory support. It was 14 months since Diane was in the CCU following an 18-day stay. Diane was married and had two children her daughter was still living at home. Diane was a housewife. Diane provided a comprehensive account of her stay in critical care. Her interview took place in the office by the front door of the CCU.

4.2 Results

The CCA identified five categories relating to patients'

reconstructive memories of critical care. These were*:* 1) *Missing memories of critical care;* 2) *sensing an altered reality from CCU through to home;* 3) *feeling reassured yet powerless* 4) *feeling abandoned;* 5) *filling the gaps, reaching closure and moving on with life and survivorship.* The first category, *missing memories of critical care* will now be presented.

4.2.1 Missing memories of critical care

Within the category *missing memories of critical care*, four focused codes represent different aspects of missing memories of critical care. These are presented in Figure 4.1.

Initial Code	**Focused Code**	**Category**
Not remembering significant life events	There's a lot I don't remember	**Missing memories of critical care**
No warning of becoming ill		
Not remembering visitors		
Not remembering what had happened		
Not remembering the nurses		
Missing time		
Feeling out of the loop		
Not remembering what had happened	Where am I and why am I here?	
Not knowing where they were		
Not understanding what was happening		
Family members knowing more	Missing memories causing discord	
Arguments with spouse over events and disclosures *(FS)*[1]		
The less you remember the better	A means of self-protection	

Figure 4.1 Category: missing memories of critical care

The significance of this category was that gaps in memories persisted long after the participants had been discharged from hospital. The former patients reported that they needed to address these missing memories in order to prevent discord with the

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[1] FS relates to the family strand which transgresses across the categories

family, reduce the burden of guilt, make sense of what had happened and to move on with life.

4.2.2 'There's a lot I don't remember.'

> *"There's a lot I don't remember."* (Beverley)

All the participants reported not remembering, although there was a variation in the reporting of missing memories across the participants. For some, they could not remember the moment they fell ill. Pete remembers walking back to hit the shuttlecock at badminton and nothing else. Alan remembers being met by his driver following his flight home from Zurich, but nothing else. Sean also reported missing memories and attributed these to the pain from his pancreatitis and that he had started to hallucinate:

> *"I don't really remember much for the four days before the ambulance brought me in. I'd been up to Scotland from Christmas...and then I was back for three or four days, I don't even remember the drive back from Scotland... I don't remember coming up to the ward from A & E, you know, that's all sort of gone."* (Sean)

Many received no forewarning that they were about to require critical care. They found the speed with which their health deteriorated both shocking and distressing, as described by Pete:

> *"I suppose because, especially in my case, there was no build up to it. It was, you know, out on a Thursday night playing badminton, being – I wouldn't say fit, but, you know, being relatively healthy and living a relatively good life to I'm waking up, can't talk, can't walk, got tubes all over the shop."* (Pete)

Due to this lack of forewarning the participants reported feeling confused and disoriented upon waking:

> *"So, I was a little bit dazed and confused obviously having had septicaemia and meningitis, so that was all quite difficult. I thought I was somewhere, and I was so confused."* (Alan)

4.2.3 Needing to address the missing memories to achieve closure and move on with life

The most significant finding from this category related to the psychological and social aspect of participants' need to remember these missing memories, to achieve 'closure'[2] and move on with their life. Lee could not remember his cardiac arrest and whilst he recognised this as a self-protection strategy, he found it frustrating. He reported that to make sense of what had happened to him and achieve closure, he needed to address these missing memories. He considered that only then could he move on with his life:

> *'Yeah, because I think it's closure for me then, and I can continue forward in a more positive way."* (Lee)

Alan found as he pieced together the missing memories he was able to achieve such closure and progress with life. Reflecting on the critical care follow-up clinic meeting he recalled:

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[2] Closure involves addressing uncertainty for an individual through providing a clear and unambiguous information which helps them process and understand a situation (Szumowska and Kossowska, 2017).

> *"They really did explain to me, and for me it was an important closure moment...to be able to say, right, now I get it...now I'm better than I was, I'm improving, and it sort of shuts the door on that episode."* (Alan)

Through such closure, Derek described being more appreciative of life. He commented:

> *"You get to appreciate life so much more."* (Derek)

Others reported that because of the care they had received, they had survived their illness, and through this they felt alive. Fiona enjoyed hearing the birds sing and appreciated blue skies, whilst Mike explained:

> *"It's not worth living if you don't feel alive... I'm really pleased to see this morning, I feel alive. It's not worth living if you don't feel alive."* (Mike)

Having achieved closure, Alan took the time to readdress the priorities in his life and took a less demanding job locally and to spend more time with his family. Fiona reported that the experience had motivated her to:

> *"... find a job now and today was the first day in two years that I drove. I am so proud of myself."* (Fiona)

To be able to achieve such closure and to move on with their life, the participants needed to remember where they had been and why they had been there. The participants recalled feeling confused and disoriented when they first woke up on the CCU. Due to their missing memories, they were left asking 'where am I and why am I here?'

4.2.4 Where am I and why am I here?

Some participants developed an idea of where they were, simply down to the amount of activity around them in the bed-space, however due to the lack of memory of falling critically ill, as they regained consciousness, many participants didn't remember where they were.

> *"My recollection of being in hospital, I have none of it, and then when I woke up and I was here I didn't know why I was here, and I'm thinking, why am I in hospital? There's nothing wrong with me, why am I here?"* (Beverley)

Many of the participants reported how this led to feelings of disorientation, confusion, fright and concern about what had happened. These feelings were often accompanied with not remembering why they were there:

> *"I was beginning to sort of realise where I was, but not knowing, I didn't know I'd had surgery."* (Colin)

As many of the participants were unable to verbally communicate, they were left to make sense of the situation for themselves which was often inaccurate and exacerbated their feelings of disorientation and fear as described by Sean:

> *"When I first woke up I didn't even know what I was in here for. I thought I'd been in a plane crash or car accident or, you know, I opened my eyes and there was a nurse in front of me and I couldn't move, and it was snowing outside so I thought maybe I'd been on a trip, you know, skiing or something and I'd been in a crash and just woken up so, yeah, it was, you know, it took me a few days to sort of get to grasps with where I was and what had happened."* (Sean)

Several participants could not remember details of their critical care stay. They attributed these missing memories to 'missing time.' This missing time caused the participants shock and further confusion when learning of this:

> "*I'm not sure, I think I went to the ward, the day the doctors spoke to me. It's a bit confusing, but he told me it was the 21 January…I said, 'Wait a minute, I never sent my Christmas cards' and that was all I could think of. Gosh, Christmas it had been and gone."* (Sheila)

Others referred to this period as when they were 'asleep:

> *'"t just feels like I've been asleep for all that time and then woke up."* (Beverley)

Not only did the participants find this difficult to comprehend, – especially if like Pete they had missed significant life events such as their children's birthdays or Dave who couldn't remember his wife's funeral, but they also reported feeling detached from their family. Beverley reported this:

> *"You kind of feel out of the loop … You know, you just feel, where was I, you know, in that time, and then sometimes they were talking about things and I'm thinking, where was I? Then I think, oh yeah, I wasn't well, you know. Because sometimes we'll be sitting there and we're chatting, and Ian [her husband] will say oh, they did this to you. And I say oh, another thing I can't remember."* (Beverley)

Missing memories due to missing time caused further confusion for the participants when they revisited the CCU. Fiona could not understand how the nurses knew Dan (her partner) and greeted him like a long-lost friend, when she couldn't remember any of them. Beverley found it very strange to meet the nurses and regretted not getting to know them before she left the CCU and went to the ward.

These missing memories also extended to receiving visitors. Many reported that they could not recall people visiting. For some this was not a problem as they regarded it to be a benchmark of how far they had come:

> *"I had a visitor come one Sunday when I was under sedation and we had a conversation apparently. I don't even remember him coming to visit. But he came and saw me the Sunday after and I was walking around and getting him a chair and everything, so he couldn't believe the difference, the change."* (Sean)

Beverley was concerned how people would perceive her:

> *"They said, oh, this person came to see you and you were talking, and I'm there thinking, did they? I can't remember, so there's a lot of, you know. I don't know if people feel that I'm saying that, but I say look, I can't remember."* (Beverley)

Janet and Lee both referred to their lack of memories throughout the entirety of their interviews. This is interesting because these two participants had received critical care most recently, Lee having been discharged just two months before and Janet four months. This suggests there could be some degree of temporality associated with the reconstructed memories of receiving critical care. However, upon probing both participants had more recall than they perhaps thought. In particular, Janet had had to walk through the CCU to get to the room where the interview took place. I noted in my memo (presented in Figure 4.2) following the interview:

Janet stated that she recalled very little of her ICU stay. However, what was interesting was that we did the interview in the seminar room on the ICU. This meant we had to walk through the unit to get to the room. As she arrived in the room, she welled up with tears. Although she said she couldn't remember her time here, just walking through the environment again had obviously raised some emotional recall for her.

Figure 4.2: Memo following the interview with Janet

4.2.5 Missing memories causing discord

For some participants the missing memories led to additional feelings of confusion and frustration which at times developed into discord between the participants who were adamant that they remembered an event, and their family members who recalled things differently. The participants reported becoming irritated by their families' actions towards them. Diane remembered:

> *"My sister in law and her husband had come to visit me and I can remember their voices being there, but I'd got it into my head that they'd brought something for me and I kept asking my daughter where was it, what had happened to it, where had it been put."* (Diane)
>
> *"My husband was stroking my hand. 'Don't keep doing that, what are you doing that for?' I didn't even know where I was."* (Diane)

Diane's irritation at her husband was that because she had no recall of falling ill she and had nearly died, her husband stroking her hand seemed inappropriate and out of context to her at the time.

Lee recalled a more serious foundation to the discord with his wife. This was related to not understanding what had happened to him:

> *"I started to come together more with myself and I couldn't work out why I was on CCU when I was being told I had a chest infection. That was the only reason I was in hospital, and later on … because I was getting very, very agitated in the hospital thinking, if I've only got a chest infection there is no reason for me to be here."* (Lee)

Lee was finally told that he had had a cardiac arrest and was angry with his wife for not telling him, however when it was revealed why she hadn't told him he felt humbled by his wife's protective actions. This led to additional feelings of guilt for his anger:

> *"Of course, when she came round the corner, and spoke to me, I tripped out at her. It was a case of 'Why didn't you tell me the truth?' She had been told not to because it was too stressful for me to undertake."* (Lee)

Others too experienced discord with family over their recall of events. Pete remembered an argument with Jess (his wife) over when he woke up:

> *"One of the first things or conversations we sort of had was me and J arguing about when I woke up, because I was convinced it was further back."* (Pete)

Pete found it difficult that his missing time whilst sedated and ventilated had contributed to his missing memories, memories which Jess now held for him instead. Pete considered this contributed to a loss of control he had over his recall of this lost time and events.

4.2.6 A means of self-protection

Some participants considered the missing memories to be a positive thing. They explained that the less you remembered, the better as this was a method of self-protection:

> *"The less you know, the better, really thinking about it. If I'd known at the time my heart probably would have stopped."* (Diane)

Janet reported feeling lucky because she could not remember. She considered this had helped her avoid the dreams, nightmares and hallucinations often associated with a critical care stay:

> *"I had a good rest. I had a good holiday"* (Janet)

Colin also reported these missing memories were beneficial for his emotional wellbeing. He knew he would have frightened if he had been aware of the situation:

> *"I don't remember a thing – and I said, in a way, I said, I would rather it happened that way than somebody coming up to me and saying, J we've just got to cut your chest open and it's not looking good, you might not make it. I said – I'm glad I did! – But I said, that would have frightened me to hell."* (Colin)

The most important finding from this category was the need for participants to address and process these missing memories in-order to make sense of their situation. Through making sense, they could achieve a degree of closure on this period of their life and only then could they truly embrace the second chance at life receiving critical care had afforded them:

> *"I am one of them people that wants to know. Yeah, because I think its closure for me then, and I can continue forward in a more positive way."* (Lee)

4.2.7 Category summary

In summary, the category *missing memories of critical care* consisted of four focused codes: 1) 'there's a lot I don't remember,' 2) 'where and I and why am I here?' 3) 'missing memories causing discord' and 4) 'a means of self-protection,' which represented the participants' experiences of living with missing memories of their critical care stay. It has been demonstrated that these gaps in memories occurred prior to, during and following the critical care stay and were reported by some to be a means of self-protection whilst others expressed a desire to address these so that they could move on with their lives.

4.3 Sensing an altered reality from CCU through to home

> *"But to me, my hallucinations weren't hallucinations, they were real."* (Jeff)

The category *sensing an altered sense of reality from the CCU through to home,* comprised four focused codes which are presented in Figure 4.3. This category generated the most data from the interviews as the participants wanted to share their memories of dreams, nightmares and hallucinations whilst on the CCU and how these continued to infiltrate their life. A key finding was that the participants were unable to ascertain which memories related to real or unreal events. This made it difficult for them to process the memories and to make sense of what they had experienced as demonstrated in the following quotation from Alan:

> *"It's almost like it didn't happen, and I mean I mentioned the hallucinations because I was very, very confused, and at first I wasn't confused, I thought I was in a war zone, I thought I was somewhere...and I was so confused... But at first I wasn't confused, it was just reality going around me...but it was a bit strange, but I think finally when I managed to realise that some of the things were odd,*

it took me quite a long while actually, that, you know, and things... that was a sort of trigger for knowing things were getting better. And then... so the reality was, it wasn't like a reality at first ... " (Alan)

Initial Code	**Focused Code**	**Category**
What was real What was not real	Distinguishing between memories of reality and unreality	**Sensing an altered reality from the CCU through to home**
Appearing to be asleep Waking up exhausted The nurses became my nightmares I saw the nurses faces in my nightmares The equipment contributed to my nightmares	Remembering dreams and nightmares	
Family being called in to pacify patients	Family providing some sense of reality *(FS)*	
Being a difficult patient Being visited by deceased relatives *(FS)* These continuing on the ward The environment feeding these Being lucky not to experience these	Remembering hallucinations	

Figure 4.3. Category: sensing an altered sense of reality from the CCU through to home

4.3.1 Distinguishing between memories of reality and unreality

> *"I remember that we had two nurses on that night and there was another patient who was laughing because he was worse off, and as I say, I don't know whether this was a hallucination again or not."* (Sean)

This quote from Sean highlights many participants' ability to distinguish which memories related to real or unreal events during their CCU stay. This experience led to confusion and disorientation for the participants:

> *"I was so confused ... But at first, I wasn't confused, it was just reality going around me. But it was a bit strange, but I think finally when I managed to realise that some of the things were odd, it took me quite a long while actually, that, you know, and things ... that was a sort of trigger for knowing things were getting better. And then ... so the reality was, it wasn't like a reality at first"* (Alan)

Sean recalled how simply moving beds within the unit demonstrated his understanding of reality and unreality. As he became less dependent he was moved from one bed-space to another:

> *"When I was in here in the first bed and then ... when I was in the second bed, they're two really distinct differences in the state in what I saw and what I remember and what was real and what wasn't real."* (Sean)

Other participants remember witnessing events which were real to them, even though they were being told the contrary. This became an issue for some participants as described below by Jeff, when the nursing staff attempted to re-orientate them to reality, the participants simply did not believe what they were saying:

> *"He says, you know, the sedation that you've been on and you're now coming off it, you will get these hallucinations, and he tried to explain it. But to me, my hallucinations weren't hallucinations, they were real...and so I was quite blunt with him actually and I said, look, I know what I can see, and I know what I can hear, so don't fob me off with this bull. And he was sort of, oh, OK, OK, and he didn't pursue it any further, because I was a bit agitated with him because I was thinking, he's just trying to cover it all up, you know."* (Jeff)

As the participants became more aware of reality, these feelings turned to guilt and contrition regarding their behaviour towards the nurses. This became an added burden for the participants, with Karen, Mike, Sean and Derek referring to themselves as difficult patients:

> *"I recall being a nightmare of a patient. I am very old fashioned. I know I put them through hell."* (Derek)

In contrast others relied on the nurse to confirm that their memories were true. Beverley recalled:

> *"I remember this lady really clear, I can't ... I don't know her name. And it was... it was like I wasn't dreaming it, it was real. It was real, because everyone said, yes, she was here."* (Beverley)

The findings demonstrate that the participants were unable to distinguish which memories related to real or unreal events. This made it challenging for them to process, interpret and understand the reality of their critical care stay.

4.3.2 Remembering dreams and nightmares

> *"Some really weird, really weird dreams"* (Karen)

Many participants remembered dreams and nightmares whilst they were sedated. This was often referred to as the time they were 'asleep.' The most significant memory they had of this time was recalling the nurses faces becoming their dreams and nightmares:

> *"When I was sedated they woke me up three times. The nurses I saw then became my dreams and nightmares when I was sedated again. I could remember their faces. I can remember that I thought they were ripping a baby out of my stomach."* (Fiona)

Karen also talked about:

> *"I associated her face into a very weird dream. She was the nurse that was trying to stop me from killing an evil patient [laughs]. But I remember her talking to me by name. It was a bit strange; it was definitely strange. I mean a lot of the faces I integrated into weird dreams."* (Karen)

A daily sedation hold is common practice on the CCU. When the sedation is stopped, and the patient's level of consciousness allowed to lighten. The rationale for this is to keep the neuro-muscular junctions active and to enhance respiratory weaning. However, Fiona recalled this to be a traumatic experience which allowed the nurses to infiltrate her dreams. Following this interview, I wrote up a reflexive memo outlining the effect of this account had had on my own feelings as a former critical care nurse. This is presented in Figure 4.4.

Reflexive memo: *When I heard more than one participant recall the critical care nurses becoming faces in their dreams, I found this really upsetting. It did however explain to me a lot of things. If these patients believed we as the nurses were trying to harm then, this explains why sometimes critical care patients would be combative towards us and not compliant with their care. It would also explain why at times the patients can appear frightened and agitated.*

It also highlighted to me that even though we are trying to do our best for our patients and that all the medical evidence supports the use of daily sedation holds as it has a positive effect on patients' muscle tone and their ability to wean from the ventilator, from a psychological point of view, if we then become their nightmares when we re-sedate them… how can this be in the best interests of the patients?

Figure 4.4 Reflexive memo on nurses faces becoming dreams

The memories of nurses infiltrating the participants' dreams and nightmares were frightening for the participants who were sedated and ventilated because they were unable to communicate that they perceived the nurses were trying to harm them. Not only was this damaging for their emotional well-being, but it also influenced their compliance with treatment as the participants believed the nurses were trying to harm them rather than care for them:

> *"I got stressed out sometimes because the dreams were … they weren't good people. I saw their faces and… but was probably when I was freak … you're accusing them of all sorts, or you're dreaming they're doing all sorts."* (Karen)

Another common theme to these dreams was water. Pete recalled being near water with trainee lifeguards. Sheila also remembered being in water:

> *"I was in this swirling water, but I was in this building, but it was attached to the hospital. They said I was an extra in this film they were doing. I said, 'I don't know if I really want to do it', and they said, 'You've got no choice now'. The next thing, I had to get into this swirling water."* (Sheila)

Drawing upon my emic stance and understanding the CCU environment and equipment, it is possible that these memories related to the humidifier attached to the ventilator. The gases audibly bubble through heated water to become humidified.

Diane remembers dreaming of a praying mantis, however her daughter explained to her that this was likely to have been when the nurses changed the drug lines attached to the central line in her neck. This memory illustrates that even the most innocuous of nursing activities can infiltrate the patient's dreams and memories of receiving critical care:

> *"I was unconscious and having my funny dreams for some reason in my dreams were these insects which I can only describe as like a Praying Mantis … and I was convinced that they were in my neck …and that birds were fluttering by my ear. But I've since been told that it would have been when they were changing the lines … and connecting things to my neck."* (Diane)

Finally, Sheila remembered the persistent nature of the nightmares and the conscious effort she had to make to manage these and prevent them from intruding on her life. This had an influence over the participants' ability to move on with life:

> *"Still to this day I remember it all so clearly, and that is amazing, because those nightmares I had to really push out of my mind and keep telling myself, don't think about it, it's gone, it was a bad dream."* (Sheila)

4.3.3 Family providing some sense of reality

Through these hallucinations and again a belief that the nurses caring for her were trying to harm her, Karen lost trust in the nurses. The hallucinations had instilled feelings of anger directed towards the nurses. The nurses were unable to pacify Karen and they had to rely on family to calm her down:

> *"Yeah, they had to phone my son up a couple of times and get him to come up and sit with me, yeah. I think it was because I recognised his voice ... and because he was ... I suppose they could calm me down to a degree."* (Karen)

4.3.4 Remembering hallucinations

Similarly to remembering nightmares when they were asleep, the participants recalled hallucinations when they were awake. For some like Derek, these were distressing, and they were still unwilling to disclose them not only in the interview but also to others including family members. This could have implications on their health and well-being. Derek recalled he still had not talked about his hallucinations as they were too vivid and frightening:

> *"I did have hallucinations and they were very frightening. They were really really bad. I have never told anybody about them they were too bad."* (Derek)

Once again, it was a common experience that the nurses figured in these hallucinations. Alan recalls seeing a Welsh dragon as he was being cared for by a

Welsh nurse. Jeff remembered wanting to report the night staff for misdemeanours he had witnessed, whilst Diane remembered one nurse smuggling champagne onto a boat. Meanwhile, Karen's hallucinations had further implications for her care:

> *"Yes, because I wasn't listening to the nurses because they were all CSIs that were trying to experiment on me … No, I was angry because they were experimenting on me and I weren't having none of it! [laughs] I was really angry at them! I think it was one of the times they were there, they couldn't … their voices and that couldn't calm me down and … yeah, because they were the ones that were trying to experiment on me"* (Karen)

The critical care equipment contributed to the hallucinations. Diane remembered:

> *"The monitor that was on the wall at the end … had a picture of a monkey on it in my head … I kept saying to them, where's that monkey up there? No, it isn't, it's the screen, he kept saying … [laughs] so I don't know where it all come from!"* (Diane)

Others made sense of these hallucinations through attributing them to the drugs they were on. As Colin reported:

> *"Another thing I found, that the morphine was causing me to have hallucinations …"* (Colin)

Sean was aware that the opiates he was prescribed were hallucinogenic, whilst Mike reconciled the hallucinations as a 'trade-off' for being kept alive:

> *"I mean it was a lot of gibberish to start with and that's down to the amount of drugs I probably had to keep me alive, which I understand, and there's going to be a price to pay which I'm going to pay."* (Mike)

Not all the participants however found the hallucinations unpleasant. Derek got comfort from seeing his deceased father whilst Lee said he:

> *"… saw lights outside my bed at 4.00am, the day of the surgery, and the only thing I can put it down to was my grandparents telling me, 'Calm yourself down, your surgery is going to go great'. I then got back into bed and slept."* (Lee)

These participants derived comfort from these hallucinations in the knowledge that they were not alone. They provided reassurance that if they did not recover, like their deceased relatives they would be fine.

There was one deviant case for this category. Janet, who had been discharged from the CCU four months before had very little recollection of anything and reported not remembering any dreams, nightmares and hallucinations. Interestingly, Janet displayed relief saying:

> *"I think I was one of the lucky ones."* (Janet)

4.3.5 Category summary

In summary, this category of *sensing an altered reality from the CCU through to home,* consisted of three focused codes: 1) 'distinguishing between memories of reality and unreality,' 2) 'remembering dreams and nightmares,' 3) family providing some sense of reality 4) 'remembering hallucinations.' The key finding from this category was, the difficulty expressed by participants to process and make sense of what had happened, because they were unable to distinguish which memories were of real or unreal events. Their inability to do this meant that for some these memories of sensing an altered reality persisted and continued to intrude on their existence.

4.4 Feeling reassured yet powerless.

Presented in Figure 4.5 are the three focused codes that represent different characteristics of the category: Feeling reassured yet powerless. The most significant finding of this category was the pockets of memories of feelings powerless yet safe and secure at the same time.

Initial Code	Focused Code	Category
Remembering voices Remembering faces Becoming emotional at seeing family members for the first time Providing reassurance Hazy recollections	Pockets of memories *(FS)*	**Feeling reassured yet powerless**
Feeling voiceless Feeling embarrassed Feeling powerless	A total dependency on others	
The one: one care Family presence *(FS)* The constant presence of the nurses	Feeling reassured	

Figure 4.5 Category: feeling reassured yet powerless.

4.4.1 Pockets of memories

> *"I've got odd glimpses of things, but I don't really remember"* (Karen)

As the participants woke up on the CCU, they reported hazy memories emerging. Alan reported:

> *"I was very hazy and unfocused"* (Alan)

Memories of voices and faces were strong for the participants. Throughout the haziness, many specifically recalled:

> *"I heard odd words. I mean I remember hearing a lot of voices ... you recognised voices."* (Karen)

Whilst hearing voices was important as it demonstrated to the participants that they were not alone, the tone of voice was equally influential. Participants recalled a calm voice provided reassurance which enhanced their compliance with care:

> *"The voice was very calm, so you didn't mind them pulling your arms around or whatever."* (Karen)

They also recalled seeing faces. Whilst as presented in Section 4.3.2, this was not always a positive memory but for some, recognising faces prompted an emotional response as they recognised their loved ones:

> *"I saw Bethany [his daughter] first and I nearly cried, because I remember being emotional for some reason."* (Alan)

Marrying the two attributes of a smiling face and calm voice together provided additional reassurance for the participants. Karen recalled:

> *"She was just a face that would … sometimes I remembered what she said, sometimes I couldn't understand what she said, but I think it was just the tone of voice and she always had a smile and she seemed nice."* (Karen)

The overall impact of these glimpses of memories was that the participants reported feeling reassured. This enhanced their compliance with care, as their level of consciousness improved.

4.4.2 Total dependency on others

> *"I was still in a bed, flat on my back, so they were doing everything for me really"* (Jeff)

Whilst the glimpses of memories of kind faces and calm voices provided reassurance, the participants also recalled a total dependency on others for their existence. They often spoke of memories of embarrassment and powerlessness at this degree of need.

The memories of powerlessness were associated with two things. Firstly, the presence of the ETT (with or without sedation) rendered them voiceless. Not being able to communicate led to feelings of terror for some:

> *"It was quite terrifying knowing … feeling what I was feeling and knowing that was happening but not being able to explain it properly."* (Sean)

Others reported being marginalised by the powerlessness, unable to have the autonomy to make simple choices. Diane recalled the radio playing:

> *"I just can remember them having the radio on and all this music and thinking, oh, I wish somebody would turn her off! But obviously I wasn't conscious*

> *enough to say anything… I couldn't say anything, or even to let them know that I didn't particularly like her music! [laughs.]"* (Diane)

Some remembered using the naso-gastric feeding tube in their nose to regain some control. Pete recalls pulling it out and the nurse having to resite it, whilst Sean remembers consciously removing it to assert control over his care:

> *"I remember doing that and I think it took them a couple of hours to notice I'd done it and that was a bit part of my actual healing process because I'd asked for it to come out and I'd explained why … and there was no way that it was going to be taken out, so when I did, and I had six or seven different doctors with me and I explained to them why I've done it and what I needed …" (*Sean)

Although embarrassed by this dependency, some were grateful for the care they received. Many remembered small things including the dignity displayed by the nurses as they washed them; having their hair washed; being moved around the bed or sat out in a chair and eating for the first time. Many recall being thirsty:

> *"I'd never been as thirsty in my entire life."* (Alan)

Beverley and Diane recalled the relief of the 'pink stick' used to relieve their thirst. This is a sponge in a small stick designed to provide mouthcare, which can be soaked in water and given to the patient to suck on to relieve thirst.

The second aspect of powerlessness related to toileting. Dave, Colin, Alan and Fiona all reported feeling embarrassed and helpless over their bowel activity. Sean summed this up:

> *"I had no warning or control over that as well, which was again quite embarrassing. So, the nurses, you know, cleaned me up and the bed and however bad it was they dealt with it really well."* (Sean)

Like Sean, others reported being ashamed but grateful for the compassion the nurses showed in this situation. Dave recalled:

> *"I couldn't toilet myself or nothing. Those poor nurses you know, they just did it, that's it."* (Dave)

To address this loss of autonomy, the participants recalled the nurses strived to return it as their condition improved. They did this through offering choices such as using the toilet or commode:

> *"When I needed the toilet, they asked if I wanted to use the bedpan by the bed or if I wanted to go to the toilet – I wanted to use the loo."* (Fiona)

4.4.3 Feeling reassured

> *"It's security to know that they're watching you, they're watching the monitors. Yeah. Well, it's just safety, I knew I was safe."* (Colin)

Despite these feelings of powerlessness, the participants recalled a strong sense of feeling reassured and safe and secure on critical care. This not only related to the face and voice, but also to the constant presence of the nurse and the one-to-one care they received:

> *"An element of that is the level of care I was receiving from the nurses, and I suppose ... what they do for me? I suppose it's a reassurance, because they're so constant."* (Pete)

The presence of the nurse reassured the participants through providing a sense of peace and reducing feelings of panic and they never felt alone or abandoned. Derek explained:

> *"Having them in sight helped me a lot. I just knew they were there."* (Derek)

The participants also recalled never having to wait for care on the CCU. For Fiona she felt she was never alone:

> *"I never felt alone. I never had to use the call button. They were always near me."* (Fiona)

However whilst the participants reported feeling safe some were concerned that such close surveillance reduced their privacy. Sean reported:

> *"Sometimes you didn't feel like you had that privacy or be able to do things."* (Sean)

The communication provided by the nurses also promoted feelings of security. This was because the participants reported feeling less anxious because they knew what was going to happen.

> *"I was constantly told what was happening to me. I was never at the point where I thought, ooh, why are they doing this?"* (Diane)

In contrast though, as their condition improved, and the level of support reduced, some reported feeling unsafe. This resulted in a conflict between staff and the participants as the nurses perceived this indicated that their clinical condition was improving, whilst they reported feeling anxious and concerned about the reduction of support. Pete bargained with the staff when they came to remove his tracheostomy:

> *"I knew it was serving a purpose and it was keeping me alive. In having it out … removes one of your safety nets."* (Pete)

For others, these feelings of security became problematic as they became over reliant on the one-to-one care. This made the process of leaving the CCU a challenge for some with them feeling anxious:

> *"In my heart of heart, I didn't want to leave."* (Beverley)

4.4.4 Category summary

In summary, this category of *feeling reassured yet powerless.* consisted of three focused codes: 1) 'pockets of memories,' 2) 'a total dependency on others' and 3) 'reassured by feeling safe and secure.' The key finding identified through this category was that as memories appear, a juxtaposition develops between memories of the powerless associated with receiving critical care and the reassurance afforded by the safety and security of such care.

4.5 Feeling abandoned on the ward

> *"When I went from the CCU to the general ward it was like going to a Third World country."* (Sean)

As their clinical condition improved, participants recalled being transferred to other wards. All found this a difficult transition in the level of care. The focused codes presented in Figure 4.6 represent the category 'feeling abandoned.' The key finding identified here was that the participants remembered feeling frustrated with the cessation of the one-to-one care and the need to wait for, or even miss treatment, when they moved to the ward. They perceived this prolonged their hospital stay and impacted on their return home to a normal life.

Initial Code	Focused Code	Category
No-one answered the buzzer A lack of staff Missing a personal approach to care A lack of 'Emotional Intelligence' Poor organisation of workload A lack of family-centred care *(FS)*	The care 'just seemed to disappear'	**Feeling abandoned on the ward**
Poor competence Missed drugs Lack of IV access	Delays in treatment	
Reduced accessibility to care Having to do things for yourself	Promoting independence	
Leaving hospital Going home back home	One last transition	

Figure 4.6 Category: feeling abandoned on the ward

4.5.1 The care 'just seemed to disappear'

> *"When I went to the normal ward it [the care] just seemed to disappear."* (Beverley)

Most participants recalled the most challenging time for them was leaving the security of the CCU and being transferred to the 'normal ward.' Most reported feeling abandoned at this point:

> *"I felt lost."* (Dave)

It was the difference in the accessibility to care that the participants found most problematic. Beverley, Diane, Colin and Sean all recalled a long wait for someone to respond to their buzzer – which was the only means of summoning assistance on the ward. Sheila recalled feeling humiliated by one particularly long wait:

> *"I had pressed my buzzer desperate for a commode, and fortunately I was wearing pads at the time, and I actually sort of timed it and it got to ¾ of an hour, and I couldn't do anything myself."* (Sheila)

Without exception, the participants attributed these feelings of frustration to the removal of one-to-one critical care, a lack of nursing staff on the wards and a difference in competence between ward and critical care nurses:

> *"If you break it down to its lowest level it's probably the numbers of staff per patient primarily and also the level of the staff, comparing the two."* (Pete)

Whilst Mike recognised there was a lack of staff on the wards, he also reported issues with accessibility to care related to nurses wasting time on inappropriate tasks such as going from bed-space to bed-space to fill water jugs up rather than doing it all at once. Sean also recalled poor organisation in the task allocation of care:

> *"In the general ward you had one nurse that came round and did the observations, one that came round and gave you your pills, one that came round and gave you IV medicine, one that came round and, you know, it was a much longer process to get what would take five minutes if one person did everything."* (Sean)

Some participants recalled the emphasis of care was different on the ward. They reported this transferred from family-centred in critical care, to patient-centred:

> *"You went from the patients and the reli's [relatives] being the priority to I suppose to an extent the patient still being a priority, but not as a package."* (Pete)

Consequently, Pete became isolated from his three children who were not allowed to visit him on the ward because the nurses felt it would be "deeply traumatic and upsetting." The nurses failed to understand that Pete's children had been visiting him regularly on the CCU, even when he was sedated and ventilated and had adjusted to seeing their critically ill father. This again had a significant impact on Pete's emotional wellbeing.

Alan attributed this situation to a difference in the emotional intelligence displayed between CCU and ward nurses. He remembered the CCU nurses:

> *"The staff were great because they were very cognisant of the impact on the family, they had the … they were trained to a high degree of emotional intelligence"* (Alan)

The participants recollection of how they were addressed by the ward nurses could also be ascribed to this lack of emotional intelligence. Dave remembered:

> *"I'd rang the bell, I wanted toileting, and she's, "Well come on then, get out of bed" you know, "Well I can't" and '"Out of bed," and another nurse joined her to help, "He has to be hoisted," "He can get out of bed" and everything, I said, "Are you ordering me to get up?" "Yes," but the other nurse stopped it."* (Dave)

Others were distressed by the manner in which the ward nurses addressed them. Colin recalled:

> *"One day I just totally lost the plot and broke down and mother went out and said, I think you'd better come and have a look at Colin, he's in a bit of a state, and she just put her head round the door and said, what's wrong with you? I thought ... isn't this big scar down the centre of my chest, the fact that I've been rushed in here and very nearly died."* (Colin)

4.5.2 Delays in treatment

Some participants reported frustration at having to wait for or even miss arranged treatments. Sean reported:

> *"The frustrating thing was the only reason I was still in hospital waiting to go home was because I needed the IV antibiotics ... and they were set for certain times ... and I wasn't getting them for hours later"* (Sean)

Some of these delays were reported as due to a lack of competence by ward staff. For Sean, the ward staff did not know how to administer the antibiotic, and he was frustrated that his treatment was delayed by 12 hours whilst they waited for the pharmacist to review the prescription. Colin remembered the staff were unable to put a cannula into him for 12 hours and he too missed treatment which led to feelings of frustration and anger.

4.5.3 Promoting independence

In contrast to the other focused codes, some participants recognised the care was still evident on the ward but it 'was just different.' Some chose to draw on the positive aspects associated with this such remembering they had to develop less reliance on the nurses and become more independent. For some, like Sean who wanted to return to independence as early as possible this was easy. Similarly, Jeff concluded:

> *"They did less for you on the ward, you're left more to your own devices on the ward, it makes you realise you've got to do things yourself rather than nurses do it for you."* (Jeff)

4.5.4 One last transition

Generally, participants looked forward to leaving hospital and going home. However, Sheila explained that she wished to hear from her lead neurologist that she was ready to go home as he had provided her care for the past three months:

> *"Hold on' I said, I've had Dr B looking after me ever since I came out of ITU, and I said, and I feel that the length of time I have been here that he ... it would be nice to hear it from him, the horse's mouth, you know."* (Sheila)

After so long in hospital she clearly found the transition to home a frightening prospect:

> *"The next thing is, I said, I am going home to what? Is this all going to come to a grinding halt? I was more concerned about that than anything ... I thought after the length of time, what I'd been through, what the nurses had been through, I'm in their hands, and they had done so much."* (Sheila)

Alan and Sean both described the breakdown in communication regarding the discharge itself. Alan's team had interpreted that he wanted to go home on a Friday before the weekend and moved fast to ensure this happened, even though he had not requested this. Sean also described the speed at which he was discharged:

> *"I was still in my hospital pyjamas, and a lady walked over with a wheelchair and said, I'm here to take you down to the waiting room. Haven't they told you that you're leaving today? I was like, yes, but not 'til this afternoon. Oh, well we need the bed. And I was like, yeah, I haven't even had my bloods taken yet."* (Sean)

Alan in contrast found getting to go home the easy bit. It was the psychological and social pressures of life after which he found challenging:

> *"I had financial security for a while and then they said, well, unless you come back to work soon we're going to have to stop paying you. That compelled me then to go back to work too soon …"* (Alan)

4.5.5 Category summary

In summary, this category of *feeling abandoned on the ward*, consisted of four focused codes: 1) 'the care 'just seemed to disappear,'' 2) 'delays in treatment,' 3) 'promoting independence' and 4) 'one last transition.' The key finding of this category was that when participants were transferred to the ward, this was a particularly challenging period in their critical care, related to the cessation of the one-to-one care, long waits for care and missed treatment. Whilst many found this difficult and attributed it not only to poor staffing levels, but issues with emotional intelligence and competence as well, others found it helpful as it encouraged their independence.

4.6 Filling the gaps; reaching closure and moving on with life and survivorship

Within the category *filling the gaps; reaching closure and moving on with life and survivorship*, two focused codes represent different aspects of this. These are presented in Figure 4.7.

Initial Code	Focused Code	Category
Reliance on family to fill the gaps *(FS)* Everyday life filling the gaps Doctors on the wards	Addressing the missing memories	**Filling the gaps; reaching closure and moving on with life and survivorship**
Having everything explained Revisiting the CCU Seeing the bedspace Meeting the nurses An important closure moment "It shut the door on that episode"	The crucial role of follow-up	

Figure 4.7 Category filling the gaps; reaching closure and moving on with life and survivorship

4.6.1 Addressing the missing memories

Some participants recalled how they had received information on the ward about their critical care stay. Lee recalled being angry and aggressive when he was on the ward as he perceived that the nurses were withholding information regarding his admission. This was because they were telling him he had been admitted with a chest infection, when he recognised from the level of activity he received and the fact he had been on CCU that this was not totally true. Eventually a doctor pulled the curtains around him when he was on his own and explained:

> *"You are here because you died. You had a cardiac arrest, and I'd advise you to calm yourself down."* (Lee)

The delivery of this news made Lee feel frightened and alone. He also then reported feeling guilty for his behaviour. Sheila too recalled being told similar news, again on the ward and on her own:

> *"This doctor had pulled the blinds round the bed not realising my legs couldn't move – he told me I had this Guillain-Barré, and he explained it can take a long time. I said, how long, and he said up to two years. He said I was going to have to be very patient, and I went, 'Oh …' Anyway, with that he left me, and the blinds were still round my bed. I was on my own. Now, I know I pulled the sheet over my head, I had a good howl, and then that was when I went to move and couldn't. That topped it."* (Sheila)

These memories demonstrate just how important it is for information to be delivered in a sensitive and timely manner. In these examples described the nature of the information- giving had left the participants feeling distressed, upset and alone.

The participants' families were also an important way of helping to address the missing memories and provided some of the schemata proposed by Bartlett's (1932) theory of reconstructive memory which may contribute to participants reconstructive memories of their care. Diane explained:

> "*My daughter and that explained to me what had happened.*"(Diane)

The family members had often kept a diary either independently or as a suggestion from the nurses. Whilst an emotional experience to read these, the participants reported the diaries helped them again reconstruct their memories of their time in CCU and these may have helped address the missing memories:

> *"I just started reading it [the diary written by Jess his wife] and, you know, don't get me wrong, it's incredibly hard emotionally, but it was like also quite what I found it very helpful in building up the whole picture, but it was filling in what happened was happening while I was asleep"* (Pete)

For some participants, events in everyday life would stimulate their memories. Beverley recalled watching a person on the television being hoisted out of bed and she reported suddenly remembering being moved out of bed that way. Others found that memories returning at unexpected moments which unsettled them:

> *"I was just busy working away and something banged, a cupboard door, and all of a sudden I was back. I went, ooh! It really unnerved me."* (Diane)

Dave found participating in the interview had helped his memories of events. This is demonstrated through the following exchange:

> *Listen Dave, it's been brilliant talking to you, it's been lovely to hear your story and your recollections. Thank you every so much.* (Me, interviewer)
>
> *'You've helped bring some back actually.'* (Dave, patient)
>
> *'What?'* (Me, interviewer)
>
> *'You've helped bring some back.'* (Dave, patient)
>
> *'Have I?'* (Me, interviewer)

> *'Yeah.'* (Dave, patient)
>
> *'And is that a good thing?'* (Me, interviewer)
>
> *'Definitely, yeah.'* (Dave, patient)

Both Karen and Pete reported the follow-up meeting helped them reconstruct memories. These helped with the gap in memories through putting the "*pieces of a jigsaw together*'." (Diane and Pete).

4.6.2 The crucial role of critical care follow-up

> *"Coming in with Marie [the follow-up sister] and Alex [the consultant] was about sort of closure …"* (Alan)

This category brings the findings full circle with the participants' need to address their missing memories. As with family members, critical care follow-up also provided some of the schemata from Bartlett's (1932) theory which contribute to reconstructive memories of critical care which may help fill the missing memories. These were provided at follow-up meeting with the lead Intensivist (that is the senior clinician on critical care) and the Sister as they gave information on participants critical care stay and answered their questions. All participants except Colin and Lee had attended this meeting where they received an explanation of events that had taken place from the moment they were taken ill to the moment they left the CCU. Participants recalled this being helpful as it provided a strong realisation of just how critically ill they had been:

> *"When I came back to the follow up, that's when it really hit home how serious I was … because they went through, having a heart attack, having kidney, my heart and all that lot, explained why I had all the machines and everything …*

> *you know, and I'm there thinking, oh my God! You know, I was ... it was really ... you know, an eye opener to me."* (Beverley)

The notion of emotional intelligence returned as Alan recalled a very well structured, meeting delivered with a high degree of sensitivity:

> *"They all showed a high degree of emotional intelligence and sensitivity."* (Alan)

Likewise, Mike appreciated a written report to which helped provide further schemata used to contribute to his reconstructive memories of critical care:

> *"It puts some flesh on the bone, if you know what I mean ... I can understand I was here, I hadn't got a clue why I was here at the time, but then they sort of said, well this happened and that happened and then this. Oh yeah, OK, it all makes sense."* (Mike)

Alan explained how the meeting explained a lot to him about his critical care stay, but he also saw it as a key milestone in his recovery explaining how much better he felt after the clinic meeting:

> *"That was an important milestone. I came out of here feeling unburdened, it really did feel like a weight had been lifted. And it was also revelation because I didn't know most of the stuff they told me."*(Alan)

During this follow-up meeting, participants visited the CCU to see where their bed was and meet the nurses who had cared for them. For many this was a difficult visit, but it helped them realise what was and was not real as described by Sean:

> *"I thought my bed had all this room behind it ... and it was only when I came in and I saw, it was like, are you sure this was the bed I was in the whole time, and they were like, yeah, and I was like ... but I had all this space behind it. But until I actually saw it afterwards, part of that seemed so real because ... the bed looked the same, everything was the same, the nurses' station was there, the windows were there, you know, in the later days that I was in, but it seemed real, but like I said, there were bits that seemed real that can't have been real."*
> (Sean)

Diane appreciated the chance to meet the nurse and put a face to a name. Others like Sean saw this as a time for atonement for their behaviour on the CCU.

As Alan explained this meeting helped him achieve a degree of closure on this episode in his life:

> *"They explained... complete debrief about what happened, because I didn't really get all of this and there are things that I'd only heard from you and they really did explain to me, and for me it was an important closure moment. To be able to say, right, now I get it...now I'm better than I was, I'm improving, and it sort of shuts the door on that episode."* (Alan)

4.6.3 Category summary

In summary, this category of *filling the gaps; reaching closure and moving on with life and survivorship* consisted of two focused codes: 1) 'addressing the missing memories and 2) 'the crucial role of follow-up.' The key finding in this category was the participants' need to address the missing memories and how reconstructive memories of their critical care may help achieve this. Through addressing their missing memories, some participants reported achieving some degree of closure on this moment in their life and the chance for their critical care survivorship to progress as they were able to move on with the second chance of life they had been given. This category demonstrates how the follow-up meeting was a very helpful strategy to support this ability to reach closure and move on, whilst family members were also helpful at filling in some of the gaps.

4.7 The importance of family members strand (FS)

	The importance of family members strand	
Category	**Identified in the Initial Code / Focused Code**	**Reference to family and family-centred care**
Missing memories of critical care	Family members knowing more Arguments with spouse over events and disclosures	X
Sensing an altered reality from CCU to home	Family providing some sense of reality Being visited by deceased relatives	X
Feeling reassured yet powerless	Becoming emotional at seeing family members for the first time	X
Filling the gaps; reaching closure and moving on with life and survivorship	Reliance on family to fill the gaps	X

Table 4.3 The family strand

Table 4.3 demonstrates the strand relating to the importance of family members on patients' reconstructive memories of critical are. It demonstrates that in all four categories identified, the presence of family or family-centred care was discussed by participants.

As the analysis of findings from the patient interviews progressed, a strand was identified across the four categories in relation to the importance the participants placed on their family members and how family members were central to their reconstructive memories of critical care. Indeed participants also considered the care on CCU was family-centred care where both themselves and family members were recipients of care:

> *"They're not looking, it's patient centric, but actually it's completely 360 of the whole family."* (Alan)

Once on the ward the family-centred approach to care seemed to diminish despite there being a continued need for this. Pete commented as he moved from CCU to the ward the focus shifted:

> *"You went from the patients and the reli's being the priority [on CCU] to I suppose to an extent the patient still being a priority, but not as package"* (Pete)

Within the first category *missing memories of critical care* as highlighted in section 4.2.3, participants would discuss how strange and disconnected they felt when their relatives seemed to know more about what had happened to them on critical care than they themselves did. They also found it odd how the nurses on CCU seemed to know their relatives really well.

Participants also recognised that at times their missing memories caused discord between them and their family members and how they felt frustrated when their family members tried to correct participants' recall of events (presented in section 4.2.4). Pete also discussed how he became aware that his family had started to plan in the event of him not surviving and how this made him recognise that his time in CCU had been more stressful for his family than for him:

> *"Mentally I think the relative suffer as much if not more because for three weeks I was fast asleep … my dad belongs to the Lions Club, I had phone call, saying 'oh hello I understand you sons ill and you're looking for a property out this way.' I'm saying 'no no it's okay I am the son. It all worked out thank you. So, you know, there were all these plans is going on, because as Jess says they didn't know I was going to come back totally … and it is the planning and the prep and all these things that have to go on for day-to-day life for the relative while the patient was fast akip."* (Pete)

In the category *sensing an altered sense of reality from CCU to home,* participants like Derek and Lee recalled being visited by deceased relatives who reassured them everything would be ok:

> *"My grandparents telling me, 'Calm yourself down, your surgery is going to go great'. I then got back into bed and slept. I heard that through my grandparents. Both of them, God bless ourselves, aren't with us anymore."* (Lee)

Others reported how they relied on their relatives to help them interpret unreality from reality. Diane demonstrated this in section 4.3.2, when her daughter had helped her interpret her hallucination of a praying mantis.

Similarly, in the category *feeling reassured yet powerless,* Alan discussed how emotional he became at recognising his daughter's face. The way Alan described this moment with both distress and shock demonstrated what an important reconstructive memory of a significant moment this was for him.

In the category *feeling abandoned on the ward* (presented in section 45.1), Pete described at length the frustration he and Jess experienced as they became aware that their children were not able to visit him on the ward and how on the ward the relatives became almost inconsequential. Whilst in 'filling the gaps,' Lee explained how his wife was trying to protect him by withholding information and that this caused him more stress through not knowing. In contrast, Pete explained how a diary his wife Jess had kept during his CCU stay helped him fill in the gaps in his memories when he went home.

At times participants would describe the guilt they experienced at exposing their relatives to such a stressful ordeal. Colin summed this up when he described being readmitted to critical care:

> *"I mean you think, you know, I've got to put the family through this ... mother was getting on in years, she was very ill, and it was obviously putting a lot of strain on her ..."* (Colin)

Others described experiencing comfort when their family were nearby. Mike recalled becoming the distress he experienced when his wife was not allowed onto the unit:

> *"There was another family outside waiting to come in and they wouldn't let Chris back in until half past ten. I was in tears that day, to be honest, because I thought that she'd had enough of me. I thought, 'oh, she's fed up of this, she's*

> *had enough.' And then Chris came in. It was half past 10. It was only for about 10, 15 minutes, to be honest, but in that short space of time I thought, oh, she's had enough."* (Mike)

Mike was particularly reliant upon his wife Chris to care for him when he was on the CCU. Mike explained how when they encouraged him to do more for himself rather than relying upon Chris, this left him feeling shocked:

> *"That was a shock to the system, when they let me do it myself as well."* (Mike)

There was just one focused code where the importance of family appeared to diminish for participants. Throughout the code 'the importance of follow-up' the role of the family was not mentioned by participants.

4.8 Synthesis of the findings

The findings from the patient interview study demonstrate five key aspects to their reconstructive memories of critical care identified through the categories: 1) *missing memories of critical care* 2) *feeling reassured yet powerless* 3) *an altered reality from the CCU through to the ward* 4) *feeling abandoned on the ward* and 5) *filling in the gaps, reaching closure and moving on with life and survivorship.* Whilst these have been presented as separate entities, in reality they intertwine as the schemata (presented in section 1.1.6.2) through which reconstructive memories are developed, to fill in the gaps in memories and co-exist to enable the former patients to make sense of what had happened, reach realisation, achieve closure and to move on with their life. This is presented in Figure 4.10. As the CCA of findings progressed, an additional strand across the categories was identified which related to the importance participants placed on their family throughout their critical care experience and how family members contributed towards patients' reconstructive memories of critical care.

The participants reported a need to process their thoughts and feelings, in order to make sense of what had happened to them. Once they had had this opportunity, they recognised a moment of realisation of how sick they had been and how close to death they were. The participants reported that only with this sense of realisation could they achieve a degree of closure on this episode in their life and proceed with the second chance at life their critical care stay had provided.

The starting point to reaching realisation and closure was recognising that they (the participants) held missing memories of their critical care stay. This was problematic because not remembering what had happened to them meant they couldn't understand where they were or why they were there in a highly dependent and powerless state. They reported hazy pockets of memories starting to return as their clinical condition improved. It was at this point that they began to reconstruct their memories of receiving critical care, to try to fill in the gaps and make sense of their situation. The participants did this through supposition of their own and also drawing on third-party memories (generally belonging to family members) and memories prompted through day-to-day life. These all contributed to their reconstructive memories of critical care.

The biggest hindrance to this processing was the participants' inability to distinguish real events from unreal (imagined or hallucinatory) events. As they were unable to establish what was and was not real, it was challenging for them to process and make sense of their experience. To address this, they continued to draw further on the memories of those around them to reconstruct more memories of this time.

It is apparent that it was not until the participants received a structured follow-up meeting and had the opportunity to revisit the CCU and the bed-space, that their memories were put into context. This meeting was fundamental for the participants to reach this essential point of realisation and for them to understand what was and was not real. Only then did they report they had achieved a degree of closure and the ability to move on with their life.

Finally, the influence of family and family-centred care was identified as a strand across all four of the categories. What is interesting is that just one participant – Alan – referred to the role of critical care follow-up clinic meetings for the family, stating that whilst this was more for the patient to learn and understand what had happened to them whilst they received critical care, the clinic still remained "family-centric". Critical care follow-up adopts a primarily 'patient-centred' model and so being that the focus of this meeting was the patient and a time for them to reflect on their own critical care stay, maybe the role of the family became less important to participants at this time. However this was not explored within this study.

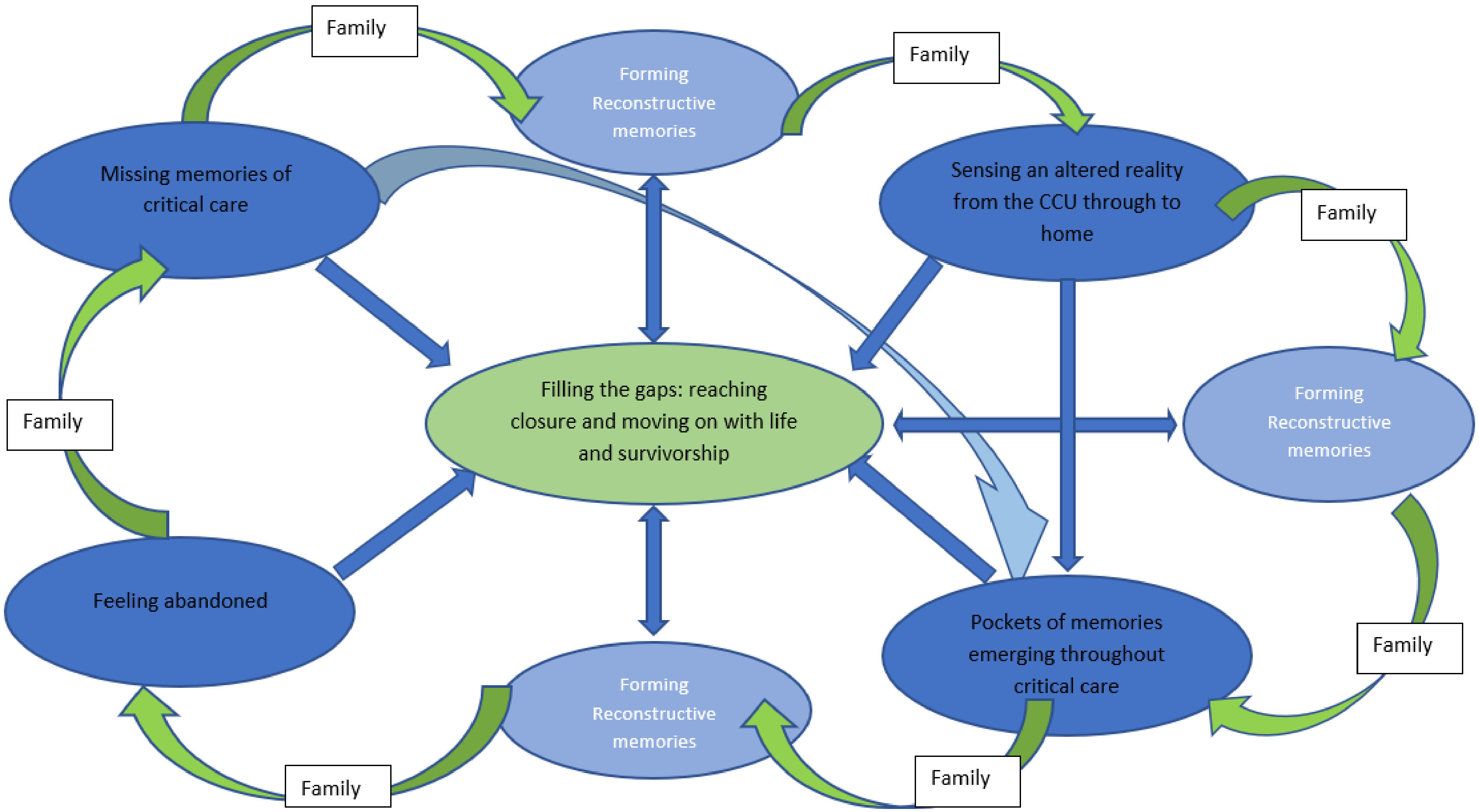

Figure 4.8 Overall schema of former critical care patients' reconstructive memories of receiving critical care

4.9 Chapter conclusion

This chapter has presented the findings from the patient interview study. Five categories were identified through the CCA of data which addressed research question one as presented in Chapter One:

> *What are former critical care patients' reconstructive memories of critical care?*

These were: 1) *missing memories of critical care,* 2) *an altered reality from the CCU through to home*, 3) *feeling reassured yet powerless* 4) *feeling abandoned on the ward* and 5) *filling the gaps, reaching closure and moving on with life and survivorship*. Additionally a strand was identified across all of the categories in relation to the importance participants placed on their family members throughout their critical care experience and their contribution to the reconstructive memories of this. Moving forward, the following chapter presents the findings from phase two of this research – the focus group study with critical care nurses.

Chapter Five: Findings from the focus groups with critical care nurses

This chapter presents the findings from a focus group study conducted with critical care nurses which addressed the second research question:

> *How do critical care nurses understand and respond to patients' reconstructive memories of critical care?*

This question comprises two components: first the nurses' understanding of patients' reconstructive memories of critical care and second, their response to these memories. Accordingly, this chapter will address their nurses' understanding of patients' reconstructive memories first and then present the findings in relation to how the nurses responded to the patients' reconstructive memories which were presented to them during the focus group.

Four focus groups were conducted with between seven and 10 critical care nurses in each group, with 33 participants in total. As presented in section 3.6 and the topic guide in appendix 3.1a, each group opened with a set of open-ended questions exploring the nurses' understanding of patients' reconstructive memories of critical care. Stimulus material (presented in appendix 3.1b) derived from the patient interview study regarding patients' reconstructive memories of critical care was then presented to the nurses to explore their response to the patients' memories.

5.1 Characteristics of focus group participants

The participants' characteristics are presented in Table 5.1. To maintain anonymity, but to again support the narrative and a humanistic perspective to the research, pseudonyms have been assigned to each participant (as recommended by Birks and Mills 2011).

The majority of participants were critical care staff nurses. These were band five nurses which is the initial grade of qualified nurse who provides direct patient care with no managerial responsibility in the UK (NHS, 2005). One participant (in focus group one) was a band six senior staff nurse who also delivered patient care but also had responsibility for managing the workload on a shift-by-shift basis (NHS, 2005).

Table 5.1 Characteristics of focus group participants

Participant	Gender	Age (years)	Length of time practising critical care nursing in the UK (years)	Band	Type of CCU
			Focus Group One		
Jenny	Female	30	4-5	5	General DGH
Sunita	Female	39	5+	5	Burns CCU
Priyanka	Female	39	2-3	5	General DGH
Susie	Female	24	2-3	5	Cardiothoracic CCU
Glen	Male	47	5+	5	Burns CCU
Rachael	Female	39	5+	6	General DGH
Bernadette	Female	32	3-4	5	General DGH
Dan	Male	34	5+	5	Cardiothoracic CCU
			Focus Group Two		
Horacio	Male	26	2-3	5	Neuro CCU
Gordon	Male	24	2-3	5	Regional Hospital General CCU
Christa	Female	27	2-3	5	Neuro CCU
Claire	Female	24	3-4	5	General DGH
Harvey	Male	27	2-3	5	Regional Hospital General CCU
Estella	Female	33	3-4	5	General DGH
Ivy	Female	25	2-3	5	Regional Hospital General CCU
Will	Male	28	4-5	5	General DGH

Table 5.1 Participants' characteristics (cont.)

Participant	Gender	Age (years)	Length of time practising critical care nursing in the UK (years)	Band	Type of CCU
Focus Group Three					
Daniella	Female	43	5+	5	General DGH
Mary	Female	27	2-3	5	General DGH
Jency	Female	32	5+	5	General DGH
Agila	Female	40	5+	5	General DGH
Helen	Female	47	4-5	5	General DGH
Jovelyn	Female	39	5+	5	General DGH
Emma	Female	24	2-3	5	General DGH
Amelia	Female	24	2-3	5	General DGH
Katie	Female	39	4-5	5	General DGH
Celia	Female	33	2-3	5	General DGH
Focus Group Four					
Casey	Female	25	2-3	5	General DGH
Beth	Female	23	2-3	5	Regional Hospital General CCU
Malaya	Female	31	5+	5	General DGH
Hope	Female	32	5+	5	Regional Hospital General CCU
Imelda	Female	26	5+	5	General DGH
Makisig	Male	26	3-4	5	General DGH
Jasmine	Female	26	4-5	5	General DGH

As presented in Figure 5.1 the majority of nurses had been practising in critical care for two to three years. Just four had practised between three and four years.

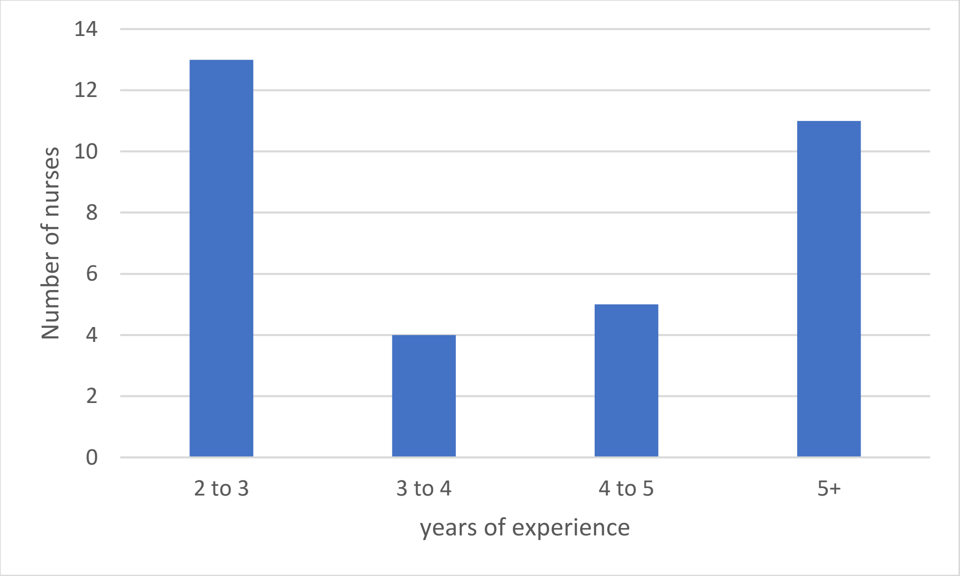

Figure 5.1 Length of time practising critical care nursing

As Figure 5.2 demonstrates 26 female nurses participated in comparison to just seven male nurses.

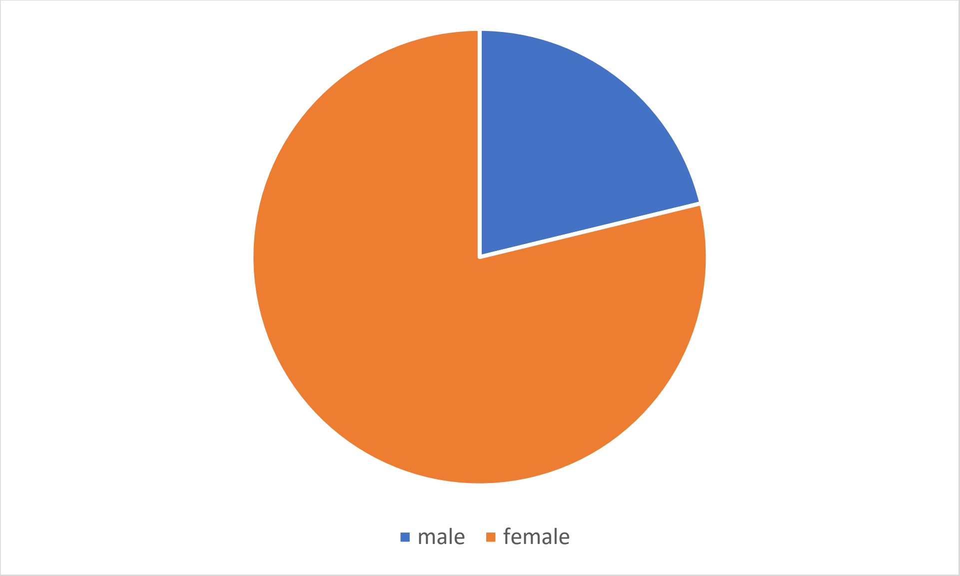

Figure 5.2 Gender of focus group participants

The age distribution of the sample is presented in Figure 5.2. The majority of participants were aged between 20 and 30 years (n=17) with just three being aged between 41 and 50 years.

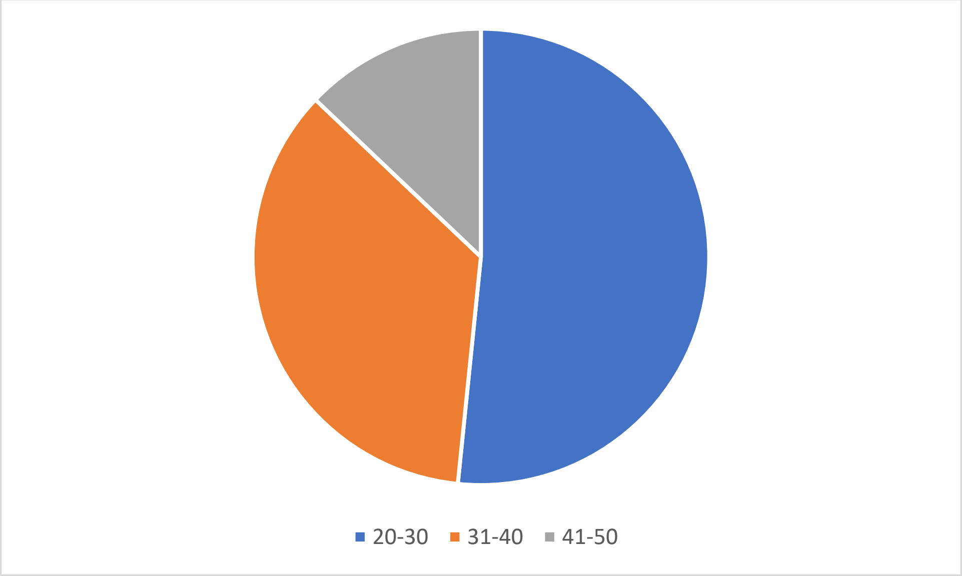

Figure 5.3 Age distribution of focus group participants

Finally, participants came from a mixture of DGH CCUs (n=22), to specialist CCUs for Burns neurosurgery and cardiothoracic critical care (n=6), which is presented in Figure 5.4. One critical care unit was situated within a large regional hospital in one of the major cities in the region and five participants practised here. Twenty participants were originally trained overseas.

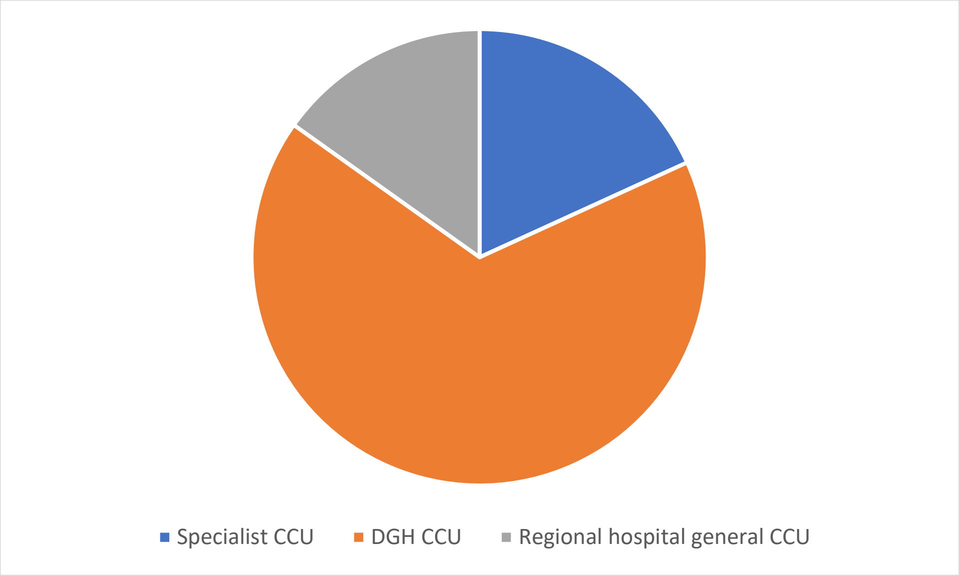

Figure 5.4 Type of CCU where nurse practice

The CCA identified five categories relating to nurses' understanding of patients' reconstructive memories of critical care which broadly reflected those identified from the patient interview study. However, the perspective of the critical care nurses was different to that of the patients and this is demonstrated through the *in vivo* codes taken verbatim from the nurses' responses. Here, the categories' substantive labelling reflected the reality of the nurses' understanding of the patients' reconstructive memories of critical care (Charmaz, 2014). The field notes described in section 3.2.2. from the focus groups also underwent CCA to identify their response to the patients' memories.

5.2 Nurses' understanding of patients' missing memories of critical care

Within this category: *nurses understanding of patients' missing memories of critical care,* four focused codes represent different aspects of this. These are presented in Figure 5.5.

Initial Code	Focused Code	Category
Not remembering anything Not remembering the bed-space Not remembering the nurses	Gaps in memories	**Nurses understanding of patients' missing memories of critical care**
Not remembering what had happened Missing out on events and time	Recognising patients do not know what had happened to them	
Arguments with spouse over events and disclosure	Recognising missing memories can cause discord	
Not believing the nurses The less they remember the better	Understanding missing memories of critical care to be a means of self-protection	

Figure 5.5 Nurses' understanding of patients' missing memories of critical care

5.2.1 Gaps in memories

Many participants across the four focus groups reported the view that patients do not remember their time in critical care. The nurses also identified this to be a problem, as described by Celia:

> *"Some patients they can't remember anything. I remember one patient recently came to visit the unit and he didn't remember anything about the space, he didn't have any memories. [It is] The problem with some of them I think."* (Celia)

Some found these missing memories surprising, particularly if the patients were regular attendees in critical care. Glen who worked on a burns unit commented on one of their frequent attendees who often tried to self-harm resulting in regular stays in critical care:

> *"He [patient] said he doesn't remember what bed spaces he was in, and he was in several."* (Glen)

There was also agreement across participants and focus groups that the patients did not recall the individual nurses who had cared for them, as reported by Horacio:

> *"They don't remember you. It happened to me I went to visit a patient on the ward, a very young chap, around 21, 22, years old, so a very young person, who I really cared for and went down to see if he was doing well, and then as soon as I went into the room, 'Who are you? Okay, fine, don't remember me that's ok."* (Horacio)

As Horacio explained this he shrugged and his mouth downturned. Whilst he stated it was fine that the patient did not remember him, his non-verbal expression demonstrated he found this to be more disappointing than acceptable that a patient he had cared for a long time on CCU did not remember him. Christa also found it *'really awkward'* when the patients came back to visit the nurses on the unit but did not know who they were.

5.2.2 Recognising patients do not know what had happened to them

Prior to seeing the stimulus material, participants were silent regarding one of the main gaps in memories experienced by the patients – that they did not know what had happened to them, where they were or why they were there.

Once participants had seen the stimulus material they recognised the confusion for patients' resulting from not remembering what had happened to them. Participants understood they were unable to make sense of what was happening to them in critical care. Priyanka reported this contributed to them feeling lost and helpless:

> *"Definitely, in the beginning, if they don't have an awareness of how they ended up there, they will feel lost, they will feel helpless."* (Priyanka)

Susie attributed these missing memories to the type of admission the patient had experienced, reporting that if patients had an elective admission, they may have visited the CCU beforehand and would demonstrate a greater understanding of the environment when they regained consciousness. However, she surmised that :

> *"If they are just in A&E and then their GCS [Glasgow Coma Scale] is reduced, and they come into the unit without really understanding or knowing how they came in, when they are awake in the unit and they see the environment it must be very scary as well and they will be like, 'Where am I? What happened to me?"* (Susie)

5.2.3 Recognising missing memories cause discord

Following the introduction of the stimulus material (presented in appendix 3.1b), all groups reported that they recognised the patients' recollections. Prior to the stimulus material, participants were silent as to the fact these missing memories can cause discord between patients and their family. It was only after the stimulus material that some of them recognised this to be the case:

> *"We've had that, yeah, a couple of times."* (Dan)

However, they also recognised this happened with nurses as well:

> *"Lots of times … It's when you tell them the date and they're like, 'No".* (Rachael)

Susie, a critical care nurse with two-three years' critical care nursing experience demonstrated surprise at this finding from the patient interview study:

> *"Really? I've never had that."* (Susie)

The other three focus groups recognised this response from the patients. However, they did not elaborate on their own experiences of this.

Some nurses understood patients missed out on life events whilst they received critical care. Hope discussed:

> *"If they've been sedated some of our patients are with us a long time, they get really sick, two, three, four weeks longer, and that's a massive trunk of their life that they've just lost."* (Hope)

Participants also understood that the patients found it difficult when they had lost time whilst on CCU. Dan reported:

> *"The thing that they can't deal with is the time that's missing."* (Dan)

They then acknowledged there was a need for the patients to address these gaps, as they wanted to know what had happened. Jency explained:

> *"A gap and that three/four days are gone so you want to know what has happened."* (Jency)

5.2.4 Understanding missing memories of critical care to be a means of self-protection

Focus group one discussed the idea that patients' missing memories of events prior to their CCU admission and their time in CCU, was a means of protection from further stress. Rachael described this when talking about a particular patient:

> *"I think that's his natural brain trying to forget all the horrid things that have happened and then perhaps with his reconstituted memory, people are going, 'This happened to you. You were over there' and does he really need to recall that?"* (Rachael)

Participants also recognised that some patients may need to remember their experience of critical care to account for the missed time. Dan expressed the view that the lost time caused further stress for patients:

> *"But they can't comprehend that they've lost time."* (Dan)

5.2.5 Category summary

In summary, this category of *nurses' understanding of patients missing memories of critical care*, consisted of four focused codes: 1) gaps in memories, 2) recognising patients do not know what had happened to them, 3) recognising missing memories can cause discord and 4) understanding missing memories of critical care to be a means of self-protection. Participants recognised there were aspects of critical care the patients could not remember. These included not remembering what had happened to them, their bed-space and most importantly for participants patients not remembering who they were. Participants did not expand on the implications of these missing memories for the patients – more significantly the nurses regarded the missing memories to be a positive thing for patients, believing it to be a means of self-protection from what had happened to them. Following the stimulus material, participants recognised the gaps in memories caused discord but related this more to discord between them (nurses) and patients, rather than between patients and their families.

5.3 Nurses' understanding of patients' sense of an altered reality in CCU

Within the category: *nurses understanding of patients' sense of an altered reality in CCU.*, three focused codes represent different aspects of this. These are presented in Figure 5.6.

Initial Code	Focused Code	Category
Thoughts in patients' heads Hallucinations Patients remembering being on a boat Snippets of reality	Understanding patients' difficulties distinguishing between reality and unreality	**Nurses understanding of patients' reconstructive memories of an altered reality in CCU**
Staff communicating in their native language A foreign language	Recognising patients being disorientated by staff conversing in a foreign language	
Frustrating for the nurses Nurses managing hallucinations Importance of family	The challenges of managing an altered reality	

Figure 5.6 Nurses' understanding of a sense of an altered reality in CCU

5.3.1 Understanding patients' difficulties distinguishing between reality and unreality

Findings from the patient interview study demonstrated critical care patients have difficulties in distinguishing between real and unreal events as they often experience dreams, nightmares and hallucinations both during and after their CCU stay (presented in section 4.3). Prior to seeing the stimulus material, participants clearly understood that patients were able to describe their hallucinations on CCU. Participants recognised that this resulted in some patients experiencing difficulty distinguishing between memories of real and unreal events. Some reported the CCU environment did not help with this, with Katie summarising CCU as:

> *"A really mixed-up world of what's real and what's not real'"* (Katie)

Emma reported many of her patients saw smoke on her CCU. She attributed this to the light casting shadows onto the ceiling. Helen spoke of how her patients remembered seeing purple rain whilst being cared for on her unit. She attributed this to everything in the unit being purple; the curtains, walls and uniforms. Helen explained that when the patients visited the unit at the follow-up session, seeing the colour of the environment explained their experiences:

> *"Then they come back later and go, "That explains it.""* (Helen)

Mary explained how her patients associated the noise of the suction equipment with a cat:

> *"One of our patients that was on our unit she thought it was a cat on her back because she could hear the suction. So every time she could hear these noise and she was always asking me if there was a cat."* (Mary)

Hope also explained how moving aprons from the roll caused patients to believe they were on a train hearing train tracks:

> *"We'll get the aprons from the thing, so it makes this sound, some of them will think they're in a train station because they think they're train tracks." (Hope)*

On the whole, participants 'understanding of this reality and unreality was restricted to patients' experiences within the CCU. Only Hope who worked on a regional tertiary referral CCU commented:

> *"Well it can be quite vivid for some patients, for them the hallucinations are real and afterwards as well."* (Hope)

Participants also attributed the patients' memories to the sedative drugs patients had received on CCU whilst Dan associated these *'snippets of reality'* with the practice of daily sedation holds. Participants also attributed the difficulty patients had of distinguishing reality from unreality with issues such as the sleep deprivation they had experienced whilst on CCU, and aspects associated with their critical illness such as the presence of infection and sepsis:

> *"Seeing those things [hallucinations] because the drugs and everything, sleep deprivation."* (Priyanka)

Similar to participants in section 4.3.3, participants across the focus groups described how patients believed the nurses were trying to harm and kill them. Mary commented that one of her patients told his wife about the nurses saying:

> *"No, they want to kill me … They're out to kill me"* (Mary)

She continued to elaborate commenting that the patient recalled being restrained in his bed and how he anticipated that because he was being restrained, something bad was going to happen to him:

> *"They think they're just being restrained in that bed because we're going to do something bad or taking over or something."* (Mary)

Will recognised the seriousness of this. He understood the implications this could have on other patients:

> *"We had a young chap who was sedated for quite a while … he had a bit of the old delirium, but the issue was it was affecting everyone else's rehab in the bay because he went to other beds, and tried taking their tubes out, because he*

> *had decided that we were trying to kill him and wanted to try and save the rest."* (Will)

Rachael reported that it was not just the nursing staff the patients recalled trying to kill them. She reported patients' claims that some of the equipment could cause such memories:

> *"I had a patient who has insisted that the haemofiltration screen, what we see are the numbers that we require, it was actually reading to him that it was going to kill him. He was that convinced."* (Rachael)

Rachael managed this by turning the display away from the patient's view.

Susie recognised how distressing these memories could be for patients. She reported:

> *"They'll be completely scared. They are in a scary moment."* (Susie)

Dan summarised the despair patients' experience with these memories. He recalled a consultant asking a long-term patient on their CCU what they could do for her. The lady simply replied:

> *"You can't take me away from the thoughts in my head."* (Dan)

5.3.2 Recognising patients being disoriented by staff conversing in a foreign language

A number of participants originated from overseas and English was not their first language. Both the overseas participants and those from the UK across the groups recognised that nurses who were conversing with colleagues in front of patients in their native tongues, caused confusion for them:

> *"They thought they were somewhere else because of people talking in their native tongue. So, we've had a lot of agency nurses that will come in and talk in their native tongue." (Rachael)*

Participants recognised that this contributed to patients' disorientation:

> *'They think they are in a different country.'* (Claire).

Some were shocked by this. Jency recalled that as she was repositioning a patient in the bed with another nurse they were chatting between themselves. Jency reported that the patient had later told her:

> *"I thought I was in India' because the nurses… supposedly two or three Indian nurses they're talking in their own language, and that he thought he was in India, and when we were rolling or something, so."* (Jency)

Participants also identified that not only can a different language disorientate patients; it can also resurrect difficult memories of prior distressing experiences abroad for patients:

> *"A couple of our patients have had such a bad experience abroad, they were in Dubai and they had such a traumatic experience so hearing Arabic language or language, again –"* (Rachael)

They were able to recognised how frightening this could be for patients:

> *"Yeah, a different language just petrified them, they were absolutely petrified."* (Rachael)

Whilst participants recognised this to be an issue for patients, they reported these lapses into native tongues were not malicious, as discussed by Emma:

> *"Our Portuguese nurses do it quite often, but I genuinely think it's by accident, because they're very good nurses but it seems to be when there's a group of them."* (Emma)

Jency described how shocked she was that one patient had understood her and her colleagues as they conversed in their native tongue. She recognised that this was unprofessional and potentially distressing for the patient:

> *"And that take me afterwards, 'Oh, my god, he is remembering all that, perhaps we should not gossip in front of him."* (Jency)

Some units had imposed strict rules about nurses speaking in their native tongue. This was to prevent such distress and disorientation for patients as explained by Glen:

> *"It's a strict no in front of the patients. There is a really big no-no, because they will understand only English so that's what we need to be speaking."* (Glen)

Jovelyn agreed with Glen commenting:

> *'But we shouldn't be allowed to talk in our language.'* (Jovelyn)

5.3.3 The challenges of managing an altered reality

Many participants described how challenging it became for them when patients developed delirium and hallucinations. Glen who was an experienced critical care nurse, described feeling helpless as patients he cared for developed delirium:

> *"I find it a challenge that when the patients are delirious I don't know what to do."* (Glen)

He also talked about his frustration with how to deal with such situations:

> *"We feel a little bit frustrated because sometimes we know that there is not a rabbit in there but, for the patient, that is what he sees. I don't know how we can tell him, how we can make him believe that it's very safe although we say, 'You're safe, there's nothing there?"* (Glen)

Casey recognised the need to assess patients for delirium, understanding that nurses fail to recognise it if they don't assess for it:

> *"Because sometimes we don't know do we, like unless we've assessed them but sometimes we don't notice."* (Casey)

However Glen displayed frustration in relation to the intubated, sedated and ventilated patient:

> *"If the patient is intubated and ventilated, the patient doesn't talk. How do we know what's in their head? How can you assess?"* (Glen)

As Glen said this, he had wide eyes and shrugged his shoulders. Whilst the group nodded in agreement with him, some described their strategies to manage hallucinations. Priyanka reported:

> *"Usually I explain to them it's normal, you seeing those things, because the drugs and everything, sleep deprivation, but I want you to be reassured that it's not there. It's alright actually, it's not real, it's real in your head only."* (Priyanka)

Dan had adopted another approach. He explained:

> *"I think it's important to use certain words so when they do wake I repeatedly tell patients that they're safe, don't worry."* (Dan)

Susie described how she used the time when patients came back to visit the CCU to support patients. She explained how she would try to ascertain the source of a patient's hallucinations during the visit:

> *"He was trying to look for a horse, because in his dream he was facing a wall and there was a horse. And we were trying to find which bed space he was and what could it be. And we found out it was the x-ray machine, possibly, because it was moving."* (Susie)

Katie was the only nurse who mentioned the importance of the presence of family during these episodes of disorientation. She commented:

> *"In a really mixed up world of what's real and what's not real, that's why family become quite important."* (Katie)

5.3.4 Category summary

In summary, this category *nurses' understanding of a sense of an altered reality* in CCU consisted of three focused codes: 1) understanding patients' difficulties distinguishing between reality and unreality, 2) recognising patients being disoriented by staff conversing in a foreign language and 3) the challenges of managing an altered reality. The nurses understood patients' have difficulties in remembering what was and was not real because of the presence of an altered sense of reality due to them hallucinating whilst on CCU. The nurses explained the presence of this altered sense of reality was due to issues such as delirium, sleep deprivation and the sedative drugs patients received on CCU. As a number of nurses originated from overseas, they reported that speaking in their native tongue could also disorientate patients. Furthermore, the nurses explained how these hallucinations affected patients' perceptions of them and how at times it was difficult and frustrating for them to deliver care as not only did patients believe they were trying to harm them, but the nurses knew what patients were seeing was not real and not there. As nurses understanding of these memories was confined to those memories of the CCU and not beyond, they were unable to demonstrate an understanding of the longer-term implications of this on patients' survivorship.

5.4 Nurses' understanding of patients feeling reassured yet powerless

Within this category: *nurses understanding of patients' reconstructive memories of feeling reassured yet powerless* four focused codes represent different aspects of this. These are presented in Figure 5.7.

Initial Code	Focused Code	Category
Critical care environment Remembering faces and voices Noise - alarms Missing out Being rolled	Nurses' understanding glimpses of memories	**Nurses' understanding of patients' feeling reassured yet powerless**
Embarrassed at needing care Feeling emotional Feeling voiceless Feeling helpless	Recognising a total dependency on others	
One to one care The constant presence of the nurse by the level of care	Recognising patients remember feeling reassured	
Flashbacks PTSD Bad memories	Lasting negative memories of critical care	

Figure 5.7 Nurses' understanding of patients feeling reassured yet powerless

5.4.1 Nurses' understanding glimpses of memories

Across the four focus groups the participants all demonstrated an understanding that patients have glimpses of memories of their time in CCU:

> *"It's fragmented, I think, what they actually remember."* (Dan)

Will, an experienced critical care nurse, recognised that these glimpses of memories can be highly distressing for patients. He reported the experience of one patient:

> *"A woman in her 50s who during that phase of being a bit sedated, not properly awake, not properly asleep, we were doing PRs and, she vividly remembers*

> *being raped, and it took quite a lot of counselling to say, no, it's examinations."* (Will)

Participants recognised that many patients found the CCU environment alien with its bright lights and technical equipment. Horacio reported that because most patients do not know what a CCU looks like, this exacerbates their distress as they regain consciousness. Prior to the stimulus material, many nurses recognised that the patients remembered the ETT however they reported that patients recalled the breathlessness associated with the ETT more than difficulties with communication:

> *"Not being able to breathe properly, because obviously you've got the cuff there and even if you've got like a size nine in situ there's still a little gas coming through."* (Hope)

The significance of a size nine ETT is that it is a larger size tube, with a bigger lumen than most and consequently will deliver more gas to the lungs during ventilation.

From all four focus groups, many participants believed that patients' most prominent memory of CCU was noises like bins closing, alarms or the MRI scanner. Some reported that being in CCU led to a heightened sense of hearing, which Emma attributed to patients being positioned on their back, unable to see:

> *'"If they're just on their back, they're staring at the ceiling, they don't really see kind of … they can't gauge what time of day it is at all, they just remember … The patients I'm talking about it's just a bit blank, you remember noises more than you remember seeing things."* (Emma)

However, most participants reported patients remembered voices. Ivy commented:

> *"We've had it as well where the patients, finally, when they have come round have put a face to the voice, so they've heard the voices and it's almost like they knew whoever that nurse was just by the fact that the voice, instead of visually seeing them."* (Ivy)

In an attempt to manage the level of noise at night and to assist patients to maintain their circadian rhythm, many units dim the lights and encourage staff to leave the level two patients to sleep. However, Helen reported:

> *"We had two patients who came back to us on our follow up and there's a lot of talk about the lights down at night and being really quiet and they hated it, the two that came back they said … 'Don't worry about the lights going down, don't worry about being quiet, we just want to be talked to."* (Helen)

5.4.2 Recognising a total dependency on others

Focus group one was a deviant case in that they were the only group to discuss how they recognised patients' memories of their complete helplessness and dependence on others to do most things for them:

> *"They kind of know they're at the mercy of other people taking care of them, so to speak. So, they're kind of helpless, they can't do much for themselves."* (Dan)

A few participants recognised that the presence of the ETT or a tracheostomy tube removed the patient's voice. Their interpretation of this was that patients reported feeling invisible as explained by Christa:

> *"She said she felt like no-one was listening to her."* (Christa)

However, not all participants held this view. Beth a critical care nurse with two – three years' experience in a regional CCU reported:

> *"I don't think I've heard anybody mention it."* (Beth)

In contrast, Dan with more than five years critical care nursing experience, recalled that an elderly patient with a tracheostomy tube received daily visits from her husband who had cancer. Due to the presence of the tube, she was unable to have a two-way conversation with her husband. Consequently, she was unable to express that she was worried he was visiting so often. Further into her stay it became apparent that she also had a 40-year-old son at home with Down's Syndrome whom she was equally worried about but who had been prevented from visiting because it was felt it would upset him to see his mother so unwell. Dan concluded that this lady felt voiceless with no autonomy over whom should visit her and when. All the groups discussed how they understood the humiliation that patients experienced at losing their autonomy. Christa reported:

> *"I think they feel loss of control; they have no way to say, this is what I want when they are wanting something to be done. I think sometimes when they come back to clinic that is what they mention, the loss of control and autonomy to say …"* (Christa)

Related to this, was the reliance patients developed on nurses delivering personal care. Many participants could relate to the memory's patients had of the undignified nature of this and how humiliated they feel:

> *"Their personal care bowels, unable to control their bowels, we have to wash… the undignified nature of that."* (Helen)

> *"They say that they can feel humiliated for us to be delivering the personal care for them."* (Imelda)

Others reported that despite being surrounded by lots of people on CCU, patients were lonely. The participants attributed this to patients' lost autonomy:

> *"I guess they do feel kind of lonely really when they're there in that bed space, not being able to do anything really."* (Priyanka)

Others considered that such lack of autonomy resulted in frightening memories for patients:

> *"Feeling that we took control over whatever control they had. It must be very scary."* (Susie)

Before they were shown the stimulus material, participants recognised toileting to be a particularly difficult memory for patients. All the groups recognised the humiliation and lack of dignity the patients experienced regarding this:

> *"Think about toilets and the embarrassment of a patient for them going to the toilet, and us helping them to the toilet, I think generally people feel that we are very professional, but it doesn't get away from the fact that that is one of the things they will always remember, because of how embarrassing it is."* (Will)

This generated a discussion amongst focus group two between participants from regional CCUs and DGH general CCUs. They began to discuss their own practices:

> *"But do you have a toilet in your ITU?"* (Christa)
>
> *"We have three."* (Will)
>
> *"We don't have a toilet for patients."* (Horacio)

> *"We have to go upstairs in the lift to go to the toilet."* (Christa)

> *"Those who are weaning have to use commodes."* (Harvey)

It became apparent that the specialist units do not have patient toilets available. This stimulated some reflection within the group as to the implications of this for patients' memories of critical care.

Participants reported the humiliation some patients remembered of receiving care from members of the opposite sex. They reported strategies they had to manage this:

> *"When it comes to manoeuvring the patient, in this case it was a young lady – we would manoeuvre but, the male staff, would stay up the head end and reassure as well that one of the female nurses is carrying out the personal care and we would maintain eye contact to reassure her"* (Glen)

Katie was the only participant to recognise patients' memories of thirst whilst on CCU despite many patients reporting this to be a problem (presented in section 4.4.2):

> *"He [a patient] remembers feeling really thirsty and not being able to have a drink and then we're going 'Have a drink', and that's the most things he can remember."* (Katie)

Following the stimulus material, some participants recognised that a few patients remembered the relentlessness of the care they received in that they were constantly being prodded, poked, touched or repositioned in the bed. Katie recognised how annoying many patients found this:

> *"Obviously you roll them every four hours, but ... he had no time awareness of how many hours it had been to the next intervention, he just thought we were*

> *doing it all the time to annoy… he's like, 'I'm trying to sleep, you've only just done it', but obviously we hadn't …"* (Katie)

Katie commented that at the time she hadn't understood that her patient had had this perception and had found him to be a *'grumpy and annoyed'* patient who wasn't compliant with receiving care. Once Katie understood the patient had an altered perception of time and believed he was not being left to rest, she changed her attitude towards him:

> *"Trying to be a bit more patient with him when he seemed really grumpy and just annoyed, but that's because his time lapse was so small he just thought we've moved him, and he'd go 'But I need to move again."* (Katie)

A number of participants reported that patients would remember having to rely on the nurses to clear secretions from their chests as they were unable to do this. This is done through applying suction down the ETT to remove the secretions and is considered by nurses to be an unpleasant experience. Emma reported a patient explaining:

> *"You just don't understand how scary it is, because for that minute you can't breathe, and having something rammed down your throat that makes you cough," he was like, "It was horrible" …"* (Emma)

Emma was quite upset to hear how unpleasant her patient remembered suctioning. She reported feeling:

> *"… really sad because it's something … we have to do it sometimes, but you feel really guilty when they tell you though, 'God, I didn't mean to, sorry."* (Emma)

Despite participants in three out of the four focus groups reporting that patients remember suctioning, patients' recall of this within this study was silent with none of them mentioning this procedure at all.

5.4.3 Recognising patients remember feeling reassured by the level of care

Before and after the stimulus material, participants' understanding that patients feel safe and secure on CCU was limited, with no-one discussing it in the depth patients had. Two groups recognised that the one-to-one care on CCU was an important memory for patients and that because a nurse was with them all the time, they did not have to wait to receive care:

> *"It's the ratio, one-to-one. People are on your beck and call the whole time."* (Gordon)

A number of participants recognised patients remembered feeling calm by the presence of the nurse. Emma commented:

> *"Patients who are on CPAP or NIV who are completely calm when you're there and the minute you leave they're terrified and it's like you're their security. The amount of times that you have to sit there and just hold their hand just so that they can tolerate the CPAP or NIV …"* (Emma)

5.4.4 Lasting memories of critical care

Some participants who had the opportunity to meet former critical care patients when they came to revisit the CCU at their follow-up meeting demonstrated an understanding that some patients develop lasting memories of critical care. They reported these were often negative 'bad memories.' The participants understood how these negative memories made it difficult for patients to return to the CCU as this was a place they associated with difficult and unpleasant experiences:

> *"We had a patient come in very recently and I asked her how she was doing, and she hated coming onto the unit because it was just bad memories."* (Rachael)

Others described how some patients experienced flashbacks. These were not only of their CCU stay, but also of the event which had resulted in their admission:

> *"They have the flashbacks of them being on fire. Not necessarily feeling the pain or the main feeling the initial pain, but it is, 'I'm going to die."* (Glen).

Related to this participants all reported that patients remembered the pain they experienced on CCU. Susie a nurse who worked on a CCU where there was no opportunity for nurses to meet their former patients, however assumed rather than knew this to be fact when she commented:

> *"I think they remember the pain. They have to remember the pain?"* (Susie)

The issue of pain was silent in focus groups two and three. However, in the other two focus groups (focus groups one and four) memories of pain were discussed at length. They described how patients associated certain aspects of care with pain:

> *"Associating pain with nurses doing stuff like when you say, 'Oh, we're going to reposition you and give you a roll', then they would say, 'That's really painful."* (Malaya)

Others understood how patients remembered nurses trying to prevent pain. For example, the noise of the patient controlled analgesia (PCA) pump would cause them to anticipate pain:

> *"They associate certain times of the day because it's going to be very painful what we need to do and, despite us giving them analgesia, it's still – they associate with beeps of the boluses to, "I'm going to be in pain" or, "There's pain coming"."* (Rachael)

Susie was the only participant who recognised that these memories could last for a long time following discharge from CCU and that they could impact on the patients' daily life:

> *"And it can follow them home, it can carry on for years and years with flashbacks and memories disturbing their daily life."* (Susie)

5.4.5 Category summary

In summary, this category *nurses' understanding of patients feeling reassured yet powerless* consisted of four focused codes: 1) nurses' understanding glimpses of memoires, 2) recognising a total dependency on others 3) recognising patients remember feeling reassured by the level of care; and 4) lasting negative memories of critical care. The nurses recognised that glimpses of memories appear for patients as they receive critical care. These relate to aspects such as remembering alarms, pain, faces and voices. Participants recognised the humiliation and embarrassment that patients remember, in relation to being totally dependent on others for care. However, participants described this as helplessness rather than the powerlessness patients remembered. Participants understood patients remembered feeling calm on the CCU due to the level of surveillance they received. When discussing memories of critical care nurses' understanding was restricted on the whole to the CCU stay. Only one participant mentioned memories of the event which triggered their need to receive critical care, whilst only one other considered the longer-term influence of these memories for patients once they had returned home.

5.5 Nurses' understanding of feeling abandoned on the ward.

Within the category *nurses understanding of feeling abandoned on the ward*, three focused codes represent different aspects of this. Additionally, having seen the stimulus material, participants recognised and were shocked by patients' reports of the length of time they remembered having to wait for fundamental care such as being given a commode. These are presented in Figure 5.8.

Initial Code	**Focused Code**	**Category**
Frightened to go to the ward Fear of not seeing a nurse Not knowing the back story	Recognising the fear of leaving CCU and entering the unknown	**Feeling abandoned on the ward**
Not knowing the system Loss of 1:1 care	Recognising having to wait for care	
Making the move a positive Lack of time The need for 'step-down' or HDU care Visiting the patient CCORT visiting the patients Elective care and pre-op visits	Nurses managing the move from CCU to the ward	

Figure 5.8 Nurses understanding of feeling abandoned on the ward

5.5.1 Recognising the fear of leaving CCU and entering the unknown

Having seen the stimulus material, all participants across the four focus groups recognised that patients were frightened to leave the CCU for the ward. They understood patients found this scary and worried once they had been informed that they were moving:

> *"We say to them, "We're going to discharge you to the ward" and they go like petrified and go, "Why are you? Am I better then?""* (Susie)

Participants identified a multitude of reasons for this concern. They reported that patients were anxious that the nursing staff on the ward would not be able to care for them:

> *"There's a thing that staff over there are not able to care for them and they get into a panic more and everything shoots up and their score goes high."* (Celia)

One participant attributed this to the ward nurse not knowing the back story of how the patient had come to be on CCU:

> *"I suppose when they go to ward people as well might not know their back story, they might not be able to relate that, they might've been through a really traumatic experience."* (Casey)

Participants recognised patients' fear of losing the one-to-one care. They reported patients believed they would be abandoned as one patient amongst many:

> *"They think their ward nurses will not be looking after them, they will be left …"* (Christa)

However, Makisig reported the concern related more to the patients' perception of their health. He understood they were scared because they still considered themselves critically ill and required a higher level of care:

> *"Because obviously coming from being really critically ill to having so much attention to then... I don't think they still really believe that they are kind of getting better, they don't need that much attention, as much attention, but I think to them they still... it's just hard going away from that."* (Makisig)

Others reported that it related to the critical care nurses' understanding of the patients' 'back story' and that they knew the patients. Participants reported patients were concerned that the ward nurse didn't know their story and so they would be unable to provide the same level of emotional support:

> *"I suppose when they go to ward people as well might not know their back story, they might not be able to relate that, they might've been through a really traumatic experience and there might be someone else who's not been there as long and can't quite understand what they've been through, just not having anyone to talk to about their experience."* (Casey)

5.5.2 Recognising having to wait for care

From the stimulus material, all participants in all the groups recognised patients had to wait for care on the ward. They found Sheila's memories of waiting 45 minutes for the commode distressing:

> *'That's bad. That's really bad.'* (Susie)

Participants recognised that patients found it difficult moving from CCU to the ward because they had to call and wait to go to the toilet and waiting in general for help when they don't know the different 'system' on the ward. Casey explained that:

> *"On CCU they are within your eyesight and on a ward they're not always put on line and worry that yeah, how do you get hold of them, they don't understand the system."* (Casey)

There was agreement amongst participants in all four focus groups that it would help patients if they reduced their input for them prior to their transfer to the ward:

> *"We have a step-down process so when we know the patient is getting near to being safe to discharge to the ward, we will back off. We will give them a buzzer."* (Bernadette)

5.5.3 Nurses managing the move from CCU to the ward

Across the focus groups there was consensus that there was not enough time to prepare patients to leave CCU for the ward:

> *"On the ward rounds in the morning we say, 'Okay, we're going to step down to the ward' until the actual time you will discharge them that's what they know. It's like five or six hours, not even that sometimes, that you have to prepare them, 'Right, you're going to a ward'. It's not really too much."* (Priyanka)

Consequently, participants believed they failed to prepare the patients for the ward. One commented:

> *"Sometimes they get pushed out so quickly as well because of bed pressures. They're literally there one morning and then an hour later, 'Right, you're off to the ward now. You've had no time to process this at all but I've got a level three that needs to come in, so you have to go'. I hate doing that but sometimes you have to."* (Emma)

However, this experience was not universal with some participants discussing complex discharges. Here they would have the opportunity to take the patient to the ward (often in a wheelchair), on the day prior to the discharge. Glen reported that this prepared the patient for the move.

> *"I took the patient in a wheelchair so, 'This is where you're going to be."* (Glen)

Across the groups' participants explained how they tried to emphasise that the move was a positive step for the patient. They explained to patients that it was a step closer to home and that their physical condition was improving:

> *"I quite often say that, "We're organ support, you don't need anything supported, your blood pressure is unsupported, your breathing is fine, you're unsupported, you're not needing any help with your kidneys. You don't need us." And I try to flip it so that they don't feel that they've got to have that nurse they've liked for toilet calls and things like that. I try and say, 'This is what our unit is, and you don't need us."* (Bernadette)

However. Makisig was more cynical. He commented:

> *"I still think... I don't think they don't buy that."* (Makisig)

Only one CCU represented by participants in the focus group made use of a separate step down High Dependency Unit (HDU) where the level two patients were cared for but still on a one-to-one basis. This was a regional tertiary referral unit for burns. The other units had their HDU beds within CCU.

A variety of strategies were discussed by participants to manage this transition. Casey reported that the critical care nurses could do more to encourage the patients' independence whilst on the CCU:

> *"I think on a ward you're very much encouraged to get people out of bed, to get them dressed, like help them wash themselves, and on ITU it's a bit like, 'Okay, you're in bed now, I'll do everything for you'. Yeah, the difference between the two I think when patients start to wake up in ITU and they're able to do things for themselves we should encourage them to do everything themselves to help them when they go on."* (Casey)

Participants from one of the larger regional centre CCUs described how their specialist nurse for follow-up would meet with patients before they were discharged from CCU. This nurse would explain the transition process and it was felt the patients then understood what to expect. This did not happen in any of the other CCUs represented in the focus groups.

Another strategy used by the smaller CCUs was for the critical care outreach teams (CCORT) to visit patients following their discharge. There was some disagreement as to whether this was an effective strategy. Some participants understood this supported the patients physically and psychologically, whilst others considered patients had no connection with these nurses not knowing them:

> *"You can have outreach; they have no connection and they have no relationship with them."* (Katie)

In contrast other participants reported that they visited patients (particularly those who had been on the CCU for a long time) on the ward following discharge, however most nurses reported they did this on their breaks. In contrast, others reported they were unable to do this as the turnover of patients was too high and they could not leave the CCU. It was regarded by all to be a positive intervention which was beneficial for patients in reducing their anxiety and participants to receive feedback on patients' progress:

> *"I don't know about, but we do a brunt of the care, the actual care and I do think sometimes a way of making anxiety less on a ward patient would be for the nurse who's looking after them last to go and visit them."* (Katie)

A key finding however was the importance patients place on having family present during this time was not discussed by participants despite it being so important for patients' (presented in section 4.5.1). Just one participant recognised the family's role in the transition from CCU to the ward:

> *"We've got to involve the family more so that they're aware of what they need to do because the nursing staff on the ward won't be able to, so it's now down to the family much more."* (Helen)

5.5.4 Category summary

In summary this category: *nurses' understanding of feeling abandoned on the ward* consisted of three focused codes: 1) recognising the fear of leaving CCU and entering the unknown, 2) recognising having to wait for care and 3) nurses managing the move from CCU to the ward. Participants understood patients found the move from CCU to the ward frightening. They attributed this to patients' concerns that ward nurses would not understand what had happened to them and that they had been so critically ill and therefore would not be able to provide the level of care they required. Participants also understood patients were scared to lose the one-to-one care they had received on CCU. Having seen the stimulus material, participants were shocked and saddened to hear how patients remembered having to wait considerable length of times for the commode. Participants discussed that there was often a lack of time to prepare patients for the ward. Some explained specialist nurses assisted with the transition whilst others made use of their CCORT, whilst others reported nurses themselves visiting patients on the ward would be helpful, but that the pressures on them as CCU nurses were so great that they could only achieve this in their comfort breaks.

5.6 Nurses’ understanding of filling the gaps: reaching closure and moving on with life and survivorship

Within this category: *nurses understanding of patients’ reconstructive memories of filling the gaps: reaching closure and moving on with life and survivorship* three focused codes represent different aspects of this. These are presented in Figure 5.9.

Initial Code	**Focused Code**	**Category**
Family filling the gaps Reconstructive memories Diaries filing the gaps Follow-up clinics filling the gaps MDT communication Achieving closure	Recognising the need to address the missing memories	**Nurses’ understanding of filling the gaps; of reaching closure and moving on with life and survivorship**
Receiving feedback reconstructive patients’ memories Knowing what happened to the patients	The bed-side nurses’ contribution to critical care follow-up	
Visiting the bed-space Meeting the nurses Difficulties visiting the CCU	Revisiting the CCU	

Figure 5.9 Nurses' understanding of filling the gaps: reaching closure and moving on with life and survivorship

5.6.1 Recognising the need to address the missing memories

Having seen the stimulus material, participants across all groups recognised different strategies patients used to develop reconstructive memories which may address the missing memories of critical care. All the CCUs represented by participants in the focus groups used patient diaries[3] although some units had been using these for longer than others and were more practiced in the content, who wrote in them and how they were released to patients than those who were less experienced in their use and application. In addition all the units represented by participants held follow-up clinics, although through the focus group discussions it became evident that the structure of these differed from unit to unit, with the smaller DGH clinics being consultant led whilst those in the regional centres were being delivered by substantive teams of specialist follow- up nurses. One of the DGH units had a clinic which was in its infancy, whilst another specialist cardiothoracic CCU limited the service to survivors of sudden cardiac arrest. Despite this, participants also recognised that family provides the schemata to develop reconstructive memories which may help them address the gap in their memories:

> *"From what relatives have told them, bits and pieces and diaries that are written."* (Rachael)

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[3] A patient diary provides a record of events which occur throughout a patient's admission to the CCU. They provide an ongoing narrative outlining day-to-day activities (Ullman et al. 2014)

As participants developed an understanding of the concept of reconstructive memories from the presentation of the stimulus material during the focus groups, most of them challenged what patients remembered. An example of this was Lee's experiences of being told by a Doctor that he had died. Helen commented:

> *"But he may not have said that, that's just how the patient may have perceived it, we don't actually know that the doctor had said that or nurse or anybody, so the perception could not be right."* (Helen)

Participants also discussed that when the patients rely on their family to fill the gaps in their memories, they are relying on the families' perspective of what happened and not their own:

> *"I think it's important as well to consider that patients that have left ITU for quite a long period of time are relying on their relatives and their next of kin to give them that information. If that's not correct their memories aren't going to be right at all."* (Will)

Participants also reported that family members have been through a traumatic experience too, as their relatives received critical care. Consequently, they reported that the relatives' memories of events may be clouded by the stress they had experienced and that patients may find this version of events scary:

> *"It probably scares the hell out of them, because obviously the relatives have gone through this side of it, seeing the person they love lying in a bed with ET tubes and lines everywhere, pumps, alarming, flashing, whatever, that's not going to have been the nice experience for them, so chances are they're not*

> *going to relay that as a positive experience because they didn't have a positive experience."* (Hope)

Across the groups, it was recognised by participants that patients rely on their diary to augment the information provided by their family and to contribute further to their reconstructive memories aimed at filling the gaps in memories. Just one participant suggested that perhaps patients needed to do this in order to be able to move on with their life:

> *"I think it helps them to, well so piece everything together and then maybe even start trying to move on from that major event in their life."* (Hope)

However, because participants again recognised that the gaps are filled more by how patients reconstruct what the diary has told them, they reported that the diaries did not represent patients' memories, but more those of the family. Emma explained:

> *"It's easier to piece things together because they get their patient diaries … and they kind of, a lot of them go, "Oh, well that makes sense because I remember that from the diary." It's not actually from their memory, it's from what they've been told from relatives, from the diary, and then they get a picture together."* (Emma)

One participant understood that not everyone wanted to remember their experience. Malaya described telling a patient about her diary:

> *"I had a young patient who wasn't very delighted that … I told her about it and the diaries and stuff, and she said, "Why would I want to remember that?" … "Why would I want to go back to that?""* (Malaya)

Others recognised the importance of critical care follow-up in helping patients reconstruct their memories and understanding of what had happened to them. Celia a participant with two to three years' experience reported patients needed to receive this follow-up sooner rather than later:

> *"I think it's quite important to look at the follow-up as soon as they get discharged, or I don't know, a month or two, but as soon as they get the information and they fill up the gaps then probably the better for them."* (Celia)

Others disagreed. They reported the gap needed to be longer to allow patients to come to terms with their experience and recover physically from their stay:

"We've got a six month and nine month and a 12 month, and what they're finding is people are okay at six months and then at nine months they're showing signs of depression and posttraumatic stress disorder. So straightaway I don't, I don't think they have time to process it. They haven't act … they've just done one of the 12 month one and they're going to write it up because they said the change when the person is six months to 12 months is amazing and they're now considering whether they need to do a two year one because their stability is completely different." (Emma)

Whilst a few participants understood that the follow-up clinics provided a degree of closure for patients, this was not their first thought when discussing the need for this service. The participants perceived that the clinics were more effective at filling in the gaps in memories and explaining things that had happened than providing closure and the chance for patients to move on with their life:

> *"I think it was at clinic, and some sort of reassurance was given, perhaps diaries, and he [a patient] was able to fill in the gaps of what happened."* (Christa)

Indeed, during the focus groups there was limited discussion from participants regarding patients' need to return to a normal life. Just one nurse mentioned that during the first six months patients were focused on the realities of returning to a normal existence:

> *"Then six months down the line you're dealing with the realities, 'How's this affecting work? Will I get back to work?' how... the change in their life."* (Katie)

5.6.2 The bed-side nurses' contribution to critical care follow-up

The majority of participants reported they were not involved in the follow-up clinics and that they stated they were missing out on an essential part of the cycle of care. Katie explained this:

> *"I do feel like we're left out of the loop as well, and we, I don't know but we do a brunt of the care."* (Katie)

At this point participants became really animated, and those who practised in the smaller DGH CCUs explained that they felt as the bed-side nurses who had cared for specific patients, it would be appropriate for them to attend the follow-up meeting with their patient. They reported this was important for two reasons: 1) to receive feedback from the recipient of their care, with the aim of enhancing their care delivery and 2) to achieve some degree of closure for themselves through learning what had happened to the patient they had cared for and if or the extent to which, they had recovered. They commented that they often didn't know what had happened to patients:

> *"We also want to hear, I mean you can say hello to them when they come round, but the follow- up clinic would be lovely to get feedback from them to*

> *say some patients are saying that, 'We do like this', and 'We don't like this', we're getting no feedback."* (Helen)

In contrast, those participants from the regional CCUs were invited to attend the clinic if they were not on duty. They reported this was a worthwhile experience:

> *"I've been to one and I thought it was really good... It's interesting to see it from the other side, because we see you know, this patient who's been sick enough to be with us and they've got better, they've gone to ward and potentially gone home, but it's interesting to see their perspective of everything that's happened and any knock-on effects from being with us and their treatment and everything."* (Hope)

Focus group four reflected that it would be helpful if new members of the team attended as well. They could then learn from what patients had to say:

> *"I think especially encouraging new members of staff to attend the follow-up clinic because it makes you more aware, higher level awareness and not just thinking bed-side you know, it just widens."* (Makisig)

For others, their involvement in the clinics was more *ad hoc*. It depended if they happened to be on shift:

> *"We get patients that come to the clinic and they will ask if a member of staff is on and then they'll ring around to us and say, "Such and such is here, are you free to come round?"* (Susie)

5.6.3 Revisiting the CCU

The stimulus material explained that as part of the follow-up meeting, patients were invited to visit CCU. Having seen the material, participants understood patients found this helpful in providing further schemata which may help address the gaps in their memories. They reported that this visit enabled patients to put faces to voices:

> *"Some patients feel happy to see the faces that were familiar."* (Susie)

Participants identified that for some, returning to the unit was a personal experience. Some regarded this as a positive experience whilst others recognised it to be difficult. They all recognised this visit needed to be approached in an individualised and controlled manner:

> *"It's different for every person. Some people appreciate it because they can see it's not quite as scary as they remembered but then others don't want to see it."* (Beth)

Participants recognised that some patients did not want to visit the CCU because it held bad memories for them. They commented it was too emotional and possibly too soon for some patients to return:

> *"She walked in with one of the nurses that was doing the rehabilitation pathway with her she just cried her eyes out. She left the unit straight away. I kind of felt this patient wasn't ready to come in and we should have avoided this and given her a little bit more time to get prepared."* (Susie)

Others reported that for others, the visit did help. Through the visit, patients realised the area wasn't as scary as they remembered:

> *"I've seen patients that come into clinic and then they come round to see the unit, and some of them look surprised, like, "Oh, okay, this makes sense.""* (Jenny)

One participant explained how meeting a patient on his return visit, changed her perception of him as an individual. This had since encouraged her to re-evaluate the way she cares for patients she find difficult:

> *"Just tailoring how we interact with patient, like with the guy I looked after for six months, maybe just trying to be a bit more patient with him."*(Katie)

The participants all felt that it was good for them to meet the patients when they visited the CCU. This helped them to feel valued:

> *"It is lovely when they come back on follow up. It just makes our job worthwhile."* (Helen)

Helen commented that she would have liked a long-term patient whom she had cared for over a length of time, to visit the CCU, just to see how he was. Katie however explained to her:

> *"He did come when he was ready for discharge, he did come on to the unit, so we saw him when he was walking, and he was going to go home, and we were all just amazed, and it's kind of nice to know what we're doing is right, and what we do is giving someone the quality of life. Because you do wonder you know, it stops at … people go through those double doors."* (Katie)

5.6.4 Category summary

In summary, this category *nurses' understanding of filling the gaps, reaching closure and moving on with life and survivorship* consisted of three focused codes: 1) recognising the need to address the missing memories 2) the bed-side nurses' contribution to critical care follow-up and 3) revisiting the CCU. Participants recognised patients had a need to address their missing memories of CCU through reconstructive memories and that the main practice participants on CCU used to support this was the use of patient diaries which documented the patients time on the CCU. Participants also recognised that relatives are important resources for patients to help fill in the gaps in their memories. Participants reported they were isolated from the critical care follow-up services and considered if they could attend this they too would achieve a degree of closure on an episode of care as well as gaining an insight into patients' experiences of the care they received on CCU . Whist participants recognised that some patients enjoyed revisiting the CCU, they reported this practice was not appropriate for everybody.

5.7 Nurses' response to patients' reconstructive memories of critical care

The nurses' response to patients reported reconstructive memories of critical care were evaluated after each focus group had been exposed to the stimulus material presented in appendix 3.12. Four focused codes represent the different aspects of the nurses' response to patients' reconstructive memories of critical care. These are presented in Figure 5.10.

Initial Code	Focused Code	Category
That sound familiar Yes, I recognise that 'We've had that' Nodding heads	Recognising the patients' reconstructive memories of critical care	**Critical care nurses' response to patients' reconstructive memories of critical care**
Looking upset Shock Disbelief Laughing	Saddened by the patients' reconstructive memories of critical care	
Smiling Sniggering	Amused by the patients' reconstructive memories of critical care	
'We're doing something right' Positive feedback	A sense of reward	

Figure 5.10 Nurses' response to patients' reconstructive memories of critical care

5.7.1 Recognising the patients' reconstructive memories of critical care

Across the focus groups there was overall agreement with all the stimulus material which presented the key findings of the patients' interviews. Dan responded:

> *"I think a lot of the statements on there ring true with things with what we do."* (Dan)

In particular they recognised the issue patients have with constantly being asked to "poke your tongue out if you can hear me?" Participants chuckled at this, nodding their heads in agreement. The groups did not demonstrate any remorse at having to constantly ask patients to do this, even though they knew the patients found it annoying.

Demonstrating further that the stimulus material was not telling the groups anything new, the participants were unsurprised by what the patients reported and would say ‘no’ and shake their heads when asked if they were surprised by the responses. However, only Sunita recognised the need to transfer this understanding into interventions to enhance practice:

> *“No, but I think we need to think how we can turn these into our interventions on our daily … because we know these a little bit, but on a daily basis do you remember what we do to prevent things?”* (Sunita)

Group four identified strongly with the patient Sean’s comment about the ward resembling a ‘third world country.’ Again, when shown this, the groups smiled, nodding their heads in agreement. One commented that she recognised this comment particularly:

> *‘…And the third world country one.’* (Malaya)

However participants started to explain Sean’s comments, particularly those who had worked on a ward prior to coming into critical care:

> *“I believe that though, I mean I’ve worked on a ward before I worked on ITU, and when you’ve worked on both it’s true, when you have 12 patients and you have one patient it is harder.”* (Casey)

There was an overall consensus that critical care follow-up was a positive experience and participants recognised Pete’s feedback regarding this to be a positive intervention. However, at this point there was discussion across the groups regarding whether all patients benefitted from such a visit.

Patients’ comments regarding the diary were also recognised by the group. Some participants expressed surprise that patients had chosen to continue writing in the diary themselves after they gained consciousness. For one participant hearing this helped her understand why one of her patients had chosen to do this in her diary on CCU.

There was no overall difference in response between those who worked in the regional tertiary referral centres and those who worked in the local DGH CCUs. There was also no difference in response between those who had been practising in critical care for over five years and those who were relatively new to the speciality.

5.7.2 Saddened by the patients' reconstructive memories of critical care

The groups all demonstrated some shock and sadness at some of the patients' memories. Lee's comment about being told he had died by a doctor generated the most shock and discussion. Three of the groups asked who had said that to him and were not only visibly relieved to discover it was not a nurse, but were not surprised:

> *"Apart from Lee, that nurse was very harsh …"* (Ivy, nurse)
>
> *"That was a doctor."* (Me, interviewer)
>
> *"That makes a lot of sense."* (Ivy, nurse)

Group one were split by the doctor's comments to Lee. One side understood why the doctor had chosen to use such an approach with him, whilst the other found the approach harsh and insensitive. Both sides listened to each other's viewpoints, but neither shifted their position.

The participants across all groups were saddened by Rachael's recollection of the nurse in critical care trying to kill her. They also recognised Alan's discussion about losing control over his bowel movements and the humiliation he experienced as a result. They were all visibly and audibly appalled that Sheila had waited 45 minutes for the commode and that when it came it was too late.

The participants were shocked to hear Fiona's comments about hearing lots of talk about a baby being ripped from her stomach. Initially, they seemed to accept this as a delusional memory, however when they learnt the context that Fiona had experienced a ruptured ectopic pregnancy, they understood more the link between her dream and her reality and it was this which visibly shocked them.

Having seen all the stimulus material, one participant in particular, Jenny from group one, was visibly upset and shocked by what the material had presented. Almost on the verge of tears she said:

> *"I wish I knew this before … it is so important that we get to hear what the patients' are remembering about critical care."* (Jenny)

5.7.3 Amused by the patients' reconstructive memories of critical care

At times all participants found some of the patients' comments amusing. They particularly found Diane's comments about a 'naughty nurse' smuggling champagne onto a boat humorous, and many nodded as they recognised this memory. Malaya spoke about patients hallucinating that they were on the ocean:

> *"Some of them think they're in the ocean because of the pressure beds."* (Malaya)

5.7.4 A sense of reward

Participants appreciated seeing and hearing this feedback from the patients. For many they reported it vindicated their approach to care and that they were doing a good job. For some participants in group three who were not involved in critical care follow-up clinics, expressed it was rewarding to hear the feedback from patients. They reported the interview findings revealed appreciation from the patients' as to the care the nurse provided.

5.7.5 The importance of family and family-centred care

As presented in section 4.7, a key finding reported in the patient interview study was the importance patients place on family and their desire for family to be present as patients received critical care, to help them address the gaps in their memories through reconstructive memories. However, the focus group study with nurses demonstrated that they have a very limited understanding of this. Katie mentioned her view that it was important to involve the family when a patient was hallucinating (presented in section 5.3.3) and there was some recognition that family members helped patients fill the gaps in their memories (presented in section 5.6.1). However, the degree to which patients drew upon their family for support and security, particularly throughout the CCU stay and at the time of transition in the level of care from the CCU to the ward (presented in section 4.5.1), was not considered by the nurses.

5.7.6 Summary of the nurses' responses

In summary participants recognised what patients reported and demonstrated this through body language such as nodding in agreement. They were often saddened by what patients were reporting in particular patients' memories of 'the long wait' for care on the wards. The participants found some of the memories amusing, especially when it related to hallucinations associated with patients' perceptions of nurses. Those not involved in follow-up appreciated the opportunity to hear the patients' memories of receiving critical care. Finally, the nurses had a very limited understanding of the value patients place on the importance of family and family-centred care

5.8 Chapter conclusion

This chapter has presented the findings from the focus group study held with critical care nurses. The findings demonstrated that participants recognised and understood some aspects of patients' reconstructive memories of critical care, including the missing memories patients experience after a CCU stay and the need they have to address these. Whilst the findings established that the nurses understood that gaps in memories can be filled by reconstructed memories from details recounted by family members, delusional memories or information gleaned from diaries, they also demonstrated a lack of insight in relation to the value patients place on having their family members close by throughout their critical care experience. The findings also demonstrated that a considerable proportion of nurses are not invited to participate in the critical care follow-up clinic and as such they fail to receive feedback from such encounters. Additionally, the nurses in the focus groups did not recognise the importance of follow-up clinics for patients and the impact on patients' reconstructive memories of critical care, helping to make sense of their experience and ultimate survivorship. In contrast, the focus group participants reported feeling 'out of the loop' and that for them, their cycle of care was never fully closed as it stopped in the CCU and they were left speculating what had happened to their patients. Another significant finding from the focus groups is that nurses reported that patients experienced confusion when nurses conversed around them in their native tongue, although patients did not raise this as a concern in the interviews. The following chapter will present the convergence and divergence of findings across both phases of this study – the patient interviews and the focus groups with critical care nurses.

Chapter Six: The areas of convergence, divergence and silence within the findings across the patient interview study and the focus group study with critical care nurses

The convergence, divergence and gaps within the findings between the patient interview study reported in Chapter Four, and the focus group study with nurses reported in Chapter Five are presented in this chapter to address the third research question:

> *How do former critical care patients' reconstructive memories of receiving critical care converge with and diverge from critical care nurses' understanding of these?*

6.1 The nature of patients' reconstructive memories of critical care and nurses' understanding of these.

A significant finding from this research was that patients reconstruct some memories of critical care which were not restricted to just the CCU but also included memories of the moment they fell ill to post-discharge, returning to their lives at home. In contrast, nurses' understanding of the patients' memories were much narrower and spatially boundaried in that their memories were limited to the CCU and lacking the richness of the patients' experiences before and after their CCU stay.

6.2 Missing memories of critical care

The findings from both groups demonstrated strong convergence regarding the category: *missing memories of critical care,* with mutual agreement between patients and nurses occurring in six of the seven focus codes. These are all presented in Table 6.1.

Table 6.1 The areas of convergence, divergence and silence between former patients' reconstructive memories of their missing memories of critical care and critical care nurses understanding of these.

Missing memories of critical care		
Focused Code	**Patient Interview Study**	**Focus Group Study with Critical Care Nurses**
There's a lot I don't remember	Convergence	Convergence
Missing memories causing discord	Convergence	Convergence
Missed time	Convergence	Convergence
Where am I and why am I here?	Convergence	Convergence
Recognising patients do not know what had happened to them	Convergence	Convergence
Needing to address the missing memories to achieve closure and move on with a second chance at life	Reported by patients	Silence
A means of self-protection	Convergence	Convergence

6.2.1 Convergence between former patients' reconstructive memories of missing memories of critical care and nurses' understanding of these

Both groups of participants recognised patients' missing memories of their CCU experience. As one patient reported:

> *"There's lots of big blank … gaps …"* (Colin, patient)

Whilst Celia a nurse reported:

'Some patients they can't remember anything' (Celia, nurse)

Nurses recognised that at times, patients experienced discord between themselves and their families over these missing memories. As presented in section 5.2.3 the missing memories also caused discord between nurses and patients because patients often did not believe what nurses were telling them, especially in respect of the missed time whilst they were sedated on CCU. The aspect of missed time was discussed extensively by patients, as illustrated by a quotation by Pete:

> *"I mean, you know, losing three weeks of your life is, I don't know, it's an interesting thing to go through. It's a very hard thing to go through, especially as I managed to choose three weeks when two of them had birthdays!"* (Pete, patient)

The nurses were also aware of this missed time. As Mary explained, patients wanted to know what had happened in this time:

> *"Missed time … A gap and that three –/– four days are gone so you want to know what has happened."* (Mary, nurse)

6.2.2 Divergence between former patients' reconstructive memories of missing memories of critical care and nurses' understanding of these

A key finding identified through comparing the patients' interviews with the nurses' focus groups was how nurses draw upon the medical model (the medical model is defined in section 1.1.4.1) to make sense of patients' memories of their experience. This was demonstrated in a number of instances during the focus groups, when participants discussed the patients' missing memories of critical care in relation to their medical condition and as a means of self-protection as Horacio commented:

> *"He had a throat infection and then the next thing he knew he was waking up in intensive care and he missed everything out. I think that's his natural brain trying to forget all the horrid things that have happened."* (Horacio, nurse)

In contrast, patients did try to explain their missing memories in terms of their medical condition. They articulated their missing memories in terms of their overall critical care experience and in particular, how it made them feel disconnected from their families (as presented in sections 4.2.4 and 4.2.5) and also caused them confusion which was difficult for them:

> *"Things of the kids that I've forgotten and, you know, just sometimes will say things and I've totally forgotten them. Losing a memory is, a lot with it as well."* (Beverley, patient)

Another key finding was how the two groups diverged regarding the importance that patients placed on addressing their missing memories of critical care in order to make sense of their experience and enhance their survivorship.

6.2.3 Areas of silence between former patients' reconstructive memories of missing memories of critical care and nurses' understanding of these

The nurses demonstrated a lack of understanding of the patients' need to reach closure in order to move on with the second chance of life that critical care had provided. They were silent as to the significance that patients place on believing critical care provides a second chance at life, which was very important for the patients who were interviewed.

6.2.4 Category summary

In summary, both patients and nurses recognised and understood there were gaps in patients' memories of critical care which often related to patients' missed time in CCU. Nurses understood this caused discord between patients and their families but also reported it caused discord between themselves (nurses) and patients too. An important silence existed with nurses not recognising the patients' desire to address these gaps and achieve closure on this period and to be able to embrace their new life, perceived as a second chance at life.

6.3 Sensing an altered reality

The comparison of findings regarding the category: *sensing an altered reality from CCU to home*, provided two areas of convergence and three areas of silence of within the category, one from the nurses and two from the patients. These are presented in Table 6.2.

Table 6.2 The convergence, divergence and silence between former patients' reconstructive memories of sensing an altered reality from CCU to home and nurses understanding of these

Sensing an altered reality from CCU to home		
	Patient Interview Study	**Focus Group Study with Critical Care Nurses**
Focused Code	**Patients' reconstructive memories of an altered reality from CCU through to home**	**Nurses understanding of the patients' reconstructive memories of an altered reality from CCU through to home**
Distinguishing between memories of reality and unreality	Convergence	Convergence
Remembering hallucinations	Convergence	Convergence
Remembering dreams and nightmares	Reported by patients	Silence
Recognising patients being disorientated by foreign languages used by staff	Silence	Reported by nurses
The challenges of managing an altered reality	Divergence	Divergence

6.3.1 Convergence between former patients' reconstructive memories of an altered reality from CCU through to home and nurses' understanding of these.

Both groups recognised patients' difficulties in distinguishing between memories of real and unreal events. This was demonstrated through these quotations from Sean and Katie:

> *"They're two really distinct differences in the state in what I saw and what I remember and what was real and what wasn't real."* (Sean, patient)

> *"In a really mixed up world of what's real and what's not real."* (Katie, nurse)

Both nurses and patients described in detail some frightening hallucinations experienced by patients. Many nurses attributed the hallucinations to a cause and effect again drawing on the medical model (presented in section 7.3) for explanation. For example, the nurses explained hallucinations in terms of lack of sleep or the presence of infection or delirium. Priyanka explained that she told her patients:

> *"You seeing those things, because the drugs and everything, sleep deprivation."* (Priyanka, nurse)

Patients also reported that having had the hallucinations explained to them at their follow-up meeting they understood they were related to the sedative drugs and lack of sleep on CCU. Diane reported:

> *"Everything was explained to me, and they said that it's the drugs that's doing it, the drugs that are making you think these things are happening …'* (Diane, patient)

6.3.2 Divergence between former patients' reconstructive memories of an altered reality from CCU through to home and nurses' understanding of these

A key divergence in findings between nurses and patients was that although nurses recognised patients' difficulties in remembering what was and was not real, they were only able to describe what they had observed and learnt from their patients accounts of this. In contrast, patients' reconstructed memories of this *altered sense of reality* were vivid and involved greater depths of description of many different experiences. Clearly, as the nurses had not actually experienced these hallucinations and dreams themselves, they could not fully appreciate the influence these had on patients' memories of critical care. For example, Derek spoke in section 4.3.3 of still being unable to talk about the nightmares he experienced on the CCU because they remained too distressing for him to revisit. This was despite his critical care stay being over 10 months previously.

Many patients attributed their memories of an altered sense of reality to their missing memories of the event which necessitated critical care. They found this disorientating as described by Alan:

> *"I didn't know where I was…I thought I was in South America."* (Alan, patient)

There was a further difference in relation to understanding the need patients place on family members helping them to manage their hallucinations. Consistently in the interviews the patients valued their family during this time, as Diane explained:

> *"I would say to my husband and my daughter, but I didn't say to the nurses: … about it."* (Diane, patient)

In contrast, only Katie (a participant from focus group three) discussed the importance of family presence as patients hallucinate:

> *"In a really mixed up world... family become quite important."* (Katie, nurse)

An understanding of how long this altered reality persisted from CCU through to home varied between patients and nurses. Two participants in focus group one recognised this altered reality could persist as PTSD as demonstrated here:

> *"And it can follow them home, it can carry on for years and years with flashbacks and memories disturbing their daily life."* (Glen, nurse)
>
> *"Okay, yeah."* (Me, focus group moderator)
>
> *"It's PTSD."* (Sunita, nurse)

Nurses reported they used assessment tools to identify a patient who was experiencing delirium, but that they did not feel equipped to manage it effectively even if they assessed its presence. This caused them frustration in their clinical practice. In contrast, patients did not remember being assessed for the presence of delirium, however as presented in section 4.3.1 Jeff did become angry with a nurse who persisted in trying to re-orientate him to reality.

6.3.3 Areas of silence between former patients' reconstructive memories of an altered reality from CCU through to home and nurses' understanding of these

Whilst the two groups independently mentioned the focused codes – 'distinguishing between memories of reality and unreality' and 'remembering hallucinations,' – however the nurses were silent with regard to patients' memories of dreams and nightmares and only spoke about patients' memories of hallucinations.

Nurses in two of the focus groups (focus groups one and two) tried to understand the patients' memories of this altered sense of reality in terms of their (the nurses) behaviour and how this may have contributed to their memories of an altered reality. An example of this was that a number of participants in the focus groups originated from overseas and that at times they conversed in their native tongue. They believed this was disorientating and distressing for patients and contributed to patients' confusion:

> *"Us talking in foreign languages as well. They think they are in a different country."* (Claire)

In contrast, despite receiving care from overseas nurses, patients were silent about this and it was not an area of focus of the interview.

6.3.4 Category summary

In summary, both groups reported that when patients experienced hallucinations, this made it difficult for patients to distinguish between memories of reality and unreality. However the patients also talked about the impact of dreams and nightmares, but these were not recognised by the nurses. Some nurses attributed the fact that patients experienced disorientation might be due to them lapsing into speaking in their native tongue, however this was not mentioned by the patients. Some patients recalled being irritated by nurses trying to re-orientate them, whilst being unaware of the frustration that nurses expressed at their inability to manage patients' perceptions of an altered sense of reality.

6.4 Feeling reassured yet powerless

Following the presentation of the stimulus material (presented in appendix 3.1), nurses recognised two of the focused codes which contributed to the category the silence from the nurses regarding two aspects of these memories. These are presented in Table 6.3.

Table 6.3 The convergence and divergence between former patients' reconstructive memories of feeling reassured yet powerless and nurses' understanding of these

Feeling reassured yet powerless		
	Patient Interview Study	**Focus Group Study with Critical Care Nurses**
Focused Code	**Patients' reconstructive memories of feeling reassured yet powerless**	**Nurses understanding of patients' reconstructive memories of patients feeling reassured yet powerless**
Glimpses of memories	Convergence	Convergence
A total dependency on others	Convergence	Convergence
Lasting memories (– the importance of faces)	Divergence	Divergence
Reassured by feeling safe and secure	Divergence	Divergence

6.4.1 Convergence between former patients' reconstructive memories of feeling reassured yet powerless and nurses' understanding of these.

There was mutual agreement that patients held fragmented memories of critical care and that the nurses understood that patients developed pockets of memories of the care they received. Dan commented:

> *"It's fragmented, I think, what they actually remember."* (Dan, nurse)

Perhaps unsurprisingly, the nurses did not describe these memories in the depth that patients did. This is demonstrated in this exchange during focus group four regarding what they thought patients remembered:"

> *"Noises."* (Hope, nurse)
>
> *"Pain."* (Casey, nurse)
>
> *"Hallucinations."* (Beth, nurse)
>
> *"Dreams-nightmares."* (Makisig, nurse)
>
> *"Monitor alarms."* (Malaya, nurse)

There was also a consensus between patients and nurses in relation to the memories' that patients had of noises and voices:

> *"I can remember, people visiting, because I know I was hearing people's voices."* (Diane, patient)
>
> *"They have come round [and] have put a face to the voice, so they've heard the voices and it's almost like they knew whoever that nurse was just by the fact that the voice, instead of visually seeing them."* (Susie, nurse)

In particular patients remembered hearing alarms whilst all nurses across the groups responded *'alarms'* when asked what patients remembered. A number of nurses reported their perceptions that patients would remember voices more than faces – however patients remembered faces and voices (presented in sections 4.3.2 and 4.4.1) with memories of the face who woke them up being one of their first memories.

Both nurses (prior to the stimulus material) and patients independently mentioned the pockets of memories relating to patients' experience of pain on critical care. Sheila recalled:

> *"All the pain I was in in my legs, I couldn't understand why it got so much worse that particular day, and in the end I was literally shaking my legs, they were shaking with the pain, and perspiration."* (Sheila, patient)

Beth recognised this too. She commented that patients remember:

> *"Experiencing it [pain]. Maybe not having as much pain relief as they could potentially have or that they'd like to have." (*Beth, nurse)

Again, Beth demonstrated reliance on the medical model (presented in section 1.1.4.1) in her explanation of patients' memories of pain. Similarly, Malaya reported that patients associate pain with interventions, but again did not explore the lasting effects of pain on patients' memories of critical care:

> *"Pain with nurses doing stuff like when you say, 'Oh, we're going to reposition you and give you a roll', then they would say, "That's really painful.""* (Malaya, nurse)

Another shared aspect was nurses' understanding of patients' memories of the humiliation they experienced at being totally dependent on others for care. Sean recalled having:

> *"… no warning or control over that [bowels] which was quite embarrassing."* (Sean, patient)

Whilst prior to the stimulus material, Will reported the:

> *"Embarrassment of a patient for them going to the toilet…they will always remember, because of how embarrassing it is."* (Will, nurse)

6.4.2 Divergence between former patients' reconstructive memories of feeling reassured yet powerless and nurses' understanding of these.

A principal area of divergence identified between the two groups, was the importance patients place on the safety and security they perceived from the one-to-one care on critical care.

> *"You were in safe hands, no matter what it was you were in safe hands."* (Karen, patient)

However nurses did not fully identify patients' memories of feeling safe and secure on CCU. Only Gordon (in focus group two) mentioned the one-to-one care patients receive, but attributed this more to the continuous care provided:

> *'It's the ratio, one to one. People are on your beck and call the whole time.'* (Gordon, nurse)

Another prominent reconstructive memory of critical care for patients was the powerlessness they experienced throughout their CCU stay, especially in relation to carrying out activities of daily living. Despite there being some recognition of this amongst some nurses, the nurses conceptualised this as 'helplessness':

> *"They will feel helpless."* (Priyanka, nurse)
>
> *"It's that feeling of helplessness as well."* (Dan, nurse)

This was in contrast to the stronger description of 'powerlessness' used by the patients:

"I was losing my bladder control, absolutely powerless to do anything about it." (Alan, patient)

Many patients remembered the voicelessness associated with the presence of the ETT and how this made them feel isolated. Diane recalled how not being able to speak meant she had to endure listening to music she disliked and how this marginalised her:

> *"I can remember the tube being in and not being able to speak… I couldn't say anything, or even to let them know that I didn't particularly like her music."* (Diane, patient)

One nurse Christa recognised (prior to the stimulus material) how a patient she was caring for was marginalised in any decision making. However Christa attributed this to her young age rather than her inability to speak:

> *"… at least a patient I had she was quite young, and she said when she came back, she felt like no one was listening to her."* (Christa, nurse)

Another really important and lasting memory for many patients was the first face they saw as they regained consciousness. Many patients remembered particularly if the face was smiling and appeared kind and reassuring to them:

> *"She was just a face ... she always had a smile and she seemed nice."* (Karen, patient)

Nurses however, demonstrated a different understanding of the role that faces play in patients' memories. These ranged from them demonstrating no understanding to acknowledging that patients do remember faces, but as these were *"just faces"* (Jenny, nurse) and were not perceived as being important memories for patients:

> *"They [the patients] don't remember faces ... They don't remember our faces usually when they come back."* (Helen, nurse)

> *"Well, probably just faces really. People staring at them."* (Jenny, nurse)

There was also variance between what nurses' understood patients remembered about critical care in contrast to what the patients reported. Many nurses reported that many patients would recall suctioning:

> *"Suctioning."* (Emma; Casey; Beth, nurses)

Yet just Derek and Diane (patients) mentioned suctioning. Likewise, as presented in sections 5.4 and 6.4.1 the nurses understood patients would recall the alarms which sound in CCU, however, they failed to explain what aspects of the alarms the patients remembered:

> *"Yeah, alarms going off the whole time."* (Gordon, nurse)

In contrast, patients remembered the nuisance of these alarms. One complained:

> *"It's only at night you hear them. But they... when you've just nodded off, you know... ah God, switch that bloody thing off."* (Mike, patient)

6.4.3 Category summary

In summary there was mutual agreement between the two groups that *glimpses of memories emerge during critical care.* Patients recalled the powerlessness they experienced at being dependent on others for their activities of daily living, and whilst nurses recognised this also to be an issue they described it more in terms of helplessness. Patients spoke at length of the importance of seeing a face for the first time after they regained consciousness and how this remained a key memory for them, whilst the nurses did not understand the significance of this for patients, talking more about the significance of voices rather than faces. The biggest divergence however existed between patients' memories of feeling safe and secure on critical care in contrast to complete silence from nurses regarding this.

6.5 Feeling abandoned on the ward

There was greater divergence than convergence between the two groups for the category *feeling abandoned on the ward.*. These are all presented in Table 6.4.

Table 6.4 The convergence and divergence between former patients' reconstructive memories of feeling abandoned and nurses' understanding of these

Feeling abandoned on the ward		
	Patient Interview Study	**Focus Group Study with Critical Care Nurses**
Focused Code	**Patients' reconstructive memories of feeling abandoned**	**Nurses understanding of the patients' reconstructive memories of feeling abandoned**
Fear of leaving CCU and entering the unknown	Convergence	Convergence
The care just seemed to disappear	Reported by patients	Silence
Having to wait for care (no longer one-to-one care)	Convergence	Convergence
Nurses managing the move from CCU to the ward (-visiting the patient on the ward)	Divergence	Divergence
Importance of family in the transition from CCU to the ward	Reported by patients	Silence (except one brief mention by one nurse)
Delays in treatment	Reported by patients	Silence
Promoting independence	Silence	Reported by nurses
Transition from hospital to home	Reported by patients	Silence

6.5.1 Convergence between former patients' reconstructive memories of feeling abandoned on the ward and nurses' understanding of these.

Although the nurses did not recognise the importance for patients of the feeling of safety provided by one-to-one care (as presented in section 6.4.2) both groups recognised how stressful the reduction of one-to-one care from CCU when transferred to the ward was for patients:

> *"I kind of miss the one to one care because…when I went to the normal ward it just seemed to disappear."* (Beverley, patient)

> *"Having someone with you 24/7 constantly there watching over you to then going to an area where they might see the nurse three or four times in a day."* (Sunita, nurse)

Both groups talked about how the ward nurses may not understand the level of care patients required following a CCU stay, attributing this to the ward nurses not knowing the 'back story' of the patient. This is demonstrated by Jenny commenting:

> *"When they go to ward people as well might not know their back story, they might not be able to relate that, they might've been through a really traumatic experience."* (Jenny, nurse)

Colin also remembered an interaction between his mother and a nurse on the ward caused him stress:

> *"She [mother] was a bit shocked when this nurse up on the ward said, "what's the matter with him?" Mother said, "what's the matter?" I said, "I think my safety fuse is going to blow." And she went up and said the same thing to the nurse,*

> *she said, "what are you on about?" Put her head round the door said, "what's wrong with you?" "* (Colin, patient)

There was also convergence between patients and nurses regarding the value both groups placed when CCU nurses visiting patients on the ward. Derek recalled:

> *"She [nurse] would also pop into see how I was on the ward. It put me at ease. I think it was because she sort of knew me."* (Derek, patient)

The nurses appreciated seeing how their patient was progressing on the ward. Horacio explained:

> *'I went to visit a patient on the ward, a very young chap, who I really cared for and went down to see if he was doing well.'* (Horacio, nurse)

Despite both parties agreeing this was a positive intervention, nurses described having to do this informally on their comfort breaks, of their own volition, in their own time:

> *"The only times I went, I went on my own breaks. And sometimes if you don't have that time and you really need to eat, and you know it's going to be a really, really busy night, you don't have time."* (Glen, nurse)

Many nurses described how instead the Critical Care Outreach Team (CCORT) would visit patients on the ward following their discharge. Jency reported this was not helpful and could result in patients feeling even more abandoned:

"You can have outreach; they have no connection and they have no relationship with them, and it would make them think, "Yeah, I'm not far from your thoughts, they're looking out for me." " (Jency, nurse)

6.5.2 Divergence between former patients' reconstructive memories of feeling abandoned on the ward and nurses' understanding of these.

Nurses reported various strategies they employed to enhance the transitions in care from CCU to the ward for patients. However, these strategies were not recognised by patients, apart from on the ward by the follow-up sister or by the nurses popping into see them. Some nurses reported that more should be done on CCU to promote patients' independence in preparation for the ward. Casey who had worked on a ward prior to moving to critical care explained her rationale:

> *"I think when patients start to wake up in ITU and they're able to do things for themselves we should encourage them to do everything themselves to help them when they go on."* (Casey, nurse)

Most important to patients though was their frustration at family members not being encouraged to assist with this transition in care delivery. Pete remembered moving to the cardiac ward:

> *"The first thing we noticed, no children, no phones, strict visiting hours …"* (Pete, patient)

Pete explained this made his transition from CCU to the ward harder as he and his family were suddenly confined by rules and regulations which they perceived excluded family members:

> *"You went from the patients and the reli's being the priority to I suppose to an extent the patient still being a priority, but not as a baggage."* (Pete, patient)

6.5.3 Silence between former patients' reconstructive memories of feeling abandoned on the ward and nurses' understanding of these.

In contrast to the nurses, the patients did not mention promoting independence as a method to aid the transition in care from the CCU to the ward.

Most nurses were silent on the role of family members as patients moved to the ward. Just one nurse (in focus group three) briefly recognised the need to include the family more in this transition:

> *"We've got to involve the family more so that they're aware ..."* (Helen, nurse)

Patients spoke at length of the discomfort they experienced relating to missing out on treatment whilst they were on the ward. Sheila spoke of missing her analgesia:

> *"... "I can't understand these pains. I've reached the stage where I am really, really having difficulty coping with it now." She said, "Let me look at your chart ...." and she said, "You haven't had any morphine." I was on four-hourly morphine, and I hadn't been given it."* (Sheila, patient)

In contrast, no nurse identified this as an issue. Patients spoke that the care just *'seemed to disappear'* (Beverley, patient) on the ward which again was not identified by nurses. Following the stimulus material prompted one nurse to be visibly shocked commenting:

> *"That's bad. That's really bad."* (Susie, nurse)

However, the non-verbal communication of many others demonstrated even greater shock at the stimulus material. Not only did they audibly gasp but they shook their heads as they saw Sheila's memory. Jasmine (a nurse from focus group four) tried to explain the patients' memories and attributed them to being discharged to the ward rapidly, with no time to prepare themselves for the move:

> *"Sometimes they get pushed out so quickly as well because of bed pressures. They're literally there one morning and then an hour later, "Right, you're off to the ward now." You've had no time to process this at all."*(Jasmine, nurse)

Nurses were also silent regarding the transition from hospital to home. Three patients recalled this to be an issue. Alan recounted a miscommunication which resulted with him being discharged too early and the doctor having to call to see if he was safe, whilst Sean was unprepared for the discharge which took place earlier in the day than expected due to 'pressure on beds.' Sheila (who had experienced the longest critical care stay at three months) was scared to go home and felt she was going to be abandoned after all the care she had received in hospital.

6.5.4 Category summary

In summary, both patients and nurses independently mentioned that leaving the CCU is a stressful and fearful time for patients. Both understood that patients find it difficult to adapt to waiting for care on the ward, however the nurses did not appear to have a comprehensive understanding of this. Both nurses and patients explained strategies to enhance patients' memories of the transition in care. However, once again nurses were largely silent with regard to the role family members play in this period of transition in the levels and places of care. Nurses were also silent regarding patients' memories of the transition between hospital and home.

6.6 Filling the gaps; reaching closure and moving on with life and survivorship

There was convergence between patients' and nurses for four of the focused codes in the category *filling the gaps: reaching closure and moving on with life* and divergence between three. These are all presented in Table 6.5.

Table 6.5 The convergence and divergence between former patients' reconstructive memories of filling the gaps: reaching closure and moving on with life and nurses' understanding of these

Filling the gaps; reaching closure and moving on with life and survivorship		
	Patient Interview Study	**Focus Group Study with Critical Care Nurses**
Focused Code	**Filling the gaps through reconstructive memories: reaching closure and moving on with life and survivorship**	**Nurses understanding of the patients' need to fill the gaps through reconstructive memories, reaching closure and moving on with life and survivorship**
Addressing the missing memories	Convergence	Convergence
Revisiting the CCU	Divergence	Divergence
The role of family members	Reported by patients	Silence (Reported briefly by one nurse)
The crucial role of follow-up	Reported by patients	Silence
Reaching closure and moving on with life and survivorship	Convergence	Convergence
The bed-side nurses' contribution to critical care follow-up	Silence	Reported by nurses
The lasting effects of critical care	Convergence	Convergence

6.6.1 Convergence between former patients' need to fill the gaps through reconstructive memories; reaching closure and moving on with life and survivorship and nurses' understanding of these.

Whilst section 6.2.2 demonstrated divergence between patients' need to address missing memories and nurses' understanding of this, there was convergence regarding the need for closure from both parties. Having seen the stimulus material, the participants in the focus groups recognised that patients used a range of strategies which helped them to address these gaps. Patient diaries and the follow-up clinic were reported by both groups to help do this, and this could relate to Bartlett's (1932) theory of reconstructive memory which may help address the gaps in memories.

The patients and nurses both recognised the importance patients placed on revisiting the CCU to meet the staff who had cared for them, put names to faces and voices and to assist in contributing to their reconstructive memories to fill the gaps. Patients also recognised the nurses could evaluate patients' progress through such visits. Nurses described how they appreciated the chance to establish what had happened to the patients and thus achieving a degree of closure in relation to individual patients, with Mary stating:

> *"Even if they are still alive sometimes, we had a patient that was in our unit for a year almost and I'd been with him so long, and then he went out and you don't know if he was still alive or not. And now he's back to the hospital, but I was very happy to see him I was like, "You are alive" … it was the only way I knew what happened to him afterwards"* (Mary, nurse)

6.6.2 Divergence between former patients' need to fill the gaps through reconstructive memories; reaching closure and moving on with life and survivorship and nurses' understanding of these.

Patients were given the opportunity to revisit the CCU as a component of the follow-up clinic appointment and many reported this helped them address the gaps in memories. They also remembered the courage it took for them to revisit the CCU, but all stated this was a very positive experience:

> *"It was scary. I managed to hold it together for about a couple of minutes then just lost the plot and just broke down, but she said I think it's a very brave thing to do to go back into that sort of clinical environment."* (Colin, patient)

For patients, the visit also explained things they were still experiencing as a result of their critical care illness and stay:

> *"Until I came back and saw the CCU for the first time a few months later, even the stuff that I thought was real, wasn't real."* (Sean, patient)

In contrast, some nurses identified that the return visit was not always a positive experience for patients. They reported some did not want to revisit a place which held such bad memories. They also reported that for others, the CCU stay was still too raw and they were not emotionally fit to undertake the visit:

> *"She hated coming onto the unit because it was just bad memories."* (Susie, nurse)

6.6.3 Former patients' need to fill the gaps through reconstructive memories; reaching closure and moving on with life and survivorship and nurses' silence relating to recognising and understanding these.

The leading area of difference identified between the two groups was the importance patients placed on family members being encouraged to support patients at the bedside and to also benefit from psychological and social care from critical care staff on CCU and beyond (from falling ill to returning home). Patients reported relying heavily on family members remaining close to them at the bedside throughout the CCU stay and on the ward, so that they could gain an insight into what was happening in these areas and also receive information which they could then share with patients at a later date. Through this patients could then develop their reconstructive memories to which may help address the gaps in memories and enable them to return to some degree of normality. In contrast, nurses rarely mentioned the contribution family members had on patients' reconstructive memories of critical care. As presented in section 6.5.2 just Helen (a nurse) referred to utilising family members to enhance the patients' memories of the transition in care from CCU to the ward.

Whilst nurses recognised that patients attended critical care follow-up services, they did not fully appreciate the effect of this service on patients' reconstructive memories. The patients reported a strong desire to achieve closure on this episode in their life and to be able to move on with the rest of their lives and achieve a reasonable level of survivorship. They reported that critical care follow-up helped them to achieve such closure on this period of their lives. However, the nurses were silent with regard to the need for closure. The nurses understood that the follow-up clinic was used by patients to fill in the gaps in memories but saw it more as a meeting without any clear rationale. Dan was not even sure if a clinic was available for his unit:

> *"I don't think we do. I think we're just starting to implement something now. But it's still in it's infancy at the moment."* (Dan, nurse)

Although patients spoke at length about their positive experiences of critical care follow-up services, they did not mention how this meeting could also benefit bed-side nurses who were responsible for delivering the care which contributed to patients' reconstructive memories of critical care. Helen reported:

> *"As nurses though we… I really appreciate them coming back and seeing them and it makes us feel that we've achieved something."* (Helen, nurse)

Despite the fact there was convergence between the two groups in so much as they both needed to reach closure on episodes of critical care, patients were silent in relation to nurses' desire to receive feedback on the progress of their patients through the follow-up clinics. Nurses also reported that due to the fragmentation of services between those who deliver care at the bed-side in the CCU and those who contribute to the follow-up clinics, there was a lack of opportunity for them to engage with follow-up services. Consequently, nurses reported they too failed to reach closure regarding an episode of critical care:

> "… *emotionally, we do get emotionally attached to the patients, some more than others because we see relatives, and it does sort of … sometimes we need that closure as well. I do feel like we're left out of the loop as well, and we do a brunt of the care*." (Katie, nurse)

Nurses also reported frustration at not knowing what had happened to patients stating that they only really obtained closure when patients died on their unit because then they knew what the outcome was:

> *"We only really know the outcome for our patients when they die on CCU."* (Emma, nurse)

Patients did not seem aware that the nurses also wanted to achieve 'closure.' Nurses reported their desire to be more involved in the follow-up services, so that they could listen and learn from patients' memories of receiving critical care. Rachael commented on the need for feedback:

> *"The follow-up clinic in our hospital is consultant-led and we don't get the feedback filtered down."* (Rachael, nurse)

After having seen the stimulus material nurses (particularly from focus group three) expressed a wish to participate in follow-up clinics. They wanted to not only learn what the outcome for their patients had been, but considered it would also help them develop future practice:

> *'I think it's very important because it's the only way to know from the patient if the care that we've given is what they seek.'* (Danielle, nurse)

Some – but not all – nurses recognised the importance that patients placed on their diary to address the gaps in memories:

> *"I've read them a couple times. I find it quite interesting because you pick up different things for each time you read it."* (Pete, patient)
>
> *"... diaries, and he was able to fill in the gaps of what happened."* (Priyanka, nurse)

Those participants who were experienced in the practice of patient diaries reported the effectiveness of this intervention was dependent upon how well established the practice was in their CCU. Participants recognised one role of the follow-up clinic was to release the diaries to patients in a controlled and supportive manner that would provide them with the opportunity to ask any questions related to the contents of the diary. They suggested using the follow-up clinic as a forum for this. In contrast the patients did not discuss the manner in which they received their diary.

A further discrepancy in understanding was that patients often spoke of critical care providing them with a second chance at their life. The nurses were silent regarding this. Fiona (a patient) reported:

> *'Having been in ICU it has made me relook at my life. I enjoy the blue sky and the birds singing. I am motivated to find a job now.'* (Fiona, patient)

Another area of divergence was the lack of understanding nurses displayed regarding patients' memories of critical care persisting with them at home. Patients reported lasting issues with cognition, short-term memory, muscle weakness, pain and insomnia:

> *"I was exhausted, I mean just eating was, you told me once, just eating would exhaust me and I'd have to sleep after."* (Alan, patient)

Not one nurse identified these ongoing issues for patients. Their focus remained solely on the patients' experiences and memories of the CCU stay and not beyond. This is unsurprising in light of the findings presented earlier in this section which demonstrated that the nurses' experiences are geographically constrained to the CCU with some permeability to the ward, however due to their lack of opportunity to engage with the follow-up clinics they have no experience of hearing of the longer term memories of a critical care stay for a patient once they have returned home.

6.6.4 Category summary

In summary, there was greater convergence between the two groups in this category than divergence. Patients demonstrated a greater need to address the gaps in their memories so that they could make sense of their experience and move on with their life. Both patients and nurses expressed the need for closure, however closure for both groups meant different things. For patients this meant gaining information so that they could process and make sense of what had happened to them so that they could then move on with the rest of their lives. For nurses this meant getting to understand what had happened to patients they had cared for especially those longer-term patients on CCU. Once again the importance of family members to help address the gaps in memories was not fully understood by nurses, nor was the importance of critical care follow-up services. Instead nurses discussed their lack of involvement in relation to critical care follow-up and their frustration with this situation.

6.7 Synthesis of the findings

Overall there are examples of areas of convergence, divergence and silence between patients' reconstructive memories of critical care and nurses understanding of these. These are presented in Table 6.6.

The CCA across the patient interviews and the focus groups with nurses demonstrated broad convergence between patients' reconstructive memories of critical care and nurses' understanding of these. The key area of convergence was that nurses recognise patients have gaps in their reconstructive memories. Out of all the strategies available for patients to address the gaps, both patients (presented in section 4.3.1) and nurses (presented in section 5.5.1), independently mentioned that to some extent family members helped address the gaps in memories which based upon Bartlett's theory (1932) may provide the schemata which could contribute to the reconstructive memories.

The most prominent divergence between patients' reconstructive memories of critical care nurses understanding of these, is nurses limited understanding of the importance patients place on family members to help and support them through critical care. Whilst two nurses briefly mentioned the role family members play in patients' processing of memories, this was not fully recognised nor appreciated by the main body of nurses participating in the focus groups.

Table 6.6 Synthesis of findings reporting areas of convergence, divergence and silence between patients' reconstructive memories of critical care and nurses' understanding of these

Areas of convergence between patients' reconstructive memories of critical care and nurses understanding of these	**Areas of divergence between patients' reconstructive memories of critical care and nurses understanding of these**	**Areas of silence demonstrated by patients and nurses in relation to the two perspectives relating to patients' reconstructive memories of critical care and nurses understanding of these**
	Missing memories of critical care	
Missing memories of critical care existed for patients Missing memories causing discord with family Missing time The importance for patients to fill the gaps	The different needs of patients' and nurses in relation to achieving closure and moving on with life and survivorship The role of follow-up The follow-up visit to CCU	Patients silence: Missing memories causing discord with nurses Nurses silence: Limited understanding of the role of family members in addressing gaps in memories
	Sensing an altered reality	
The presence of hallucinations Medical model cause and effect explanations for these	Cultural influences on an altered reality Managing an altered reality	Nurses silence: No understanding of dreams and nightmares Patients silence: Nurses conversing in native tongue Patients silence: Being assessed for the presence of delirium

Areas of convergence between patients' reconstructive memories of critical care and nurses understanding of these	Areas of divergence between patients' reconstructive memories of critical care and nurses understanding of these	Areas of silence demonstrated by patients and nurses in relation to the two perspectives relating to patients' reconstructive memories of critical care and nurses understanding of these
	Feeling reassured yet powerless	
Humiliation Voicelessness and marginalisation Hazy memories/ pockets of memories	Environmental aspects of care Powerlessness	Nurses silence: Understanding of powerlessness
	Feeling abandoned when leaving critical care	
The lack of time to prepare The need to visit the patient on the ward	Managing the transition in levels of care	Nurses silence: The importance of family members during this transitional period Nurses silence: The long wait for treatment

Filling the gaps in memories		
Critical care follow-up services The role of outreach	The bed-side nurses’ contribution to critical care follow-up services	Patients silence: regarding nurses’ desire to know what had happened to the patients following their discharge from CCU
		Patients silence: the nurses need to hear and learn from their stories
	The lasting legacy of critical care	Nurses silence: The lasting legacy of critical care in the shape of PTSD for some patients following discharge home
		Nurses silence: that patients recognise a second chance at life

Another noteworthy divergence related to the concept of closure. Whilst nurses understood patients need to achieve closure, the patients interviewed did not recognise this as a two-way process and that nurses also need to achieve closure. These findings were associated with the role of critical care follow-up services; all the patients reported the effectiveness of this service at helping them achieve closure and to move on with life. In contrast, most of the CCU nurses reported not being included in the follow-up process, and consequently did not recognise the importance of this service for patients. The nurses also reported that they rarely achieved closure themselves especially relating to what happened to their long-term critical care patients. Nurses reported remaining in this never-ending cycle of caring for critically-ill patients, seeing them leave the CCU simply to be replaced by another critically-ill patient. The majority of band five CCU nurses in the focus groups had no opportunity to hear and learn from patients after they left CCU, nor receive feedback regarding what had become of them, because they were excluded from the follow-up clinic. The only time the nurses reported they achieved closure was when patients died on the CCU.

Whilst both patients and nurses spoke at length about patients’ hallucinations, there was divergence in relation to dreams and nightmares which patients talked about, but the nurses did not. In all the focus groups, nurses reported their perceptions that if they originated from overseas and spoke in their native tongue, this was confusing and disorientating for patients and may have contributed to the hallucinations. However, this issue was not mentioned by the patients interviewed. Nurses also attributed patients’ altered sense of reality to factors such as sleep deprivation, sedative drugs, infections and, most importantly for nurses, the presence of delirium. They spoke at length of the challenges they had managing these for patients, whilst patients made little mention of these. In contrast, it was the continuing presence of this altered sense of reality on their memories of critical care which patients found the most distressing and debilitating rather than the cause and the difficulties with management which was the focus of nurses. This consequently had an influence on patients' reconstructive memories of critical care in that they struggled to understand what were real and unreal experiences on CCU. This made the experience difficult for them to process and understand.

Whilst initially it appeared nurses understood aspects of the pockets of reconstructive memories of critical care which emerge for patients, the depth of analysis provided through the CCA demonstrated they have different understanding of these to the patients. Nurses recognised that the patients remembered environmental aspects such as noises and alarms. They also believed patients would remember aspects such as suctioning more than they actually did from the patients' interviews. This demonstrates an inaccurate understanding of what patients find infiltrate their memories and nurses' perceptions of what patients remember. Equally, patients spoke at length of the powerlessness they perceived whilst in critical care, however just two nurses spoke of helplessness and none recognised the stronger emotion of powerlessness. Nurses also understood that patients remember faces but did not appreciate the extent to which patients remember these nor the influence facial expression can have on longer lasting memories of critical care.

Patients' spoke at length about how their reconstructive memories of critical care remain with them long after their discharge from CCU, and how distressing this could be for them. In contrast, the nurses' focus was on patients' reconstructive memories of the CCU stay in isolation. This was unsurprising because nurses practising at the bed-side on CCU are spatially constrained within the confines of the unit. Consequently, there is a lack of permeability of information and contact with patients for these nurses after patients have left the CCU. It is only nurses specifically employed to deliver the critical care follow-up services referred to as 'follow-up sisters' who experience interaction with patients after they have left the hospital. In contrast, bed-side nurses can choose to gain informal contact with patients once they have left CCU, but they do this out of choice and often on their comfort breaks during a shift.

6.8 Chapter conclusion

Chapters Four, Five and Six have presented the findings in response to the three research questions:

1. *What are former critical care patients' reconstructive memories of critical care?*
2. *How do critical care nurses understand and respond to patients' reconstructive memories of critical care?*
3. *How do former critical care patients' reconstructive memories of receiving critical care converge with and diverge from critical care nurses' understanding of these?*

The principal findings across the three chapters identified that despite former critical care patients holding some often vivid memories of critical care, they remained distressed by persistent gaps in their memories. Through Bartlett's lens, these gaps could result from the patients not having already formed schemata relating to critical care as they had no previous experience critical care and thus had not had the opportunity to form schema upon which to draw upon to form their reconstructive memories of critical care and thus make sense of their situation.

Patients also placed tremendous value on their care when family members were included throughout their critical care experience. Through facilitating family members to provide support to patients at the bedside often through simply just being there for them, family can also contribute to patients' reconstructive memories of critical care. In contrast, nurses were silent in relation to the value patients place on family presence during critical care and the contribution this had on their memories of care.

Critical care nurses displayed a narrow and limited understanding of patients' reconstructive memories of critical care (generally limited to patients' CCU stay). They drew extensively upon the medical model (presented in section 7.3) to explain patients' recollections and demonstrated no coherent understanding of the influence that psychological and social aspects of patients' reconstructive memories of critical care have on critical care survivorship. Whilst both parties demonstrated a need to achieve closure following an episode of either delivering or receiving critical care, they both held different understandings and needs in relation to what this meant.

Chapter Seven: Discussion

This chapter presents a statement of the principal findings from this programme of research. Responses to the three research questions are presented followed by a discussion of the strengths and weaknesses of the methods used here including a reflexive reflection on the research process followed by how the findings relate to the existing body of evidence. This then enables what new contribution to the body of knowledge in this area this research has identified. The implications and recommendations from the research for nursing practice and education. Finally the chapter concludes with some suggestions for future research. Firstly though, the key research findings are presented.

7.1 Setting the scene for the reported programme of research

This programme of research commenced with a mixed studies review (presented in Chapter Two) of critically-ill patients' experiences of receiving critical care. The review question: *What are former critical care patients' experiences of critical care as demonstrated through existing primary research*? was addressed through a thematic synthesis which identified four analytical themes: 1) experiences of remembering critical care, 2) experiences of discomfort, 3) experiences of hope and 4) experiences of returning to life after critical care.

As reported in section 2.3.10.1, the Mixed Study Review (MSR) identified 13 studies which reported on patients' memories of critical care. These studies focused on either memories which they assumed to be factual memories of the critical care stay (although such factual memories were never defined in any paper) and delusional memories relating to patients' recollections of dreams, nightmares and hallucinations.

None of the included papers within the MSR explored how constructing these reported memories as reconstructions based upon Bartlett's theory (1932) of reconstructive memory, allows them to be interpreted differently. This could contribute to a greater understanding of patients' memories or lack of memories of critical care, and irrespective of their objective accuracy, the implications these have on patients' emotional well-being and longer-term critical care survivorship.

A further gap identified by the MSR in section 2.3.5.5 was that all the included papers except one reported on patients' experiences of aspects of critical care in isolation, in contrast to the entire critical care experience. For example, the majority(n=70) of the 116 included papers focused solely on patients' experiences of the CCU stay, whilst others (n=10) explored their experiences of transitional care between CCU and the ward. Just one study by Ringdal et al. (2008) explored the experience of 18 patients from four hospitals in Sweden, across all aspects of critical care from the moment of injury until the discharge home. This study identified four themes relating to patients' memories: 1) a surrealistic world; 2) an injured body; 3) care and 4) a gratitude for life. Thus apart from the study by Ringdal et al (2008), the current literature does not provide a comprehensive understanding of critical care patients' experiences of their entire critical care experience from start to finish. Instead, the literature is fragmented, addressing the patient experience in separate stages focused on the CCU stay, transitional care or critical care follow-up, in isolation.

As presented in section 2.3.5, the MSR identified 14 mixed method research (MMR) studies involving both quantitative and qualitative methods to collect and analyse data relating to patients' experiences of critical care. However, as the MSR reported in section 2.4.2, none of these papers reported integrated findings from both phases of the research, to provide rich analyses of patients' experiences of critical care. Additionally, the review did not identify any QUAL → qual MMR designs from patients' and nurses' perspectives in relation to patients' experiences of critical care and nurses understanding of this.

To summarise, Table 7.1 presents the gaps identified in the MSR which contributed to this programme of research. Five gaps in knowledge were identified in the review: 1)a lack of analysis as to why patients develop gaps in memories of falling critically and their critical care stay; 2) a paucity of research into patients' reconstructive memories of critical care, 3) lack of analysis regarding the patients reliance on family members to address their gaps in memories; 4) the focus on specific aspects of critical care in isolation and 5) the lack of qualitative MMR integrating findings which explored patients' reconstructive memories of critical care and nurses' understanding of these. Consequently, this programme of research was designed to address these gaps in knowledge and methodological approach through the research aims and questions presented in sections 1.2 and 1.3.

Table 7.1 How the programme of research addressed the gaps identified in the MSR

Gaps in the literature identified through the thematic synthesis within the MSR into patients' experiences of critical care.	How the programme of research here addressed the gaps identified through the MSR
Current evidence acknowledges that patients experience gaps in their memories of their becoming critically ill and their stay in critical care. However, there no explanation as to why the gaps exist and persist for former critical care patients evident within the evidence base.	Bartlett's theory of reconstructive memories proposes that schemata developed through previous experience are drawn upon to reconstruct memories of an experience. This was the first critical care stay for all the participants. Through Bartlett's lens, this research addressed this gap through proposing that the missing memories exist because the participants had not previously experienced critical care and had not developed the schemata within their memory, upon which they could draw upon to address these gaps.
Current research into patients' memories of critical care focus on factual and delusional memories. There is no identifiable research into patients' reconstructive memories of critical care	This study identified similarities, differences and silences between patients' reconstructive memories of critical care and critical care nurses' understandings of these. Through this analysis, recommendations were made for nursing practice, research and education.
Within the literature, it is recognised that patients use critical care follow-up clinics and patient diaries to fill in the gaps in their memories. There is no evidence within the literature regarding the degree to which patients rely on family members' memories to address their own lack of memories, to help them to make sense of their situation and enhance the quality if their survivorship..	A key finding was the importance patients placed on family members recall of events to help them fill in the missing memories of critical care.

Gaps in the literature identified through the thematic synthesis within the MSR into patients' experiences of critical care.	**How the programme of research here addressed the gaps identified through the MSR**
Most studies identified in the MSR focused on individual aspects of critical care in isolation in contrast to the entire critical care experience.	The programme of research reported on patients' reconstructive memories across the entre of critical care from the moment of becoming ill to returning home.
Critical care is recognised to be a complex healthcare intervention and MMR is recognised to be helpful in researching such complex interventions. Currently, there are no identifiable QUAL → qual research studies from a patient and nurse perspective into patients' reconstructive memories of critical care and the implications of these for patients' emotional well-being and survivorship as well as future nursing practice.	The research adopted a qualitative exploratory sequential research design drawing upon the work by Creswell and Clark (2011)

7.2 Principal findings

The programme of research addressed the following aims:

1. *To explore patients' reconstructive memories and subsequent survivorship of critical care.*
2. *To develop an understanding of how nursing practice can contribute to patients' reconstructive memories and experience of critical care*
3. *To identify similarities and differences between patients' reconstructive memories of critical care and nurses' understandings of these, and make recommendations for nursing practice, research and education.*

The principal findings in response to the research questions were:

What are former critical care patients' reconstructive memories of critical care?

- Despite holding some vivid memories of critical care, former patients continued to be distressed by significant gaps in their memories which could persist long after returning home.
- An explanation for these gaps in memories identified through the theoretical lens for this research, was that this was the patients' first experience of receiving critical care. Thus they held no previous schemata upon which to draw upon to fill in their missing memories.
- Despite this patients displayed great need to address these missing memories of critical care, to help them proceed to a positive critical care survivorship.

- At times, patients would draw upon other schemata within their memories to try and address the missing memories particularly in relation to where they were and what had happened to them. This would result in inaccurate deductions being made by patients which caused them further distress and confusion.
- Patients described relying on their family members, and the follow-up clinic meeting to provide the schemata to help them reconstruct their memories of critical care and to clarify the pockets of memories they had whilst also trying to address the gaps in their memories.
- Because of this, patients expressed a desire for the focus of critical care to be family-centric where family members were not only supported to be with their relative throughout the entirety of critical care (from the moment of illness through to returning home). Furthermore, it was evident that family members also benefitted from the psychological and social aspects of nursing care provided by nurses at all stages of the patients’ critical care experience.
- Irrespective of the objective accuracy of patients’ reconstructive memories of critical care, it is the influence these have on their emotional well-being and longer-term critical care survivorship which is ultimately the most important thing for former critical care patients.

How do critical care nurses understand and respond to the patients’ reconstructive memories of critical care?

- Critical care nurses displayed a limited understanding of patients’ reconstructive memories of their entire critical care experience, with their understanding of patients' memories being confined to the CCU stay.

- Nurses drew extensively upon the medical model to understand patients' memories. They demonstrated a lack of understanding of the psychological and social implications of the patients' recollections of critical care and how these may influence their subsequent well-being and critical care survivorship.

How do former critical care patients' reconstructive memories of receiving critical care converged and diverge from critical care nurses' understanding of these?

- Patients placed extreme value on the presence of family members at all stages of their critical care. In contrast, nurses were silent in relation to the importance patients placed on the contribution of family members' memories to help them develop their own reconstructive memories of critical care and gain closure on the critical care experience.
- Both groups [patients and nurses] demonstrated a need to achieve closure in relation to an episode of receiving critical care [patients] or delivering critical care [nurses]. However, patients and nurses hold different understandings and needs in relation to closure within the context of critical care. For patients' closure referred to being able to *"close the door on that episode."* (Alan: patient) and move on with their life. For nurses it referred to knowing what had ultimately happened to the patient once they had left the CCU.

- Many patients reported achieving closure through attending the follow-up clinics, However, because most nurses were not involved in these clinics, they did not recognise the importance patients placed on this service.
- The longer-term psychological and social aspects that influenced patients' reconstructive memories of critical care were not recognised by the nurses.

7.3 Theoretical perspective – Bartlett's theory of reconstructive memory

This study was the first exploratory study into former critical care patients' memories of critical care to adopt Bartlett's (1932) theory of reconstructive memories as a theoretical lens. As presented in section 1.1.6.1 all previous studies which have made use of this theory sat within the field of experimental psychology (Gauld and Stephenson 1936; Mori 2008).

Bartlett's theory was helpful for the reported programme of research in four ways: Firstly, the theory helped explain why missing memories of critical care are present (section 4.2.1).

The basis of Bartlett's work is that through previous experiences schemata develop and are stored within the memory, and provide the basis for remembering (Bartlett, 1932). These schemata are embodied, dynamic, temporal, holistic and social (Wagoner,2013). As Bartlett explained:

> *" When an event occurs, some trace is made and stored in the mind. Later an immediate stimulus re-excites the trace... this carries with it a temporal sign, the re-excitement seems to be equivalent to recall."*
>
> (Bartlett, 1936:196).

This theory can be helpful when explaining why gaps in patients' memories in relation to critical care develop – especially those concerning the first few moments as a patient regains consciousness and asks: *"Where and I and why am I here?"* (presented in section 4.2.1 as a focused code within the category 'Missing memories of critical care'). For all the participants in this study, this was their first experience of receiving critical care. Therefore, a lack of exposure to the experience meant that they had yet to develop schemata within their memory in relation to a critical care stay. Thus they had no schemata to draw upon to try to address their gaps in memories and to understand their situation at that time… particularly when first gaining consciousness.

Secondly, the theory helped to explain why some patients make incorrect deductions to address the gaps in their memory, in an attempt to make sense of their situation. These incorrect deductions can contribute to additional confusion and disorientation patients report as they try to address the gaps and make sense of their situation. This was demonstrated through Sean who in section 4.2.4 explained how he drew upon the schemata he held in his memory in relation to going ski-ing and having an accident. Sean explained that when he regained consciousness on the CCU, the first thing he recognised was that it was snowing outside and there was snow on the trees. He also recognised that he was immobile and in a hospital bed. Drawing upon his previously developed schemata, Sean incorrectly deduced that he was in a foreign hospital having been in an accident on a ski-ing trip. He was actually on a CCU in the UK having experienced multi-organ dysfunction secondary to acute pancreatitis. Sean recalled that his inaccurate deduction caused him confusion, disorientation and distress as he tried to make sense of his situation as he gained consciousness on CCU. Thus using Bartlett's theoretical lens the missing memories of critical care which persist in former patients can be explained, as can the confusion and disorientation which results from schemata from previous experiences being erroneously applied to address the gaps and help make sense of the situation.

Thirdly, the theory provided a practical approach to structure the CCA of data from the patient interviews and focus groups with the nurses. Bartlett's concept of schemata was applied throughout the CCA of data to identify the mental representations and understanding patients had of their memories of their critical care experience. The categories presented as the findings in chapter four related directly to the previously held schemata within patients' long-term memory. It was such schemata that the patients drew upon to reconstruct their memories of critical care and to try to make sense of their experience and situation.

Finally, the theoretical lens helped explain how the hazy, glimpses of memories which emerge as patients regain consciousness on CCU, can be used to reconstruct their memories of critical care. The most striking of these *'pockets of memories'* related to patients' memories of nurses' verbal and non-verbal communication skills, particularly during those first moments when they regained consciousness on the CCU. Such memories can remain with patients for a long-time after their critical care stay and influence their emotional wellbeing upon their discharge home.

In particular voices formed reconstructive memories for patients. As their level of consciousness improved the voices they heard developed as schemata within their memory. When asked to recall their critical care experience, patients drew upon these to describe their memories of this time. Karen reported in section 4.1.1 :

> *" I remember hearing voices… your recognised voices."* (Karen , patient).

This is useful for critical care nurses because if they are aware that their voices, what they say and how they say it, forms schemata within a patients' memory, which they draw upon later to help then reconstruct their memories of this period and support them to make sense of their situation, the nurses maybe more cognisant of how they address patients and what they say to them.

Similarly, section 4.4 demonstrates how patients use faces to reconstruct memories of critical care, with the faces they see forming schemata. Karen in section 4.4.1 remembered a kind face who smiled and made her feel safe and secure. In contrast, Fiona experienced daily sedation interruptions. During this time she would see nurses faces which she remembered. As she was re-sedated, Fiona recalled the nurse she had seen whilst conscious, became the subject of terrifying nightmares which she could still recall (presented in section 4.3.2). This is important for nurses to understand as it demonstrates how facial expression can contribute to the development of schemata and patients' reconstructive memories of this time.

The findings from the patient interviews also demonstrated that patients rely heavily on other people and specific interventions to help reconstruct their memories and enhance their understanding of what happened to them. Specifically, these included: 1) family members' explanations and memories of events (presented in section 4.7); 2) information and explanations received through the follow-up clinic (presented in section 4.6.2) and 3) revisiting the CCU and bed-space (presented in section 4.6.2).

To conclude, this research has demonstrated that irrespective of how patients' memories of critical care are formed and the objective accuracy of these memories, it is the reality experienced through them and the influence this can have on their long-term emotional response and survivorship, which is important.

To test Bartlett's theory further within the context of former critical care patients' memories of critical care, a recommendation for future research is to compare the reconstructive memories of patients who have had just one critical care stay in comparison to those who have had more than one critical care stay. This would test Bartlett's theory that schemata developed from previous experiences contribute to reconstructive memories of critical care as well as trying to address the missing memories of this time and make sense of what had happened to them.

7.4 Strengths and limitations of the reported programme of research

This section presents the strengths and limitations of the methods adopted for the reported programme of research, in relation to other studies in this area of nursing practice

7.4.1 Strengths of the reported programme of research

There are a number of strengths to this research. Firstly, as presented in section 7.3, the research is underpinned by Bartlett's (1932) theory of reconstructive memory. A strength of adopting this theoretical perspective allows the patients' memories of critical care to be interpreted differently from previous research which assumed patients' memories to be either factual or delusional. Through interpreting patients' memories differently, a greater understanding of patients' memories of critical care, irrespective of their objective accuracy, the implications of these on patients' emotional well-being and longer-term critical care survivorship can develop.

This theoretical lens also provided an alternative explanation for the presence of gaps in memories which previous research did not identify. As patients had not experienced critical care before, they had no schemata of this experience to draw upon to address their missing memories. The theory suggests that patients' missing memories of critical care relate to an absence of schemata within patients' memory, relation to receiving critical care.

Secondly, the MSR presented in Chapter Two demonstrated that reconstructive memories have not been explicitly explored before in the literature. Consequently the findings presented here are new in comparison to previous work. As presented in section 7.3, Bartlett's theory of reconstructive memory has been used to underpin this research through identifying the schemata patients draw upon to inform their reconstructive memories of critical care.

Thirdly, this research took a longer-term perspective of patients' reconstructive memories of their critical care experience beyond the CCU and hospital ward, right through to up to two-years following discharge home, exploring patients' experiences and memories of the post-discharge period. This is in contrast to previous research presented in section 2.3.9 of the MSR. The strength of this programme of research is that by adopting a longer-term perspective evidence has been identified that significant distress related to the critical care experience can endure beyond the CCU stay and this has clinical implications for critical care nurses and indeed all of the clinical team working in CCUs. .

Fourthly, the multi-lens design adopted by this research, explored both patients and nurses' perspectives. This enabled patients' reconstructive memories of critical care and nurses understanding of these to be explored as a relational phenomenon. This meant that the findings and recommendations drawn from this study have implications for both patients and the nurses who cared for them. An additional strength of this multi-lens approach was that the findings identified a considerable divergence between the nature of patients' reconstructive memories of critical care and nurses' understanding of the patient experience. Whilst nurses understood gaps existed in patients' memories, they lacked an understanding of the challenges that patients experienced to address these gaps and in particular the value patients placed on having family members present with them throughout critical care; the importance of critical care follow-up and revisiting the bed-space.

Finally, as presented in sections 3.5 and 3.6.1 a further strength of this research is that as a nurse researcher, I was cognisant of my *emic* and *etic* positions, and the need for continuous reflexivity in relation to these positions as I collected and analysed data (Burns et al. 2012). My *emic* and *etic* positions have been presented in section 3.5.1 and both positions provided strengths to the research process. As an *etic* researcher, I held no preconceived ideas of level or quality of care provided by nurses on the CCU where participants had received critical care. Participants did not know me and as I explained at the start of the interview anything they discussed would remain confidential. Consequently, they were open to sharing their reconstructive memories of critical care and I hope that they were empowered through the research process to speak honestly about their experiences. This is in line with Haigh et al's (2005) findings of the benefits patients' experience taking part in qualitative research.

My *emic* role as a senior lecturer in critical care at a university, enabled me to recruit a large number of practising critical care nurses to participate in the focus groups, away from the interruptions and pressures of the CCU environment. This was because I had direct access to critical care nurses undertaking post-graduate education at my place of work. A further enabling possibility was over the course of my career as a former nurse and now lecturer, I had developed active listening and facilitation skills which lent themselves to facilitating focus groups with nurses. Additionally, the participants appeared to enjoy taking part in the focus groups as they discussed and learnt from each other. This reflects Bradbury-Jones et al.'s (2011) findings that students benefit from participating in nursing research as this strengthens their self, knowledge and clinical practice.

Only one paper was identified which discussed the insider researcher perspective in the context of critical care. Manias (2000) described her experiences as an ethnographic researcher on the CCU where she practised as a clinical nurse specialist. Therefore my experiences from an insider-outsider researchers' perspective as a critical care nurse academic researching critical care patients and nurses on a CCU where I did not practise provides a different perspective to Manias' (2000) as an ethnographic researcher.

It is also helpful to reflect upon my position as a relatively inexperienced qualitative researcher and the 'journey' I have taken through my experience as a doctoral candidate, to develop and refine my expertise in qualitative research design, methods and data analysis. Through the support of my two supervisors, reading at length around qualitative and mixed method research designs and methods and attending a week-long summer school in qualitative research at Kings College, London, along with numerous data management workshops, I have gained the knowledge and confidence to develop these methods into a reality which is presented here. The most challenging aspect of this for me was identifying the most effective research design to address the research questions.

7.4.2 Limitations of the reported programme of research

There are a number of limitations to this research. Firstly, the patient interview study was a single-centre study conducted in the UK. Whilst the sample reflected the local population, it may not have reflected the wider critical care population in other national or international regions.

Secondly, the nurses were discussing patients' memories of the care they delivered in their CCUs which may not have been representative of the care provided on the CCU where the patients had received care. This was because the focus group study involved nurses practising in a range of CCUs within the UK (both from DGHs and regional referral centres). However, these nurses did not practise in the CCU where the participants in the patient interviews had received critical care.

Thirdly, as presented in sections 3.3.1 and 7.3, former critical care patients are notoriously difficult to recruit to research studies following discharge from hospital (Burns et al. 2012; Reay et al. 2014). As an outsider researcher no longer in clinical practice and one who had never practised on the CCU where the participants had received their care, a constraining possibility was I had no direct access to recruiting patients. Consequently, I had to rely on the sister who managed the critical care follow-up service on the unit to approach and recruit the patients on my behalf. This resulted in the study sample of former patients being restricted to only those attending either the ICU steps support group or the follow-up clinic being invited to participate, whilst those who did not attend these groups were not afforded the opportunity to participate in the research. Consequently there is a risk that rich and diverse data from this group may have been missed and the current study cannot claim to be generalisable of all critical care patients.

Fourthly, as introduced in section 3.3.1.6, a further limitation was that four of the participants were accompanied by their family members. The role of the 'uninvited participant' and the dilemma it presents in relation to ethics and gaining access to participants is recognised within the literature (Haahr, et al. 2015). I was faced with the quandary as to whether to ask the family member to leave or stay. Drawing upon my own ethical stance as a registered nurse and researcher and recognising the supportive presence of family members for the participants, I let the partners stay. Consequently there was the risk that their presence during the interview may influence the data and provide expressions of shared rather than individual memories of critical care. Thus, during data analysis I only drew upon patients' responses to contribute to the findings.

Not being able to include partipcants' spouses within the interview because this was not anticipated in the ethics submission may also have presented itself as a missed opportunity to gather data in relation to their experiences and memories and how these influenced the patients' own memories of critical care. As presented in section 4.7, a family strand across the categories was identified. This highlighted the importance patients placed on family members to support them with developing their memories of critical care. A limitation to this study could be that through excluding spouses, there was a possibility that rich data relating to how these can influence patients' reconstructive memories of care were missed.

Finally, participants in the focus group study were studying at my place of work. Consequently, they may have felt there was an imbalance in the power relationship (even though I did not teach nor assess these participants), which could have affected their ability to open up about their practice. There was also the risk that they were only telling me what I wanted to hear (Holloway and Wheeler, 2002).

7.5 Findings in relation to the literature

This section aims to contextualise the principal findings from this study by drawing comparisons with existing literature. The discussion represents the reported categories which aimed to identify similarities and differences between patients' reconstructive memories of critical care and nurses' understandings of these.

7.5.1 Missing memories of critical care

A distinct area of convergence identified in this study into the understanding of patients' reconstructive memories of critical care which was reported by patients *and* nurses was the missing memories patients had of their critical care stay (presented in sections 4.2.1 and 5.2).

The issue of patients' missing memories of critical care is prevalent throughout the literature. Adamson et al (2004) used a qualitative design to examine the memories of six former critical care patients six months following their discharge home. Thematic analysis of the findings identified patients lack recall at this time with the memories of unpleasant episodes fading faster than pleasant memories. Maddox et al (2001) also studied the presence of memories of critical care at six months post-discharge and also found memories were scant in their sample of six partipcants, attributing this like the nurses in this study to the drugs patients had received on critical care. Care need to be taken when considering both Adamson et al's and Maddox et al's' findings, as had very small sample sizes and neither paper indicates that data collection ceased at data saturation. Consequently important data may have been missed if data saturation had not been achieved. The presented research programme had a larger sample size with data collection ceasing at data saturation. This demonstrates that whilst a proportion of patients had gaps in their memories of this time they all had memories of other parts of this experience.

As the body of evidence into memories of critical care adopted a phenomenological theoretical lens to explore the patients lived experience of critical care, they did not examine the underpinning reasons for these gaps in recall. A phenomenological approach coupled with thematic analysis of data may have contributed to the broadly descriptive accounts of memory gaps the literature presents without considering the underlying causes of memory loss.

In contrast, Chahraoui et al (2015) did provide some explanation for these missing memoires. Consistent with the nurses in the presented programme of research, Chahraoui et al reported such memory loss was explained through the lens of the medical model. (As presented in section 1.1.4.1) where the amnesia was primarily a defensive mechanism for patients to protect themselves from knowing how unwell they had been. Like the nurses in this study, (Chahraoui et al also attributed the missing memories to the drugs they had received, metabolic factors such as hypoxia or mechanical factors such as restraints. However, Capuzzo et al's (2001) quasi-experimental research into the relationship between sedation and memory of CCU was more definitive in reporting the length of length of stay contributed more to memory loss than sedation. This reported programme of research did not identify any patterns between length of CCU stay and patients' memories.

The present research provided a different explanation for patients' memory loss. As the first study to view patients' memories of critical care through the lens of Bartlett's (1932) theory of reconstructive memories the findings here propose that as this was the first critical care stay for all the participants, they did not have the schemata present in their memory which they could draw upon to form memories of their critical care stay. It is proposed here that this may contribute to missing memories forming of the CCU stay.

Whilst this all helps to understand patients missing memories, it is important to consider whether such gaps in memories matter? Whilst Olsen et al (2017) argue that not all patients have the need to recall what happened in CCU, they fail to elaborate further on this statement. In contrast and congruent with the findings presented here, Griffiths and Jones, (2001) did consider them to cause issues for patients. They reported that if patients cannot remember their time in critical care, they fail to understand how sick they have been and why their recovery is so protracted. Griffiths and Jones (2001) also agreed with the findings here that patients need to make sense of what had happened to them on CCU and that to do this they have to maximise their memories of this period in their life.

7.5.2 Sensing an altered reality

This programme of research identified patients recalled *'an altered sense of reality'* from their stay in CCU. This is echoed in many other studies relating to patients' experiences and memories of critical care (Ballard et al 2006; Maddox et al, 2001; Olsen et al 2017; Tembo et al 2013; Wang et al 2008). The difference with the findings from this study was that by viewing these memories through the lens of both patients and nurses' divergences were identified between patients' memories of this altered sense of reality and nurses understanding of these. The striking finding here was that the patients remembered not just the presence of hallucinations, but of dreams and nightmares too. In contrast the nurses only recognised patients' hallucinations. They made no mention of patients' dreams nor nightmares on the CCU or beyond. The nurses lack of understanding to dreams and nightmares could be because patients hallucinate when they are 'awake' on the unit and this becomes overt in their behaviour which nurses often have to manage.

The presence of patients' dreams is also highlighted by Ballard et al (2006). In their phenomenological study of 11 patients' memories at just 48 hours after receiving neuromuscular blocking agents on CCU, patients reported having weird dreams. Whilst Ballard et al do not explore the reason for these, their key recommendation was that nurses assess the degree of sedation prior to administering the drugs in an attempt to reduce the effects of sedatives on patients' dreams. This is important in the context of this study, because as the nurses demonstrated no awareness that patients dream or have nightmares whilst sedated, they may not understand the need to assess for the minimum level of sedation required to reduce the prevalence of dreams and nightmares which as this study identifies become significant memories of critical care for patients.

Tembo et al (2013) also adopted a phenomenological approach to explore 12 patients' experiences of sleep deprivation following discharge from CCU two weeks earlier. They reported that patients were scared to go to sleep once they had left CCU because their frightening nightmares about CCU persisted. These impacted on their quality of life and prevented them with moving on with their life. Such findings are echoed in this study where patients reported that they continued to experience nightmares once they returned home and they found this difficult. However, the present research additionally highlighted that nurses demonstrate little understanding of how an altered sense of reality can remain with patients once they have left CCU through continuing nightmares or how patients dwell on their memories to try to understand their situation, and the impact this can have on their critical care survivorship.

The limitations of the phenomenological studies reporting patients dreams, nightmares and hallucinations were that they only focused on the lived experiences of the patients and used thematic analysis to present broadly descriptive accounts of these experiences. In contrast by including nurses in this study, areas of silence in their understanding of patients' memories of critical care and their survivorship such as the persistence of dreams and nightmare were identified. These findings were used to underpin recommendations to develop nursing practice in relation to the improved management of patients' dreams and nightmares on CCU more than the previous studies into the patients' experiences of this altered sense of reality in isolation.

A final issue relating to patients' memories of an altered sense of reality is that each patient within this study reported different memories of CCU because each patient experienced different dreams nightmares and hallucinations and subsequently developed different memories. The nurses were aware patients' hallucinations contributed to patients' unique memories of critical care. Concurring with Olsen et al's (2017) findings, this study identified that individualised care within the CCU and beyond is essential to address each patients' own experiences and memories of this altered sense of reality in critical care and beyond, and the implications these have on patients' critical care survivorship.

In response to the disturbing psychological symptoms experienced by some patients through this altered sense of reality, in critical care, the Intensive Care National Audit and Research Centre [ICNARC] has led a multi-centre study involving 24 CCUs within the UK. The Provision Of Psychological support to People in Intensive care trial (POPPI), investigated whether psychological training for critical care nurses improved patients' well-being after a critical care stay. The findings have very recently been published and reported that the POPPI intervention did not significantly reduce PTSD in former critical care patients (Rowan, 2018). The study concluded that the POPPI intervention should not be adopted in CCUs in its current form and that further exploratory work is required to address the high rates of psychological morbidity currently seen in former critical care patients (Rowan, 2018).

7.5.3 Feeling reassured yet powerless

A significant finding identified through the reported programme of research, was the juxtaposition patients recalled in relation to feeling reassured by the safety and security on the CCU – yet powerless at the same time. The nurses recognised patients' feelings of safety and security, however they described patients' experiences of helplessness in relation to activities of daily living in contrast to the powerlessness patients used to describe their entire existence throughout critical care.

Patients' experiences of feeling safe and secure on CCU are widely reported within the qualitative literature (Engstrom et al 2013; Hupcey 2000; Linberg et al 2015; Locsin and Kongsuwan 2013; McKinley et al 2002; Wahlin et al 2009). The only quantitative study to identify such feelings amongst patients was Rattray et al (2004) whose Intensive Care Experience (ICE) questionnaire found 70% of patients feel safe on CCU.

The findings of this present research agree with the largely descriptive body of qualitative evidence that patients' feel safe and secure on the CCU because of the constant presence of competent staff to provide comfort, reassurance, confidence information and support (McKinley et al 2002; Wahlin et al 2009).

Again, as these studies adopted a largely phenomenological approach, the sample sizes remained small and once again there was no mention of data collection ceasing at the point of data saturation, therefore potentially significant findings may not have been gathered. Again the use of thematic analysis provided largely descriptive accounts of patients' experiences. All studies apart from Wahlin et al (2009) only explored the patients experiences of CCU. Whist Wahlin et al's work explored experiences of patients, nurses and next of kin, this was in relation to patients' feelings of empowerment on CCU compared to that of their family members and the staff. Again the body of evidence did not explore patients' memories of feeling safe and the nurses understanding of these.

This research identified that patients strongly value the presence of family members on CCU describing the support they provide to pay a significant contribution to their memories of feeling safe and secure on CCU. Hupcey (2000) developed a grounded theory relating to promoting patients' feelings of safety and their psychosocial needs whilst on CCU and this too recognised that family members presence and input on critical care contribute to patients' feelings of safety and security here. What remains unclear from the evidence is whether Hupcey evaluated her theory in clinical practice. The findings from this research suggest not. There is a significant gap in understanding between patients need for the family members presence in critical care and the nurses understanding of this need, with no nurses in this study identifying the important contribution family members provide for any memories developed by patients' whilst on CCU. This is a significant finding which highlights that CCU nurses need to receive support and further education to understand the role of the family further in relation to patients' experiences and memories of critical care.

Whilst this study recognised patients' felt safe and secure on CCU, it also identified the powerlessness patients' simultaneously experience. Powerlessness and vulnerability are well documented within the literature with many qualitative studies identifying these experiences for patients whilst on CCU (Ballard et al 2006; Johnson 2004; Karlsson et al 2012; Lykkegaard and Delmar 2013; McKinley et al 2002; Moen and Naden 2015; Stayt et al 2015; Wang et al 2008).

This research reported how such feelings of powerless on CCU particularly revolve around the inability to perform their own activities of daily living such as washing, dressing and using the toilet. This is echoed in Engstrom et al's (2012) work which also found patients felt humiliated receiving help with toileting.

As patients start to recover from their critical illness, Johnson (2004) described the need they developed to reclaim power and control over their environment. This too is reflected here particularly where Sean describes his battle not to have his NG tube replaced in section 4.4.2.

Some but not all studies within the evidence base recognised patients felt vulnerable on CCU but safe at the same time (Ballard et al 2006: Engstrom et al 2012; McKinley et al 2002). This was a key finding in this study where patients described the juxtaposition between feeling reassured yet powerless. This was also an area of convergence between patients' memories and nurses understanding of these. Whilst the nurses described the helplessness patients experience, particularly in relation to things such as toileting, they also recognised how patients felt safe and secure when they were present. What was not identified in the literature though but apparent in this study was how the constant presence of the nurse on CCU can impose a lack of privacy on patients as reported by Sean (presented in section 4.4.3). This lack of privacy was not identified by the nurses in this study.

7.5.4 Feeling abandoned when leaving critical care

The patients in this study describe a lack of preparation and feelings of abandonment once they had been discharged from CCU to the ward. Whilst the nurses in the study recognised the level of care on the ward was different to CCU, they demonstrated visible distress when they heard of patients' long wait for care. The nurses did not understand how the transitions in the level of care from CCU to the ward could influence patients' memories and stay with them for a long time. This is despite the difficulty's patients face as they move from CCU to the ward being well documented within the literature (Bench and Day 2009; Chaboyer et al 2005; Field et al 2008; Forsberg et al 2011; McKinney and Denny 2002; Odell 2000; Strachan and Brown 2005).

In particular the patients' in this study remembered significant distress in relation to moving to the ward and having a long wait to receive care. For some they felt '*the* *care simply disappeared.'* (Beverley: patient) (Section 4.5.1) This manifested itself in feelings of abandonment and unimportance for patients. These feelings are reflected by Forsberg et al (2011) and Chaboyer et al (2005). Chaboyer et al's descriptive study on just seven patients' experiences of the transition in the level of care from CCU to the ward attributed these feelings of abandonment to the special relationship formed between patients on critical care and the CCU nurses, which was difficult to sever. Through probing during the interviews, this special relationship was explored further within this study. Patients reported for the first time in the literature remembering the whole team on CCU to be like a 'critical care family' (Beverley: patient). As such it felt like they were abandoned by this family as they moved from CCU to the ward. Carpentinio (2000) described this as a type of separation anxiety.

Field et al (2008) described patients feeling like they were 'one patient amongst many' on the ward. To explore this further, this study examined how nurses prepare patients for this transition. The nurses here described how they would simply promote the positive aspects of the move to the patients and that rather than them being abandoned this move indicated that they were getting better and no longer needed such intensive levels of care. This strategy was not identified through the literature.

A final salient finding evident in this research, which was not apparent in previous studies, was that patients remembered how the family-centric nature of critical care disappeared on the ward. Patients described how all members of their family including children were welcomed onto the CCU throughout the day. In contrast on the ward rules and regulations prevented children from visiting and restricted spouses to only certain times of the day. For some former critical care patients, this compounded their feelings of vulnerability and abandonment on the ward.

To summarise that despite such clear evidence that patients find the transition in care from the CCU to the ward difficult, this study demonstrates that their memories of this time remain poor. To address this, Bench and Day (2012) have developed a 'User centred critical care discharge information pack' (UCCDIP)– however there is yet to be an evaluation of the impact of this tool on patients' memories of moving from CCU to the ward.

7.5.5 Filling the gaps in memories

The patients in this study demonstrated an overwhelming desire to address their missing memories so that they could make sense of their situation, achieve closure on this episode in their life and move on with the second chance their CCU stay had afforded them with. This reflects the findings of Deacon (2012) and Haraldsson et al's (2015) qualitative exploratory work.

To try to address these gaps in memories, the patients in the present study described four strategies they used to address these: 1) attending critical care follow-up services; 2) patient diaries; 3) revisiting the bedspace and 4) using family members memories to help them fill the gaps. Again looking at this through Bartlett's lens is that it was evident that what is of paramount importance for patients is not the objective reality of these memories but how they reflect the patient's current experience of previous events.

All patients in this study described how the critical care follow-up visit with the lead nurse for follow-up and the lead critical care intensivist, helped them to make sense of their memories and to move on with their life through achieving a degree of closure. This echoed the findings of Prinjha et al (2009) who recognised patients valued having someone with a critical care background help them make sense of their experience. The need for a competent critical care practitioner to co-ordinate follow-up programmes is also recognised in the NICE (2009) guidance.

These reflect the findings of Haraldsson et al. (2015) who also found that the 10 patients in their study into patients' experiences of follow-up could move on with life following their visit having gained clarity and security from the meeting. Those patients in this study yet to receive their meeting with the critical care staff, described how they still did not understand what had happened to them and still had not received closure on this episode of their life.

In this research, it was evident that for patients' closure related very much to being able to move on with the new life critical care had presented and related closely to the concept of critical care survivorship (presented in section 4.2.3). This echoed Keane et al.'s (2016) concept of survivorship, with patients needing to redefine themselves by acknowledging the presence of any lingering Post Intensive Care Syndrome (PICS) (Harvey and Davidson, 2016) and thus gaining control of their lives again. Endacott (2010) also reported that survival following critical care is a complex concept which reaches far beyond mortality and morbidity figures and relates more to the quality of life (or survivorship) which is important to patients and their families as a survival measure following critical care.

Despite such evidence though, Cuthbertson et al's (2009) PRaCTICaL trial found no significance in the difference in HRQoL outcomes between those who did and did not receive a nurse-led follow-up appointment. Cuthbertson though did acknowledge the first meeting was at three-months following critical care and that this may already have been too late for some patients. In contrast Engstrom et al (2015) considered this to be a good time to receive follow-up as patients had had the chance to clear their thoughts and process information better. In future, a longitudinal trial would be helpful to clarify the point at which critical care follow-up services provide the most benefit to patients.

What was interesting from this study is that none of the nurses reported how helpful they understood the critical care follow-up clinic was to address patients' memoires. This could be related to the sample included in this study. All were nurses practicing at the bedside in a CCU and as such are not invited to participate in follow-up even for patients they have cared for in the CCU. This is a new finding and is counter to the policy of 'Critical Care Without Walls' (DH, 200) which as presented in section 1.1.2, underpins contemporary critical care practice within the UK stating critical care is patient not location-focused. The nurses expressed their disappointment at their inability to attend the follow-up clinics stating that they too needed to know what had happened to patients they had nursed on CCU, so that they too could achieve closure on that episode of critical care. They also felt that if they attended follow-up they could listen and learn from patients' experiences of care. Haraldsson et al (2015) agree with this stating that if both CCU staff and ward staff attend follow-up it would provide them with the knowledge and understanding of patients' experiences of their time in hospital.

Some patients in this study also received a patent diary which they found helpful to fill the gaps. There is however limited evidence regarding the impact of these diaries – with a Cochran Review (Ullman et al , 2014) into three Randomised Controlled Trials (RCT) finding no difference in patients' level of anxiety or depression between those who had and had not received a diary. A limitation of Ullman's et al's review is that it only included RCTs and thus excluded the plethora of findings from the qualitative studies into critical care follow-up services. An important point though the review did raise was that the current evidence fails to assess the safety and effectiveness of patient diaries. That being said, the nurses in this study all reported they felt diaries were helpful in addressing patients gaps in memories as did the patients.

A further strategy adopted to address these missing memories of critical care was to revisit the bedspace on the CCU which patients reported as helpful especially to address memories of their critical care bedsapce. Engstrom et al (2015) agreed as they reported through their thematic analysis of nine patients' experiences of revisiting the bedsapce found seeing all the technology as valuable and that it helped things fall into place for them.

A recommendation to be made from these findings is that there is no identifiable MMR into critical care follow-up and the effectiveness of this service. To address the concerns with follow-up raised in the current literature it would be helpful to undertake a full MMR to establish the effectiveness of this service.

The fourth and final way, patients reported addressing their missing memories of critical care was for them to use the schemata developed by their relatives to form their memories of this time. Which the patients then used to reconstruct their memories of critical care (presented in section 4.6.1). The existing literature already acknowledges that patients rely on family members to help address the gaps in memories (Hupcey and Zimmerman 2000). Indeed, Page et al (2018) reported that patients have little recall of the factual events of their CCU stay, but that their family members have lived the whole episode in a real and ingraining manner. Page et al (2018) discuss how this leads to two very different experiences of the same episode in their lives and that family members maybe used by patients to help them address their gaps in memories.

The present research demonstrated how nurses had an extremely limited understanding that family members could help address the gaps (section 5.6.1).Indeed throughout their interviews the patients spoke at length about how important family members were to them throughout their critical care experience, from the moment they became critically ill to when they went home and needed their support there (presented in section 4.7). Despite this only one nurse briefly mentioned 'we should make more use of the family' and this was in relation to the transition of care between the CCU and the ward. This is a really key finding and highlights that work is still to take place on the role of family-centred models of critical care.

As presented in section XXXX, family-centred care focuses on the care patients' family members receive whilst their loved one is receiving critical care. This research identified that patients and family are important for each other whilst the patient is on CCU and as such the model of critical care needs to extend beyond simply family-centred critical care to a model which embraces both parties. It is therefore recommended that a patient-family- centred model of critical care nursing practice is developed which encompasses the care and involvement of both parties in critical care.

7.5.6 The use of the medical model to explain patients' memories.

Another important finding from this research was how both patients and nurses relied on the medical model to explain patients' memories of critical care (presented in sections; 5.4.4; 6.4.1). This is unsurprising as the critical care environment is so technically focused, it is inherently more conducive to the medical model which treats dysfunction and disease, rather than a theoretical nursing framework based on holistic nursing care (Hurlock-Chorostecki, 1999). What is interesting though is how some patients also relied on the medical model to explain their memories – for example in section 4.3.3 when Colin is describing his hallucinations being attributed to the drugs he had been receiving. However as this research demonstrated, whilst technology is important to sustain life, it cannot provide care for the whole being (presented in section 1.1.4.2.)

This research has highlighted the difficulty critical care nurses face with regard to balancing their technical competence in managing a patients' critical illness, within the art and science of nursing (presented in section 1.1.3.1), which provides holistic patient-centred care that promotes adaptations in a health crisis – such as a stay in CCU (Hurlock-Chorostecki, 1999). As technological advances continue within critical care, the focus on the art of critical care nursing has perhaps become lost to the science of such nursing, with priorities in care focused more on nurses' competence to manage technology such as mechanical ventilators, continuous renal replacement therapy and continuous cardiac output monitoring, in contrast to the focusing on the actual patient. This is reflected in the National Competency Framework for Registered Nurses in Adult Critical Care (Critical Care Networks National Nurse Leads [CC3N], 2015). This framework is based upon a four-step competency programme, where step one competencies relate to novice critical care nurses through to step four which aims to develop leaders of critical care. Only the step four competencies identify the need for competence in 'patient and family support' (CC3N, 2015). Not only does this relate to the nurses' perceptions that critical care follow-up is more in the domain of senior, specialist critical care nurses, but it would also indicate that within critical care nurse education the art of critical care nursing has evaporated as the emphasis has become the scientific and technological competence of nurses rather than their ability to deliver holistic individualised patient-and-family-centred care. There is relatively little literature on the content of critical care nurse education in the UK. However, Baid and Hargreaves (2015) described a contemporary post-registration undergraduate critical care course in the UK, which focused on developing '*informed critical care nursing practice'* (Baid and Hargreaves, 2015 p175) based upon clinical skill competence.

7.6 Recommendations for practice

- **To develop a patient-family-centred model of critical care nursing practice.**

In contrast to a family-centred model of critical care (presented in section 1.1.4.3) this research has clearly identified that critical care nurses need to be supported to develop a holistic approach to patient- family-centred care which is based upon the art and science of critical care nursing practices where the focus is on the biopsychosocial aspects of critical care as well as technical competence. Findings from this research suggests that critical care nursing practice has a strong reliance on the medical model which focuses on treating dysfunction and disease within critical care nursing and as a result attention to the individual as a whole being within the context of being a member of a family unit is currently overlooked.

The value that patients place on the role of family members throughout the critical care experience is consistently emphasised throughout this work. However, the nurses in the focus groups seemed to have little awareness of this. It is recommended that critical care nurses should be encouraged to adopt patient-family-centred models of critical care nursing which focus on information provision, involving family and patient with aspects of non-technical care such as activities of daily living and demonstrating general courtesy and respect to both family members and patients at what is an incredibly stressful time for them. Associated with this nurses need to ensure that the information provided to family members is accurate and based upon current research evidence. This is important as this research has demonstrated that patients often draw upon their relatives' understanding to develop their reconstructive memories of critical care, and to try to address their missing memories and achieve 'closure.'

- **Critical care nursing practice should facilitate strategies for patients to address gaps in memories.**

Critical care nursing practice should support patients to address the gaps in their memories of critical care from the moment they regain consciousness through to them returning home. This would help them make sense of their experience, to reach closure and move on with their new chance at life. The engagement of bed-side critical care nurses with critical care follow-up services could facilitate with this.

- **Bed-side critical care nurses should be enabled to engage with critical care follow-up services to listen, hear and learn from patients' memories of care whilst also having the opportunity to gain their own closure.**

All levels of critical care nursing staff should engage with critical care follow-up services. This would enable bed-side nurses to not only listen and learn from patients' experiences but assist the nurses themselves to achieve closure on episodes of critical care for patients they have cared for. This may also enhance their job satisfaction. This is important because critical care nursing is not immune from staff shortages with turn-overrates for critical care nurses in the UK being quite high at between five and 27 percent (Khan et al. 2015).

Through contact and engagement with follow-up services, the critical care nurses would hear about all aspects of critical care which are important to patients. This could then go some way to address the disparity between what become important memories for patients of their time in CCU in contrast to nurses' current understanding of these.

- **Ward visits by critical care nurses should be embedded within transitional care practice**

The present research identified that patients felt abandoned when they moved to the ward from CCU. In terms of providing additional psychological and social support to patients during this transition, it is recommended that time be identified on a shift (possibly during the rest periods frequently practised on critical care in the early afternoon) when nurses can be released from CCU to visit the last patient they discharged to the ward. This could help patients' sense of abandonment and support their transition in care, whilst also provide nurses with a glimpse of how critical care continues beyond the confines of the CCU.

7.7 Recommendations for postgraduate critical care nurse education

Critical care nurses are encouraged to undertake a postgraduate critical care nursing course delivered in Higher Education Institutions in partnership with local critical care networks. The National Standards for Critical Care (CC3N, 2015) require these programmes to provide 60 educational credit points and last for up to a year in length. The curriculum is driven by the National Competency Framework for Registered Nurses in Adult Critical Care (CC3N, 2015). Consequently, these courses are driven to focus upon technical competence rather than holistic patient -family -centred care. A key recommendations for future postgraduate critical care nurse education is the:

- **Development of a postgraduate critical care nursing curricula which incorporates a patient-and-family-centred approach to critical care**

Critical care nursing education needs to shift from a technically competent-oriented approach based upon the medical model (C3NN, 2018) to one which encompasses the biopsychosocial aspects of critical care which contribute to individualised holistic patient-family-centred care and truly encompasses the art and science of nursing. The role of family-centred care also needs to be promoted through these postgraduate nursing studies, to address the lack of awareness nurses currently display regarding this important aspect of critical care. Service user and carer involvement in the delivery of the curriculum is one way to address this.

Critical care nurse education curricula need to address nurses' lack of understanding of the value patients place on addressing the gaps in their memories of critical care and the role of family members in this. Again the adoption of a patient-family-centred model of critical care could enhance critical care nursing practice to assist patients to address their gaps in memories. Likewise nurse education needs to focus on the long-term effect of patients' dreams and nightmares, in addition to hallucinations, on their memories of critical care and the contribution of the practice of daily sedation holds may have on these as this was an area of silence in nurses understanding in this study.

7.8 Recommendations for future research

A number of recommendations for future research have been identified from the findings of this study.

- **A qualitative exploratory study to examine how patients' significant others (i.e. partner / spouse / family members / friends) memories of critical care can inform patients' reconstructive memories of critical care.**

A number of patients were accompanied by their spouse during the interviews. Unfortunately as their presence in the interviews had not been anticipated at the ethics submission, this study had no ethical approval to include spouses' experiences in the findings for this study. Consequently the family members contribution to patients' reconstructive memories of critical care remains unclear.

- **A qualitative exploratory study to evaluate the acceptability of a patient-family-centred approach to critical care in relation to the development of patients' reconstructive memories of critical care**.

The importance of family for patients receiving critical care is emphasised thought this work. However there is presently limited evidence relating to a patient-family-centred approach in critical care. Thus it is recommended that once the model of patient-family-centred critical care has been developed and implemented, an intervention study to evaluate the effectiveness of a family-centred approach to critical care, in relation to the development of patients' reconstructive memories of receiving critical care and subsequent experience of critical care survivorship should take place.

- **A mixed study review into the effectiveness of critical care follow-up in relation to patients' psychological HRQoL outcomes**

The MSR into patients' experiences of critical care identified a lack of understanding regarding the influence critical care follow-up services have on psychological outcome and critical care survivorship, despite a range of studies being published in this area. It is therefore recommended that a mixed study review (MSR) takes place into the effectiveness of critical care follow-up in relation to patients' psychological HRQoL outcomes.

- **An intervention study to evaluate the effectiveness of engaging nurses practising at the bedside in critical care with critical care follow-up services, to establish if:**
    (a) this impacts upon nurses' job satisfaction and turnover of staff rates.
    (b) this move critical care practice away from the medical model and towards the biopsychosocial model to enhance patients experience of critical care in relation to their longer term critical care survivorship.
    (c) this may also develop nurses' understanding of patients' reconstructive memories of critical care.

This research has demonstrated how bedside nurses are isolated from critical care follow-up services. Consequently, it is recommended that an intervention study is conducted to evaluate the effectiveness of engaging nurses practising at the bed-side in critical care with critical care follow-up services to establish if this practice has a positive impact on nurses' satisfaction and turnover of staff rates along with developing nurses' understanding of patients' reconstructive memories of critical care, and how these influence the quality of critical care survivorship.

- **A study which compare the degree of missing memories in relation to those who have received critical care before and those who have received it for the first time.**

This will evaluate Bartlett's (1932) theory that schemata developed from an experience are stored within the memory and then drawn upon to reconstruct memories at this time to provide understanding and clarity on the CCU experience in relation to those who have not yet formed the schemata as they have not experienced a critical care stay before.

7.9 Chapter conclusion

This programme of research (the MSR and the qualitative exploratory sequential studies) has drawn upon former critical care patients' reconstructive memories of critical care and nurses' understanding and response to these. The analysis has identified that patients experience missing memories of their CCU stay, which they find troublesome and have a need to address in order to make sense of their experience, reach closure on this episode of their life and move on to live the second chance at life critical care has provided. Central to achieving this is patients' strong reliance on family members and critical care follow-up provision.

In contrast, critical care nurses demonstrate a limited understanding of patients' reconstructive memories which is restricted to the CCU stay. The nurses in this study appeared unaware of the external elements to the CCU of critical care – namely family members and critical care follow-up provision. In particular, the nurses did not recognise the value that patients place on these to help reconstruct their memories of critical care, make sense of what has happened and support them to achieve closure and an acceptable level of critical care survivorship. Consequently there is a disconnect between nurses' understanding and patients' memories. Finally it is not the objective reality of these reconstructive memories of critical care, which is important,. but more how they reflect the patient's current experience of previous events. and the contribution this can have to their ongoing critical care survivorship. Finally, to demonstrate what is most important to patients the concluding words are left to Pete and Alan (both of them participants in the patient interview study reported in Chapter Four):

> *"Mentally I think the relative suffers as much if not more because for three weeks I was fast asleep."* (Pete)
>
> *"The easy part was the critical care...the aftercare is where the difficulties were, and those were the hard yards."* (Alan)

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