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"Critical illness survivorship and implications for care provision; a constructivist grounded theory"

Pamela Page

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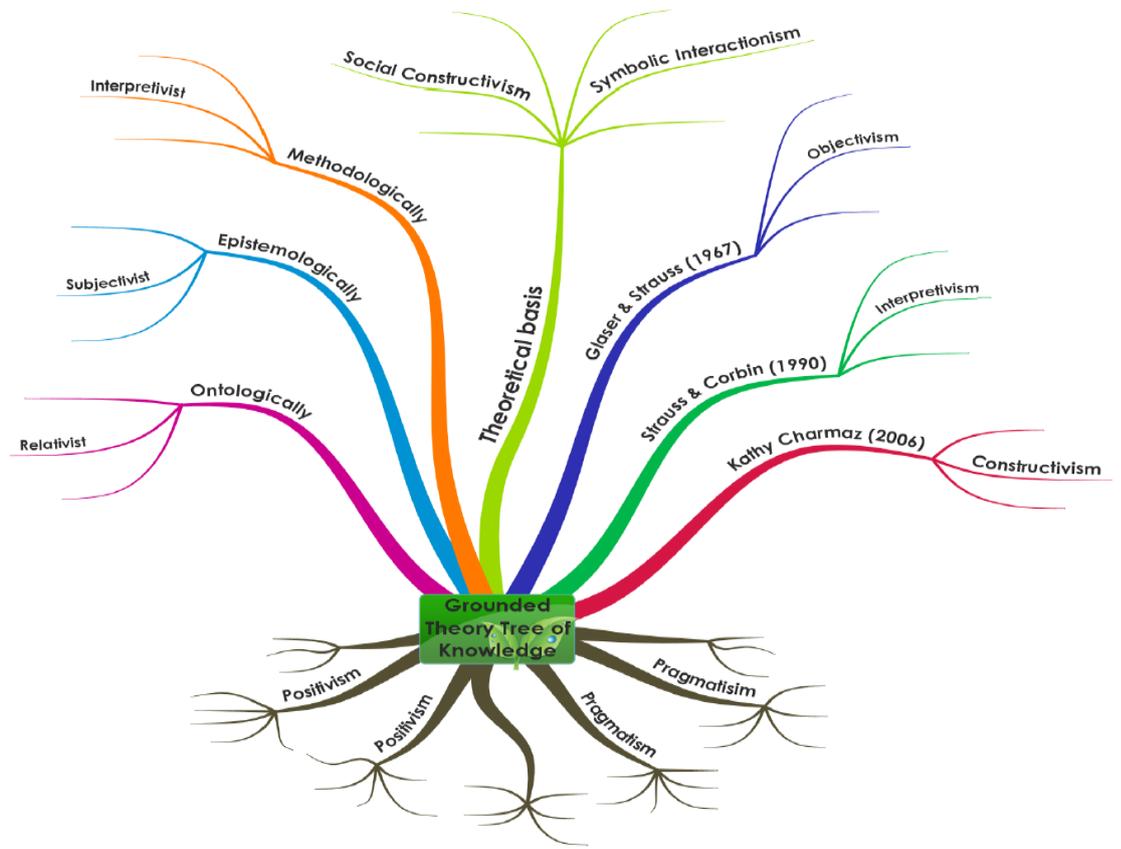
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Acknowledgements

Primarily, my thanks go to all the survivors, family members and nurses who participated in this study. I am indebted to you all for the time spent sharing your experiences; through both tears and laughter. I have learnt so much and hope that this study can contribute towards the wellbeing of the people that you represent.

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This thesis is dedicated to survivors of critical illness and their family members who were central to this study and also to the staff who deliver critical care, and experience the emotional labour of caring. Your stories have, and continue to, inspire me.

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Abstract

Background

In the context of increasing survivorship from critical illness it is important to enhance our understanding of the subjective experience of survivors and their families. The critical illness experience is enormously complex, varied and multifaceted. The need to consider the legacy of critical care beyond physiological survival is imperative.

Aims of the study

The study aimed to formulate a substantive, middle range theory in relation to patient and family's critical illness trajectory. Further, to discern and understand the responses of critical care nurses to survivorship needs.

Methods

Working within a relativist ontology and a constructivist grounded theory methodology, a series of in-depth interviews were undertaken with survivors of critical illness (n=16), family members (n=15) (phase 1) and critical care nurses (n=11) (phase 2). Interviews were undertaken in a District General Hospital setting in England. All interviews were transcribed verbatim. Constant comparative analysis and data collection occurring concurrently with theoretical sampling commencing from the outset.

Findings

Survivors of critical illness invariably entered a liminal state between life and death on admission and during their stay in the Adult General Critical Care Unit (AGCCU). They frequently experienced vivid, hallucinatory experiences which placed them in a different world or liminal space where they could move or transcend in and out of different realities or worlds. The core difficulty can be summarised as follows; survivors have little recall of the factual events of their critical illness within AGCCU but relatives have lived the whole event in a very real and ingraining manner. This can result in family members and survivors experiencing totally different versions or narratives of the critical illness episode; constructing the concept of *dualistic worlds.*

Nurses working within AGCCU found themselves *bounded* by the walls of the critical care unit and experienced personal and professional conflicts in their role, as they *bear witness* to critically ill patients and their families. The critical care environment was identified as a demanding place of work which appeared to limit nurses to immediacy of care in the here and now. The specialist knowledge and skill that nurses provided were central to physiological survival but they are unable to support the onward survivorship trajectory.

Conclusion

Survivors of critical illness, together with family members experience numerous challenges and adversities when endeavouring to readjust to life post critical care. This study has identified a middle range theory of *dualistic worlds* between and within the survivor and family member experiences. These temporal events occur during and after critical illness and expose a non-linear, fluid journey towards a *new normal.* Exploring the dynamic interplay between intrapersonal, interpersonal and societal factors has provided theoretical insights into critical illness survivorship and the legacy of critical care. Nurses in AGCCU *bear witness* to the early stages of the survivorship trajectory and provide complex care in support of survival; however they, are *bounded* by the walls of AGCCU such is the proximity to death and the pressure of work. They are unable to support the onward survivorship journey.

Presentations and Publications

The following work has been presented at conference or published following peer review.

Page P., 2016 *Challenges to constructing a cyborg ontology in critical care: crafting person-centred practice.* BACCN 31st Annual Conference, 19th and 20th September, Glasgow, UK

Page P., 2015 Critical Illness Trajectory for patients, families and nurses – a literature review. *Nursing in Critical Care* doi: 10.1111/nicc.12199

Page P., 2015 *The Critical Illness Trajectory- a parallel experience for survivors and their relatives*. BSA Medical Sociology Group, Annual conference, 9-11th September, York, UK.

Page P., 2015 *The Critical Illness Journey- a parallel reality for survivors and their relatives*. BACCN 30th Annual Conference, 7th and 8th September, London, UK

Page P., 2015 *The Critical Care Trajectory- a parallel experience for survivors and their relatives.* Doctoral Conference, City University London, 27th April, London, UK

Page P., 2015 *A humanistic trajectory of Critical Illness – patient perspectives* RCN International Nursing Research Conference, 20th-22nd April, Nottingham, UK (Awarded best paper).

Page P., 2014 *Survival is not enough- patient perspectives post critical care*, BACCN 29th Annual Conference, 7th and 8th September, Cardiff, UK

Page P., 2014 *A Humanistic Trajectory of Critical Illness*, Doctoral Conference, City University London, 22nd April, London, UK

Page P., 2012 *Care and Compassion in Critical Care* BACCN Eastern region conference, Ipswich, UK.

Page P., 2012 *Care and Compassion* BACCN 4th International Conference; Going Global in 48hrs. Brighton Dome, UK.

Page P., 2012 *Critical to Care- Adult Acute Care* Preliminary meeting 9th China Guanghua International Nursing Conference; Railway Hotel, Bejing, China.

Glossary of terms and abbreviations

AGCCU	Adult General Critical Care Unit
ASSIA	Applied Social Sciences Index and Abstracts
BACCN	British Association of Critical Care Nurses
CINAHL	Cumulative Index to Nursing and Allied Health literature
Constant Comparative Method	Analytical method that generates successively more abstract concepts and theories through inductive processes.
ICNARC	Intensive Care National Audit & Research Centre
ICS	Intensive Care Society
ICU Steps	UK charity for patients, relative and health care professionals
Medline	Medical literature Analysis and Retrieval System Online
NHS	National Health Service
Psychosocial	Interrelation of social factors and individual thought and behaviour
PTSD/S	Post-Traumatic Stress Disorder/Symptoms
RN	Registered Nurse (registered with the Nursing and Midwifery Council in UK)
Reflexivity	An awareness of the influence the researcher has on the research process and outcomes.
Scopus	Largest database of peer reviewed literature
Symbolic Interactionism	A theoretical perspective assuming people construct selves, society, and reality through interaction
Theoretical Sampling	A type of grounded theory sampling to develop theoretical categories
Theoretical Sensitivity	Ability to extract importance from data and provide meaning, thereby having relevance for the emerging theory
Well-being	An overall condition of an individual or group in relation to their social, economic, psychological, spiritual or health status.

Chapter One Introduction

1.1 Background and rationale for the study

> "*Emaciated, frail and unable to wash or dress myself I was discharged from hospital to the care of my parents. For those around me, leaving hospital was a milestone, a confirmation that I had survived. For me, it was a moment I had to face the skeleton in the mirror, an imposter masquerading as me. Where was the real me? Would I ever be me again? In my childhood bedroom, I sobbed silent tears. I had survived, but which part of me?*"

This extract, taken from a letter written by a 35 year old woman involved in a road traffic collision, illustrates some of the difficulties of surviving critical illness. Having survived the physiological trauma incurred, and following a prolonged stay within an Adult General Critical Care Unit (AGCCU) there were significant consequences for her, and her family to contend with.

This quotation reveals the complexity that lies beyond the physicality of surviving critical illness and the associated impact on the identity of an individual and their family. The effect of critical illness on patients and their families more widely can, and frequently does, have life changing and lifelong effects (Bernis-Dougherty and Smith 2013, Davidson et al 2013, Endacott 2011, Misak 2014, White 2016). Exploring the critical illness trajectory from the perspective of survivors of life threatening illness, family members, and critical care nurses provides a unique insight into this journey. The critical illness trajectory or journey commences at the onset of critical illness (which is both unpredictable and unplanned), extending through a period of time subjectively perceived by individuals.

This introductory chapter offers a brief context of critical care provision within the United Kingdom and provides an exploration of the personal and professional drivers for this study.

The first intensive care units were established in Scandinavia in 1953 in response to the polio epidemic (Berthelsen and Cronqvist 2003). In the

following sixty years, there have been dramatic improvements in the interventions and techniques that provide life sustaining treatment. This capability to support and sustain organ function within critical care has led to a range of iatrogenic effects that are a consequence of the treatment rather than the original pathology (Bernis-Dougherty and Smith 2013). Such iatrogenic effects are evident within this study.

Twenty five years ago we could not even quantify how many people would survive admission to Critical Care (Kings Fund 1989). Subsequently, utilising a medical model, we have gained quantitative knowledge of the survival rates of patients and correlation with clinical conditions (Endacott 2011, ICS 2015). Survival is, however a far more complex phenomenon; surviving the stay within intensive care is just one milestone on a much longer journey (Iwashyna 2010) as evidenced in the above quotation. In the 21st century we are beginning to discover, and understand, the longer term sequelae of critical illness for both patient and family members with consequential effects on physical and psychological function and the social landscape which is being slowing revealed (Govindan et al 2014, Hart 2014). Studies have indicated that in patients surviving critical illness, physical, psychological and cognitive dysfunction are significant for up to two years following discharge from AGCCU (Cuthbertson et al 2005) and for some survivors this can last for much longer (Storli et al 2008, Barnett 2006a). The potential for a significant societal and individual socioeconomic burden following critical illness has also been confirmed by Griffiths et al (2013).

Family members previously considered as a "*repository of information*" (Griffiths 2014 pg. V) are becoming recognised as playing a much greater role in patient recovery. It is also now recognised that they, themselves, are traumatised by the critical care experience (Jones 2014a, Dithole and Thupayagale-Tshweneagae 2013, Sundararajan et al 2014, van Beusekom et al 2016). We are at the beginning of understanding the long term legacy of critical care. Indeed, Hart (2014 pg. 419) has claimed that understanding and supporting '*critical care survivorship'* is the greatest challenge for practitioners working within this care setting.

As a critical care nurse by background, I have witnessed and engaged with the many challenges faced by patients, families and practitioners. Family members' experience of both critical care and critical illness has been a particular research interest for me (Wilkinson 1995) and others (Engstrom et al 2011, Eriksson and Bergbom 2007, Olsen et al 2009, McKiernan and McCarthy 2010, Van Horn and Kautz 2007). As an educator in adult critical care, I have held research interests in the patient and family experience of critical illness for many years. I have often reflected on the seemingly dichotomous position of the technological and invasive treatment modalities, combined with humanistic care, that are delivered within adult critical care units. I have witnessed nurses providing intuitive and compassionate care, but also witnessed nurses struggle to cope with the technological demands of critical illness and simultaneously meeting the needs of family members. I have experienced challenges between my professional self and humanistic self on several occasions.

A driving imperative for this study is developing a greater knowledge of the experience of survivors of critical illness and their families. This study gives survivors and family members a voice and vehicle to inform clinical practice. As Catherine White a survivor of critical illness and founder member of ICU Steps states:

> "*As an ICU patient, you have no voice (you are often unable to communicate and are confused), so many patients are therefore unable to contribute to their care and express their wishes while in intensive care. This is why it is so vital that the voices of former patients and relatives are heard at all levels to help fill this gap.*" (White 2016).

Understanding what knowledge critical care nurses have of the critical illness trajectory and, what role they may play, if any, in preparing patients and relatives for their onward journey runs in parallel. Thus, this study seeks to understand the critical illness trajectory from all three perspectives. Use of multi perspective, qualitative interviews allows comparison of perceptions of patients, family members and registered nurses in critical care. According to

Kendall et al (2009), such interviews may help reveal the complexity of individual situations and help in understanding deficiencies in care from different perspectives thereby contributing to formulation of workable recommendations for improving care delivery. Before, during, and after critical illness, the family is an integral part of a patient's life and *vice versa*. Critical illness marks a significant disruption to a person's daily routine; an understanding of the course and causes of changes in health overtime (health trajectory) may allow enhancements to care by health professionals and through self-care (Henly et al 2011).

The Registered Nurse, working in AGCCU, cares for critically ill patients and their families who have been suddenly, and unexpectedly, thrust into an alien technological environment as well as confronted with a life threatening illness. Patient acuity is progressively higher as technology blurs the boundaries between life and death (Siffleet et al 2015). This can cause both moral distress and compassion fatigue for nurses (van Mol et al 2015). As patients, family members and nurses interface constantly in AGCCU this is further justification to consider the phenomenon from more than one perspective.

In addition to my previous clinical and current educational roles within adult critical care, there have been further stimuli for this study.

In 2011, I was invited to join an expert guideline group working with the British Association of Critical Care Nurses (BACCN) to formulate a position statement in relation to visiting in Adult General Critical Care Units (AGCCUs) in the United Kingdom. In keeping with patient and public involvement in research (PPI) critical care survivors and family members were integral members of the group (Staley 2013). A review of the literature in conjunction with expert opinion resulted in the publication of the guideline in March 2012 and presentation at BACCN national conference (BACCN 2012). During the process of submitting the guideline for publication, a recommendation was made to frame the paper from patient, family member, and practitioner perspectives; the published literature did not permit this, thus providing an additional driver for this current study. Whilst these guidelines

have been available since 2012, they have not necessarily been applied in practice. The concept of the theory/policy-practice gap being well documented (Buckley and Andrews 2011).

In relation to adult critical care there are National Institute for Health and Clinical Excellence (NICE) guidelines that relate directly to adult critical care nursing practice; CG 50 (2007) Acutely Ill Adult, CG 83 (2009) Rehabilitation after Critical Illness (2009) and CG 103 Delirium (2010) being the most applicable. Several policy and guidance documents from the Intensive Care Society (ICS 2015) promote best practice, and sometimes evidence based practice, but there is evidence of disconnect between the theoretical recommendations and enacted practice (Belanger and Ducharme 2011, Cotton 2013, Connolly et al 2014). The reasons are, of course, complex and wide ranging with funding challenges, organizational culture, and individual behaviours all playing a part.

Gaining greater insight into the way in which patients and family members experience both critical care and critical illness, and indeed how registered nurses respond to their needs, is of increasing relevance and interest. Medical and technological advances permit greater life prolongation that could not be conceived of at the inception of intensive care units (Crocker 2007, Endacott 2011, Wright et al 2015,). Understanding the consequences and legacy of critical care from a sociological perspective are important drivers for this study.

Further impetus for this study has emerged during the course of data collection. Whilst collecting my own data I have also participated in a research prioritisation exercise with the James Lind Alliance (Reay et al 2014). This consensus study, utilising a modified Delphi and Nominal Group technique sought to identify and prioritise unanswered questions about adult critical care that were important to people who have been critically ill, their families and practitioners. The need to establish how patients and their families can be supported post critical illness was within the top three priorities for future research. The way in which patient and family experiences can be used to improve critical care are also highlighted as a

research priority (Reay et al 2014). Further recent analysis of the data from this research prioritisation exercise has established that health care professionals, patients, and family members sought further research into the '*comfort/communication/psychological*' category together with '*post-ICU/rehabilitation/follow-up*' (Arulkumaran et al 2016). This provides further support and rationale for this study.

Critical Care nurses know very little about what happens to patients following discharge from AGCCU and practitioners are often left to wonder whether the interventions and associated suffering were "*worth it*" (Ramsay 2010). In relation to achieving family centred care in AGCCU, Benner et al (1999) suggests that it requires '*astute clinical judgment, wisdom, skill and coming to terms with the human significance of critical illness and injury to care for family members of the critically ill*' (p. 294). In addition, Endacott and Berry (2007) provide a salutary reminder for staff not to make assumptions about family members' needs, highlighting dfferences between practitioner and family members' perspectives.

Maintaining the emotional literacy of practitioners is an important and contemporary theme in this post Francis era. The extent of the failures at Mid Staffordshire NHS Foundation Trust, investigated and reported on by Robert Francis QC led to 290 recommendations; first and foremost that patients are at the centre of the care system (Francis 2013). There are however challenges confronting practitioners when caring for both patients and families in AGCCUs. There is evidence that registered nurses face a fundamental conflict both between role expectations and patient care, and between professional ideals and being a human (Stayt 2007). This not only highlights a disparity between nurses' everyday patient and family care practice, but may also contribute to occupational stress and compassion fatigue (Siffleet 2015). Whilst it is imperative that practitioners are enabled to meet the needs of patients and family members this should not be at the expense of their own emotional wellbeing or the development of burnout.

Preparation of the research and ethics proposal required engagement with the literature which revealed a single phenomenological, doctoral study from

the USA. The study explored a triad of registered nurses, patients and family members with five participants in each category (Cypress 2009). Further studies, such as this one, with larger numbers of participants and a methodology that may allow for concepts and categories to *travel* (as opposed to the notion of generalizability associated with positive paradigms) has led me to constructivist grounded theory as a research methodology. (Charmaz 2014). Such an approach allows for abstract understanding of studied life, located within a time, place and context and builds upon a volume of small scale descriptive studies (see chapter two).   Uniquely, there is a gap in the literature with regard to understanding and explaining the patient and family member's collective critical illness trajectory. The sociological literature has a wealth of knowledge around chronic illness but very little in relation to critical illness. The auto ethnography's of two sociologists being notable exceptions (Rier 2000, 2014; Richman 2000).

1.2 Clarification of terms

Within this thesis, a number of terms or concepts are utilised that may have multiple definitions, operational meanings, and overlap within the literature. To provide consistency and clarity, key terms are defined.

Survival and survivorship

Survival and the associated term survivorship is subject to a range of definitions (Blows et al 2012). Within the context of this thesis the term '*survival*' is used in the most literal sense of avoiding death. As critical illness is characterised as an acute life threatening episode, survivor is used to describe individuals who live beyond this event and are termed as a '*survivor*'. The term '*patient*' and '*survivor*' are used interchangeably.

Intensive Care Unit and Critical Care Unit

Both terms are used interchangeably within the published literature (ICS 2015). For the purposes of this study all patients have received level three care as defined by the ICS and documented in table 1.1. The environment where this care has been delivered is referred to as Adult General Critical Care Unit (AGCCU). This reflects the age (18 years+), and the generalist rather than specialist nature of the critical care unit. Many survivors will have transitioned from level three to level two care, often referred to as High Dependency Care or HDU.

Family member and relative

These terms are used interchangeably within the thesis however the definition is constant. The European Federation of Critical Care Nurses definition is broad and inclusive;-

"…*those people who are most important to the patient. This includes patient's family, loved ones and close friends*" (Fulbrook et al 2008).

1.3 Context of study

Intensive care units have been established in the United Kingdom since 1962 having evolved from units for treating the polio epidemics of the 1950s (Crocker 2007). Subsequently, the Department of Health (2000) has modernised services and encouraged the combination of Intensive Care and High Dependency Units into Critical Care Units together with an emphasis on caring for the patient and their family for the entire course of their critical illness. Hence, the term Critical Care will be utilised for this study although reference to Intensive Care or Intensive Therapy Units are used interchangeably throughout the literature. Patients admitted into this care setting are deemed to be critically ill and at risk of actual or potentially life threatening health problems (ICS 2015). The Intensive Care Society (ICS 2015) provide a classification of illness severity; the patient participants in

this study have either been admitted at an illness severity of level three (table 1.1) as an emergency admission and not an elective admission.

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.

Table 1.1 Levels of care as determined by Intensive Care Society (ICS 2015)

Currently there are 223 Adult Critical Care units in England. In December 2013 there were 3,829 Critical Care beds in England with bed occupancy rates of between 77-88%; 237,710 patients were admitted that year (Masterson and Baudouin 2015). Survival rates have risen steadily since 1992 when only 68% of patients admitted to AGCCU survived to leave hospital; mortality rates are currently between 15-20% (van Beusekom et al 2016).

According to the Intensive Care Society, Critical Care unit size can vary from four to over fifty beds (ICS 2015). Survivor participants in this study were recruited from an 800 bed district general hospital (DGH) in England with fourteen Critical Care beds; ten level three beds, four level two (see Table 1.1) but able to "flex" between the two levels. This is considered to be a medium sized AGCCU and typifies many DGHs in England. The DGH is operated by an NHS Trust which provides elective and emergency services to 380,000 people from rural, semi-rural and urban areas. The cost of an intensive care bed is £1,931 per night and there is a prediction for a 4% year on year increase in demand for critical care in the U.K. (ICS 2015).

Following ethical approval, data were collected from sixteen survivors of critical illness who had previously been admitted to this fourteen bedded AGCCU. The AGCCU had 700 admissions in 2014 of which 490 were emergency in nature accounting for 70% of all admissions to critical care. Fifteen relatives were interviewed whilst their family members were patients within the AGCCU, or at follow up clinics. Eleven registered nurses from a total of 71 in post, (January 2015 data) were recruited from the same AGCCU to discuss their own experiences and knowledge of the critical illness trajectory. Further details of recruitment and consent processes are detailed in Chapter four.

Adult General Critical Care Units (AGCCUs) have long been recognised as highly stressful environments, particularly for family members visiting their relatives (Berry et al 2006). Patients admitted to AGCCUs are the sickest in the hospital, requiring both respiratory and organ supportive interventions. The patient may be unconscious, due to abnormal pathology or sedation. Alternatively, they may experience varying levels of consciousness. Whilst physiological safety is paramount there is an increasing awareness of the psychological harm that can occur over the patient's (and family members) critical illness trajectory (Hart 2014). Gaining further understanding and subsequent explanation of these experiences may, ultimately, help develop strategies to mitigate against both physiological, cognitive and psychological sequelae.

1.3.1 Chosen methodology and methods

A qualitative methodology; constructivist grounded theory has been selected for this research study to yield rich, in-depth descriptions and theoretical insights into experiences of patients, family members and practitioners within AGCCUs. Such enquiry requires a process of systematic documentation and description which can be achieved via interviews or observation (Welford 2012). Subsequently, inductive and abductive theory is co-constructed bringing new knowledge (substantive or explanatory mid-range theory) into view through the processes of constant comparative analysis and theoretical sampling. Full details are provided in chapter three.

1.4 A personal orientation; insider perspectives

This doctoral research is an extension of my clinical background and research interests. As a critical care nurse, I have several years of clinical experience within this speciality. Latterly I have taught and researched within higher education particularly around the experience of family members within AGCCU (Wilkinson 1995, Page 2009, 2010, 2011, BACCN 2012). Given the above, and the intention to undertake a qualitative research method, in particular, a constructivist grounded theory approach, it is imperative to be candid from the outset (Charmaz 2014). As a researcher, I come from a particular class, culture, and background that may be value laden and may affect and effect the interaction with research participants. Further exploration of both emic and etic perspectives are provided in chapter three.

I first became aware of my own inadequacies as a practitioner when appointed to a sister's post within AGCCU in the 1990s. I felt wholly inadequate in supporting family members who were experiencing probably their most traumatic life experience ever. As I started to research the literature and also further develop my knowledge and skills in counselling, I realised the paucity of UK based research. The literature was, and to some extent still is (Bandari et al 2015), dominated by Molter and Leske's (1979 to 2000) work from the USA, and the quantitative Critical Care Family Needs Inventory questionnaire. This tool was derived from the experiences of third year student nurses and, it could be argued, is fundamentally flawed as the need statements were not derived from family members themselves (Burr 1998).

In 1995, following ethical approval, I commenced a small scale qualitative study. I undertook in-depth interviews with family members whilst their loved ones were in AGCCUs (Wilkinson 1995). I espoused this to be a 'grounded theory' study however I am now conscious of '*method slurring*' (Baker et al 1992); failing to be true to grounded theory. I had in fact undertaken a qualitative study with thematic analysis and thematic coding. This paper whilst published several years ago is still frequently cited, only one literature

review to date has identified the methodological flaws. This highlights the importance of methodological critique when reviewing the literature and preventing what Charmaz (2014) refers to as, the generalisation of grounded theory, since coding and memo writing have become evident in most qualitative enquiry. Perhaps more importantly, the research provided a rich, deep insight into the experience of visiting a family member who was critically ill. This was a profoundly powerful and humbling experience for me. My subsequent research interest and teaching has naturally widened to include the patient experience and the bedside RN in AGCCUs. This approach resonates with the underpinning theoretical framework of Symbolic Interactionism and is explored in more detail in chapter three.

1.5 Structure of the thesis

An outline of the thesis chapter headings, and their contents, is provided to orient the reader.

Literature Review

In chapter two the literature review aims at '*setting the stage'* (Charmaz 2014) and helping the researcher develop theoretical sensitivity. The place of the literature review in grounded theory, and in particular, constructivist grounded theory is explored.

Methodology

Chapter three offers a detailed discussion of the methodological issues that underpin and challenge the study. This includes philosophical background to qualitative enquiry and justification for the chosen theoretical framework in relation to constructivist grounded theory. The context and principles of constructivist grounded theory, as offered by Charmaz (2014), are detailed concluding with strategies to ensure methodological rigour.

Method

Chapter four details the study protocol and operational detail of how the study was conducted. It focuses on the interview as a data collection method

and the nature and meaning of the relationship between interviewer and interviewee. Gaining entry to the field of study will be discussed together with the recruitment of participants. The process of informed consent with the ethical considerations and safeguards are discussed. The procedure of data collection and the challenges experienced by the researcher are considered in a reflexive manner. The chapter concludes with details of data analysis; - starting with verbatim transcription, followed by initial coding, focus coding, and selective coding. References to memos and diagrams as well as the iterative, constant comparative process of data analysis is made.

Findings

Chapter five provides details of the findings from interviews with survivors and family members, illustrated with vignettes from transcripts. Initial codes, focus codes and, finally, the selective code or core category is identified.

Chapter six details the findings from interviews with registered nurses working within AGCCU. The format of the chapter replicates Chapter Five.

Discussion of core category and conclusion

Chapter seven expounds the analysis of the findings, focusing on the core categories and the process of scaling up the theory utilising liminality as a conceptual lens.

Integration of this new knowledge into critical care practice and beyond the 'walls[1]' of critical care is explored. The strengths and limitations of the study are discussed and recommendations for future research identified. Original contribution to knowledge is identified.

1.6 Aims of Study and Research Questions

For purposes of clarity, the research aims and questions are provided.

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[1] The term "Critical Care without walls" was the strapline from Comprehensive Critical Care - (DoH 2000)

The study aims to formulate a substantive (middle range) theory in relation to patient and family's critical illness trajectory and to discern and understand the response of nurses to survivorship needs.

Research questions;-

- How do patients and family members experience their critical illness trajectory?

- How do registered nurses in AGCCU respond to the survivorship needs of patients and family members?

The importance of conducting research on illness experiences has been well documented by Frank (2004) and others (Sakellariou et al 2013). Illness is rarely experienced as a solely individual experience; illness is lived and co-constructed within the social context that people inhabit (Sakellariou et al 2013) providing further justification for the triadic approach of this study. Whilst health care *per se* does not always provide solutions, the process of health care should allow understanding of the positions of everyone involved (Mol 2008). Such understanding may be achieved through the synthesis of different voices and by making sense of the intersubjective and heterglossic world of illness (Good 1994). By listening and co-constructing the stories from survivors, family members and registered nurses the intersubjective nature of the illness trajectory is embraced, and subsequently, knowledge is enhanced.

As we espouse to have patient centred health care aligned to the NHS Constitution here in the UK (Department of Health 2013) it is imperative to understand patient and family experiences in order to inform practice. Chenail (2011) advocates qualitative enquiry as a means to enhance this knowledge base. This is detailed in Chapter three. There are also significant implications for educating health care professionals in Higher Education as well as the practice setting (Chapter seven). Within the context of Adult Critical Care Rattray and McKenna (2012) argue that;-

> "*Establishing person centred care has implications not just for those who deliver care but for those who educate nurses and those engaged*

in research. It should be a thread throughout our undergraduate and post-qualifying programmes and at the centre of our research programmes" (p226).

Such a statement clearly resonates as I am in the privileged position of educating both groups of students within the context of Higher Education.

This study seeks to support and develop the evidence base for providing patient and indeed family centred care within AGCCU and beyond the '*walls of critical care'* (Department of Health 2000). The concept of '*critical care without walls*' established following the influential Department of Health policy document '*Comprehensive Critical Care'* has shaped the services we have today. The need to care for both patient and their families during and after critical illness was, and is still, slowly being realised. Whilst the full socio-economic impact of critical illness on patients and families has yet to be determined there is evidence that survivors in the United Kingdom face a negative impact on their employment and frequently have care requirements for up to five years post discharge (Griffiths et al 2013). Early rehabilitation and in particular, funded implementation of NICE CG 83 (NICE 2009) may warrant consideration.

The contribution of new knowledge from this study and the supplementation of a growing, contemporary knowledge base, provides exogenous practice implications that, if implemented, may benefit all three participant groups. In addition to recommendations for undergraduate and post graduate education of health care professionals, there are implications for Clinical Commissioning Groups (CCGs) and policy makers.

1.7 Summary

Millions of people now physiologically survive critical illness around the world (Iwashyna 2010, Lasiter et al 2016), however, there is a deficit both in knowledge and provision around critical care survivorship which may be contrasted with that of cancer survivors; from whence the term survivorship developed (Blows 2012, Govindan et al 2014). This research provides novel perspectives on the relational effects of critical illness between survivors and

family members and considers the views and experiences of registered nurses working in AGCCU. Data from this study additionally augments the growing corpus of knowledge around the long term sequalea of critical illness.

The subjective experience of critical illness is poorly understood by health care professionals, survivors and their families (Stevens et al 2014, White 2016). The critical illness experience is enormously complex, varied and multifaceted. This study seeks not to medicalise this experience rather to provide a conceptual lens to focus on, and understand the dynamic interplay during the illness trajectory. Liminality, as a conceptual lens has been selected for this purpose. This removes the focus from illness affecting organs and systems and helps visualise the embodied suffering that can occur as a consequence of surviving critical illness.

In summary, chapter one has provided the background, rationale and context for the study. It has outlined personal and professional motivations for embarking on this research, presented research aims and questions and, importantly, declared my own experiences and perspectives on the subject area. This has been presented to enhance reflexivity and transparency because being the researcher and interviewer, I construct meaning with research participants. Therefore prior knowledge and values need to be made explicit (Charmaz 2014). Further details relating to reflexivity are provided in Chapter 3 and throughout the thesis.

Chapter Two Literature Review

2.1 Introduction

This chapter presents and considers the recent literature in relation to the patient, family member and nurse experience of critical illness and critical care. Methodological literature is presented in chapter three. Specific literature focusing on the selective codes from the co-constructed data is considered in chapter seven. Appendix 1 explicitly outlines how literature is used throughout the thesis.

The contentious debate over the timing of the literature review within the context of a constructivist grounded theory study is also explored. This is followed by a critical review of literature to synthesise and draw conclusions from the current state of knowledge in this area of critical care practice (Polit and Beck 2010). It should be emphasised that the central purpose of this literature review is to enhance theoretical sensitivity. Theoretical sensitivity is the ability to extract what is important in the data and the process of giving it meaning, thereby having relevance for constructing theory (Birks and Mills 2011, see also 3.9). In addition, literature can provide '*conceptual levers'* (Schatzman and Strauss 1973) to enhance abductive thinking. Within the context of constructivist grounded theory, Charmaz (2014 p308) argues that the literature review should not "*stifle your creativity or strangle your theory*". Remaining *'open'* to the data is a central tenet of grounded theory.

This literature review examines the extant literature as it relates to the triad or '*family as a unit'* (Cypress 2011) within AGCCUs. Explicitly these are patients who have survived critical illness, family members whose relatives are or have been critically ill, and registered nurses within AGCCUs who care for both patient and family members. The literature review '*set[s] the stage'* (Charmaz 2014 p.308), focusing on the key aspects as they relate to this study. Appendix 2 details the literature reviewed and how it relates to the data collected in this study (final column). Such constant comparison demonstrates methodological congruence with the study as a whole.

A systematic approach to searching the literature in a methodologically integrative manner is evidenced. In addition to primary research, literature reviews and grey literature were selected to ensure I was sensitised to literature familiar to practitioners within AGCCU. Results of the literature search are presented in a synthesised, constant comparative manner demonstrating further methodological congruence.

2.2 The disputed literature review in grounded theory

Before proceeding, it is pertinent to address the contention that exists around the timing of the literature review within the context of a constructivist grounded theory study. This is an area that has long been disputed and misunderstood; indeed it was a factor in the well documented split between Glaser and Strauss with Strauss deviating from the original Discovery of Grounded Theory (Glaser and Strauss 1967) and advocating an early review of the literature in alignment with Juliet Corbin (Strauss and Corbin 1990, Dunne 2011, Charmaz 2014). Glaser (1998, 2012) remains adamant that the literature should not be reviewed until the grounded theory has come in to view, then and only then should the literature be reviewed and woven into the data as part of the ongoing constant comparative method. His rationale is to prevent data being viewed through a '*contaminated lens'* of earlier ideas and forcing data into pre-existing categories (Charmaz 2014, Dune 2011).

On a practical level, this is largely unworkable, particularly for doctoral students where an initial research proposal, together with ethical approval is a prerequisite to admission to doctoral studies and data collection. Both of these require a preliminary review of the literature (McCallin 2003). Progression through the doctoral process may also require submission of a literature review. There are also some practical benefits to an early review of the literature. It may help identify pertinent lacunae in existing knowledge, provide some context for the study and orient the researcher, helping to develop theoretical sensitivity. Finally, failure to review the extant literature may ignite criticism, particularly from colleagues outside the grounded theory field (Dunne 2011). Henwood and Pidgeon (2003 p138) argue not for "theoretical innocence" but to develop a critical stance of "theoretical

agnosticism" similarly Coffey and Atkinson (1996 p157) remark, *"The open-mindedness of the researcher should not be mistaken for the empty mindedness of the researcher…"* A further imperative is to ensure an evidence base to clinical practice and as a professional registrant, I would be negligent not to do so (Nursing and Midwifery Council 2015).

Thornberg (2012) goes further and overtly opposes the position of dismissing extant theory and research literature arguing for informed grounded theory. This is in contrast to classic grounded theory tradition (Glaser and Strauss 1967) but in keeping with constructivist grounded theory and the pragmatic notion of abduction (in addition to the established process of induction) that is; "*a creative inferential process aimed at producing new hypotheses and theories based on surprising research evidence*" (Timmermans and Tavory 2012 p167).

In this study, a middle road is taken whereby the literature is being used as an instrument to aid sensitisation and to enhance theoretical sampling. Following an initial review of the literature for the purposes of gaining ethical approval, the substantive review was researched and written mid-way through data collection. This is arguably, ideally placed to enhance theoretical sensitivity to emerging concepts and forming part of the iterative, constant comparative analysis. Strategies to mitigate against developing a '*contaminated lens'* (Dunne 2011) include a growing reflexivity (Cutcliffe 2003). This acknowledges the researcher as an individual, holding a particular social identity and background, which impacts on the research process. The process of '*memoing*' is based on reflective thinking. It forms a central part of grounded theory and may be applied within the literature review process itself (Dunne 2011). Examples of reflexive memos can be viewed in Box 3.1 and 4.3 and theoretical memos Box 4.4.

2.3 Search strategy

The aim of the literature search was to identify current and established literature relating to patient and family member experiences in AGCCU. The nurses' experience in relation to both knowledge and understanding of these

experiences and the subsequent impact was also sought in order to provide a holistic approach to the phenomenon.

An initial literature search was conducted between June and September 2012 in order to establish preliminary research questions with associated aims prior to commencing doctoral study. This early review was integral to the application for registration on a doctoral programme and in obtaining ethical approval with consequential access to the field of research. In keeping with constructivist grounded theory the literature was more formally and extensively reviewed during data collection (2014-2015) to enhance theoretical sensitivity as outlined above.

The search strategy involved iterative searches of the following electronic databases; Medline; Assia; CINAHL Plus; SCOPUS; Web of knowledge/Web of science. Searches from 2000-2015 were conducted using the search terms identified in 2.3.1 with advanced search options. These searches were supplemented by hand searching of two subject specialist journals *Intensive and Critical Care Nursing* and *Nursing in Critical Care.*

2.3.1 Inclusion and Exclusion Criteria

Before commencing the search, inclusion and exclusion criteria were identified. English language papers published between 2000 and 2015, where individuals (patients and/or family members and/or nurses) had experienced AGCCU either as a surviving patient, visitor or Registered Nurse were included. The time frame (2000-2015) reflects the need to consider the contemporary context of AGCCU given the impact of new technology. Search terms included "critical care" or "intensive care" or ITU or ICU; patient*, relative*, family member*, experience* nurse*. All articles meeting the inclusion criteria were included for review with searches using truncation and Boolean operators as advocated by Polit and Beck (2010) (see Figure 2.3).

Exclusion criteria applied were child*; paediatric; neuro*; brain; cardiothoracic; burn*; "end of life care", bereave*; dying; obstetric; CPR; resuscitation as the focus of the study is on adult, general critical care

patients, and their families. The study did not focus on a clinical speciality nor end of life care within critical care.

2.4 Search outcome

The flowchart (Fig. 2.3) details the process of selecting the 78 publications included in the final literature review. The methodological composition of the selected literature is broadly represented in Table 2.1 and more specifically identified in Appendix two. These papers were subsequently sorted in to patient, family members or registered nurse focused papers, with dyads and triads reviewed separately (see Appendix two and Table 2.2).

Design	Number of papers
Qualitative	47
Quantitative	11
Mixed Method	6
Case study	1
Grey Literature and Literature reviews	13
Total	78

Table 2.1 Literature reviewed by research design

A review of the papers was undertaken in an iterative, constant comparative manner as recommended by Wolfswinkel et al (2013). Wolfswinkel et al (2013) highlight the use of grounded theory as a method for reviewing the literature that can enrich social science.   Memos and notes on the literature were made and a matrix of published literature established (see appendix two). Each row of the matrix detailed the individual papers and included details such as research design, sample size, population and a summary of the key findings. The final column cross references the paper to the co-constructed data; providing evidence of constant comparative analysis and synthesis. Every paper was reviewed in depth and key themes gave rise to new column headings in a separate matrix. Through the process of constant comparison, themes were refocused and coalesced yielding a synthesis of the literature framed around seven key themes. Each theme is discussed as a narrative synthesis (section 2.6).

Appendix two provides an overview of the literature and highlights the significant volume of research emanating from Scandinavia. Such work provided rich, thick descriptions which enhanced understanding of the experience of patients and family members. However, despite several of the studies claiming to be grounded theory, very little middle range or explanatory theory had been generated. Table 2.2 confirms the participant or subject focus of the literature reviewed.

Subject Focus	Number of papers
Family Members	21
Registered nurses	16
Patients	33
Triads	3
Dyads (patients and FMs n=3; FMs and nurses n=1, patients and RNs n=1)	5
Total	78

Table 2.2 Literature review by nature of subject focus

Literature listed by country of origin is illustrated in Figure 2.1. It is perhaps appropriate that Scandinavian countries have undertaken a significant volume of research in critical care given that the first intensive care unit was opened in Copenhagen in 1953 (Berthelsen and Cronqvist 2003).

Research by Country

Australia, 8
Botswana, 1
Canada, 3
Germany, 1
Greece, 3
Hong Kong, 1
Iran, 1
Ireland, 4
Italy, 1
Spain, 1
The Netherlands , 2
UK, 17
USA, 5
Scandinavia, 33
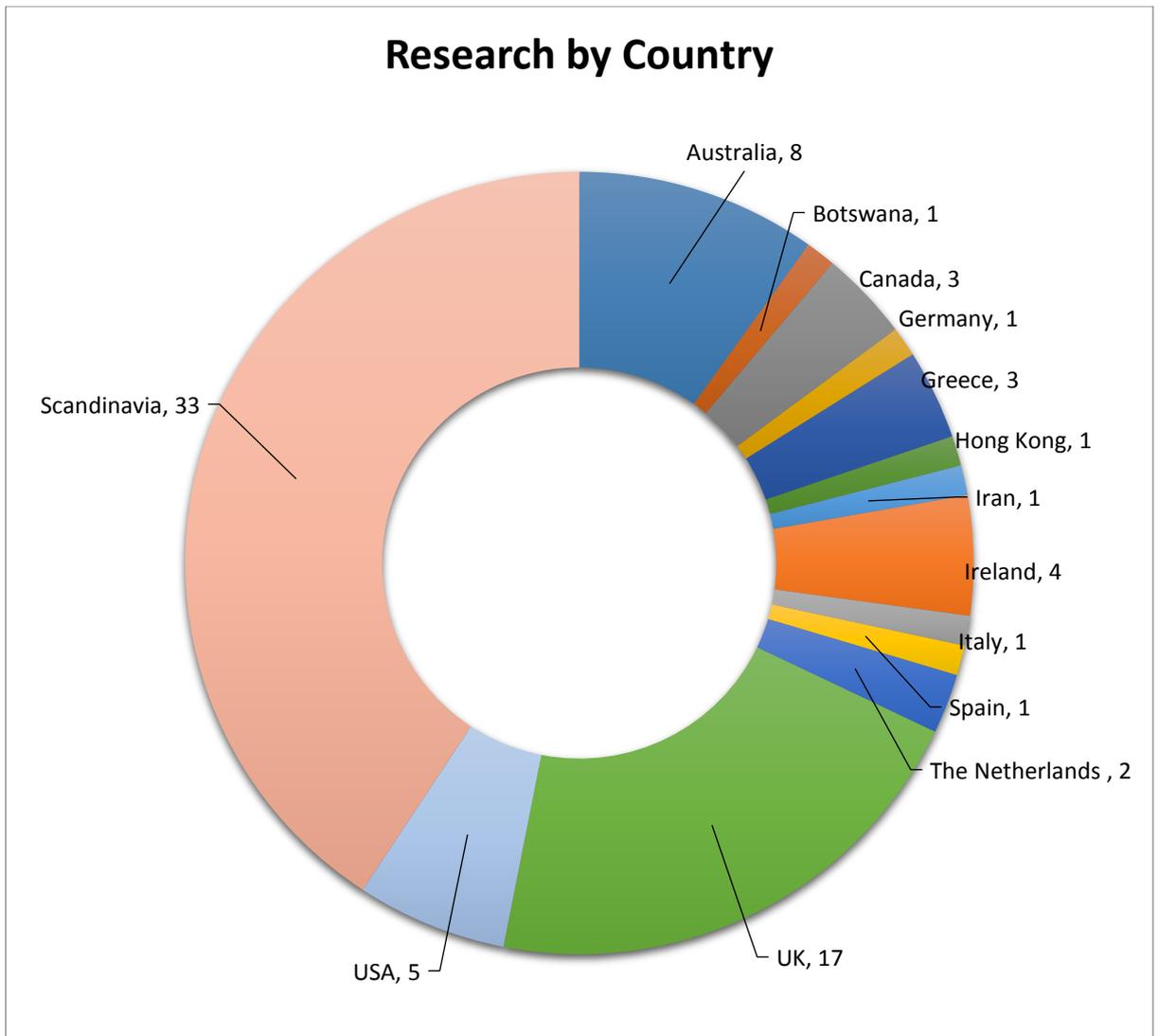
Figure 2.1 Literature listed by country of origin

Variation in provision and access to critical care services is evident in the
countries highlighted in figure 2.2 (Austin et al 2014). There is limited global
data although Rhodes et al (2012) demonstrates the wide variability of critical
care bed provision with Germany having the greatest number per head of
population (29.2/100,000), whereas Portugal had the lowest (4.2/100,000)
(31 countries surveyed). The UK has 6.6/100,000. This may impact on
transferability of results when reviewing global research but what is common
is the patient, family member and RN experience of, or exposure to, critical
illness.
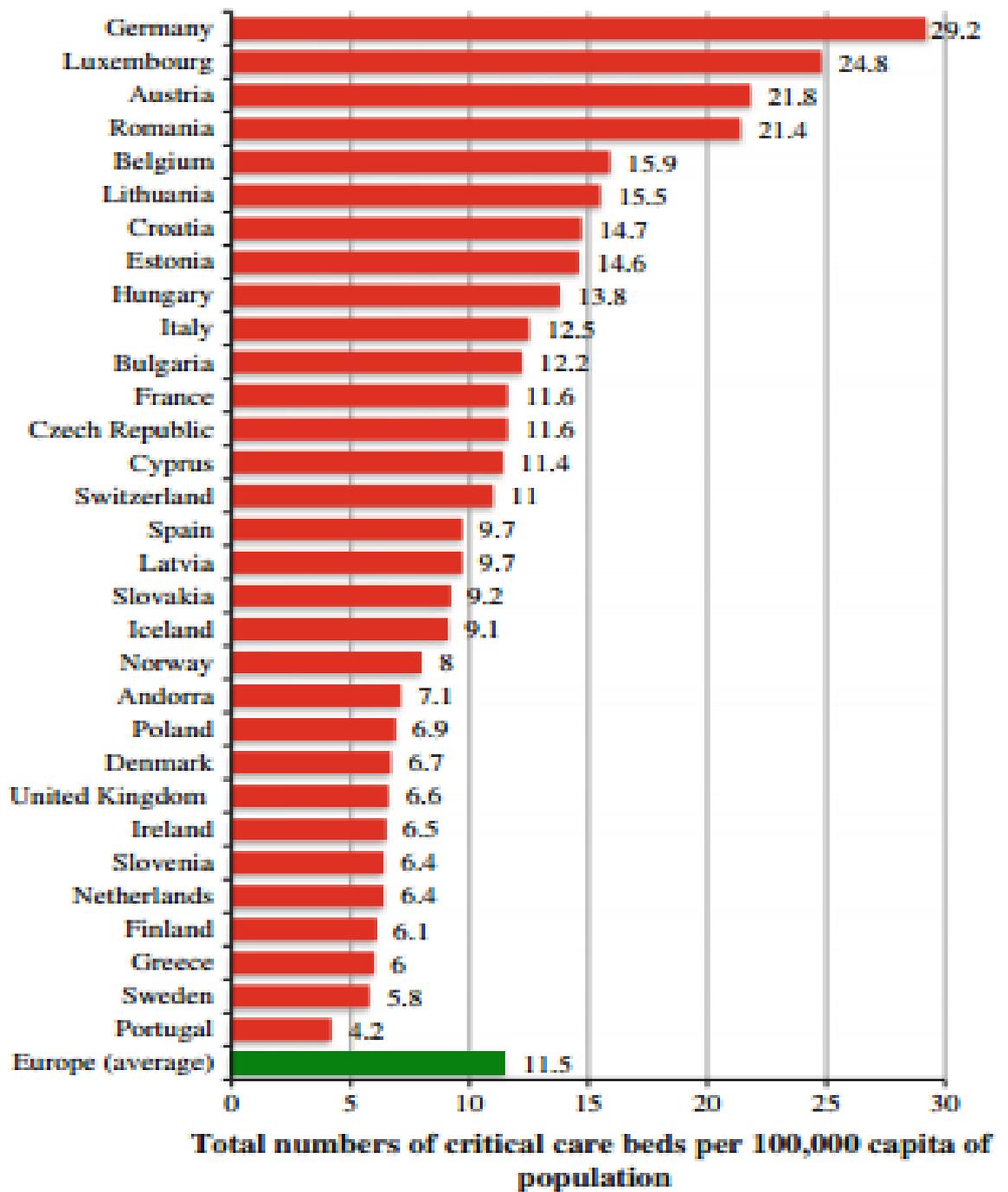
Figure 2.2 Number of critical care beds (per 100,000 population) in Europe
(Rhodes et al 2012)
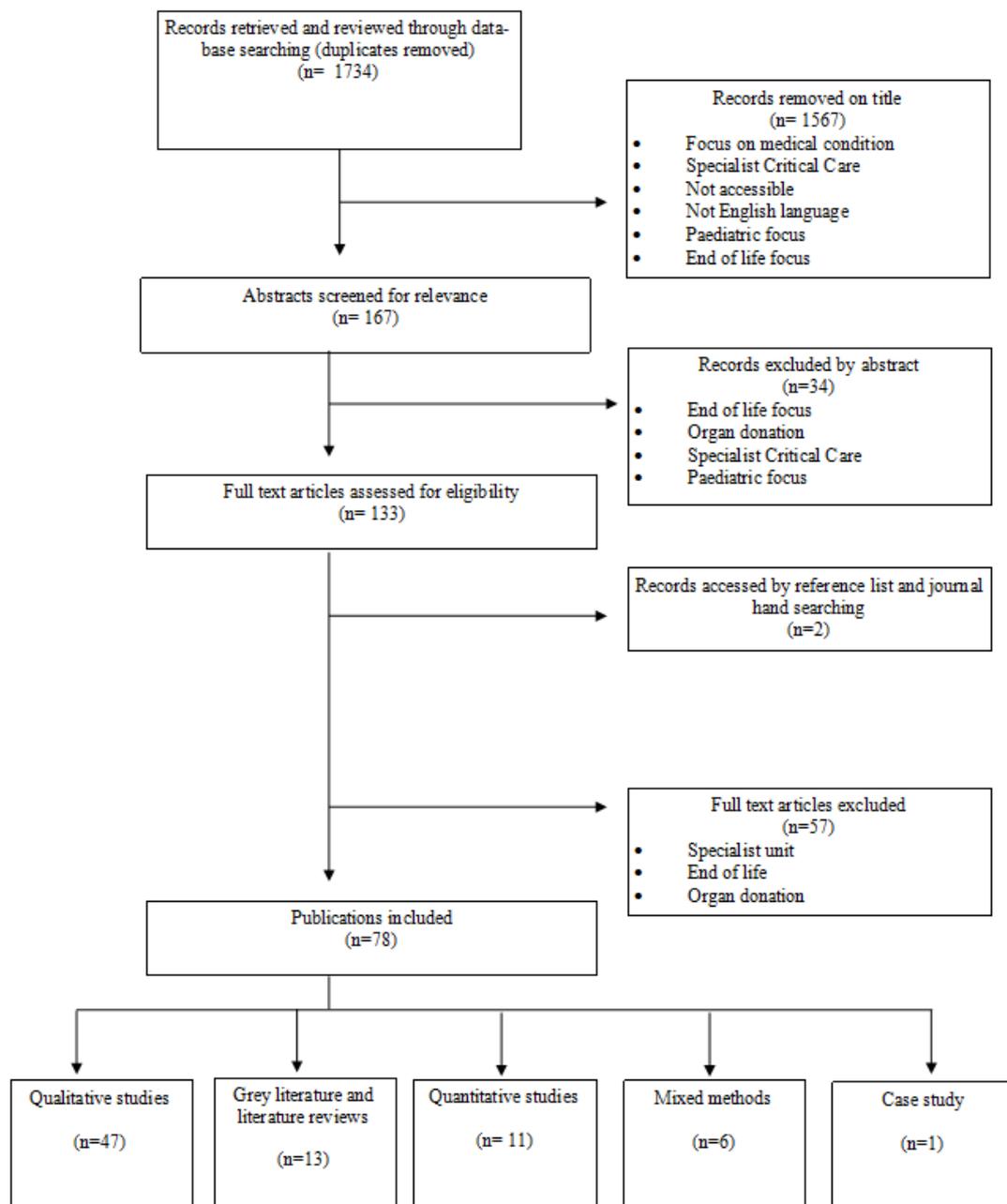
Figure 2.3 Literature Search flowchart

2.5 Quality appraisal

The papers were evaluated according to authenticity, methodological quality, informational value and representativeness to the research questions. Such measures are appropriate to a critical review with the aim of making research based knowledge more accessible to clinical nurses (Kirkevold 1997) and enhancing *theoretical sensitivity*. Publication of this literature review aimed to help overcome the traditional schism between theory and practice (Page 2015).

The 47 qualitative primary research papers were additionally appraised using the CASP (critical appraisal skills programme, 2013) with one adaptation. Relevance to the research questions rather than the organisation was a necessary but minor adaptation of the framework and one that has been applied elsewhere (Cutler et al 2013).

Figure 2.1 illustrates the dominance of Scandinavian research in this field of research. Of all primary research papers reviewed (n=65), 45% (n=33) originate from Sweden, Norway, Denmark or Finland. They provide rich description of experiences from either a phenomenological or grounded theory perspective, however, there is very little emerging substantive or explanatory theory.

A further observation of the literature reviewed relates to the sample size. In the literature reviewed, 36% (n=45) of qualitative studies had 8 or less participants. (Agard and Harder 2007, Blom et al 2013; Engstrom and Soderberg 2004; Engstrom et al 2011; Kutash M and Northrop (2007); McKiernan and McCarthy (2010); Tunlind et al 2015; Bergbom and Askwall 2000; Engstrom et al 2011; Karlsson and Forsberg 2008; Lof et al 2008; McKinney and Deeny 2002; Cypress 2011). Whilst sample size is less of an issue in qualitative research design, and indeed it would be contentious to identify a definitive number, (Smith et al 2011, NCRM 2012) the ability for themes or emerging theory to '*travel*' (Charmaz 2014) may be reduced.

2.6 Narrative synthesis of findings

A matrix was constructed to enable full immersion in the literature and aid constant comparison. The key themes identified from the papers gave rise to new column headings in the matrix. Heading descriptors were expanded and focused throughout the review by the constant comparative process. This resulted in a synthesis across all published papers which gave rise to seven key themes namely; - '*facing mortality*', '*critical junctures*', '*physiological sequelae*', '*psychological sequelae*', '*family presence*', '*beyond meeting family member needs*', '*technology v humanity*'.

The narrative synthesis of findings follows in section 2.6 with headings articulating each theme and some cross referencing. The table of literature reviewed in appendix two identifies research design, sample size, population, and key findings of the 78 papers under review. In addition, similarities or otherwise with this research study are identified in the final column, being mindful that a key purpose of this activity is to enhance *theoretical sensitivity*. As data collection continued during the course of the literature search and review, literature was compared directly with the data in true grounded theory, constant comparative style. Hence, the final column of the matrix shows relevance to my research questions and data (see appendix two). Comparing data with literature is a central element of grounded theory and assists in theoretical sensitisation and abductive thinking together with demonstrating methodological congruence (Charmaz 2014).

2.6.1 Facing mortality

Confrontation with one's own mortality or that of your loved one has, unsurprisingly, a profound effect on one's outlook on life (Cutler 2013). For some patients this leads to incomprehension and profound feelings of discomfort (Belanger and Ducharme 2011, Almerud et al 2007). For others, the disquiet caused by the threat to their own life may be ameliorated by the presence of family members (Bergom and Askwall 2000). For many patients these memories are enduring; Storli et al's (2008) phenomenological study

interviewed patients ten years after their critical care admission revealing intact recall of the fear of dying and remembering that death was "*all around*" whilst they were in critical care. Chiang's (2011) grounded theory study confirms the contribution of family presence and that "*Mutually being there for each other*" is a core category contributing to patient survival. Perhaps surprisingly there was limited evidence in the literature reviewed of the impact on critical care nurses in relation to their daily confrontation with death within AGCCUs. This is in the context of a fifth of patients not surviving AGCCU and one third not leaving hospital (Intensive Care Society 2015).

2.6.2 Critical Junctures.

The shock of admission to critical care is most keenly felt and expressed by family members rather than the patients (McKiernan and McCarthy 2010, Engstrom and Soderberg 2004). Facing extreme uncertainty leads to feelings of chaos and loss of control (Agard and Harder 2007). Physically seeing their loved one critically ill and the physical transformation they have undergone exacerbated the feelings of shock and incredulity. Such emotions have physical, psychological and cognitive effects; family members may not be able to retain information (Zaforteza et al 2005, Wong et al 2015) which has implications for information transfer and the ability to make sense of having a loved one who is critically ill. In contrast, patients frequently have little recall of their actual admission to critical care (Lof et al 2008, Eriksson et al 2011), but may awake to chaos and incomprehension or suffer complete memory loss of the whole time spent within critical care (Johnson 2004, Uhrenfeldt 2013, Samuelson 2011).

The next significant critical juncture in recovery from critical illness is transition from critical care to the ward. This has attracted a significant amount of research interest and there is a general consensus that transitioning from a high dependency to a low dependency care area may be problematic from the perspective of patients, family members and nursing staff (Belanger and Ducharme 2011, Lof et al 2008, Bench et al 2012, Johnson 2004, Uhrenfeldt et al 2013, McKinney and Deeny 2002, Field et al

2008, Misak 2014, Ramsay et al 2014, Lin et al 2013, Strahan and Brown 2005). For patients, the physiological and psychological sequelae of critical illness can be significant (Rattray 2014) and this will be discussed in more detail in section in 2.3.3 and 2.3.4 respectively. It is acknowledged by Ramsay et al (2014) that negotiating the transition between dependence and independence is a significant source of distress, particularly following ward transfer. This qualitative study reveals high levels of psychosocial distress experienced by patients as they are '*getting better*'. Acknowledgement of the multiple origins of distress are provided; fundamentally the physiological critical illness, but the subsequent impact on muscle loss and therefore mobility and the profound, disabling delirium are striking components (Ramsay et al 2014).

Whilst discharge from critical care can infer the positive association of '*getting better*', for many the transfer was simply an inevitability over which the patient and their family had no control (McKinney and Deeny 2002). Indeed Lin et al's (2013) ethnographic paper reports that competing priorities, (other than the patient's readiness for discharge) influenced the discharge process, in particular competing demands for critical care beds. The overall recommendations from Lin at al's study include the need for registered nurses (in critical care and ward areas) to develop greater situational awareness to improve the quality of patient discharge from critical care with team work and effective communication being central. Whilst cognitive artefacts such as discharge summaries were in place they were found not to be used effectively. With increased pressure on critical care beds in the UK becoming ever apparent (ICS 2015), it appears likely that the '*relocation stress*' (McKinney and Deeny 2002 p320, Mitchell et al 2003) experienced by patients and families is likely to continue. The role of a Critical Care Family Liaison Nurse is described in Mitchell's (2005) invited editorial where she highlights a single centre of outstanding excellence at St Vincent's medical centre, Massachusetts, USA. This does, however, appear to be aspirational rather than transferable in the current economic climate here in the UK. In Australia, the role may be subsumed within the Rapid Response Teams (Eliot et al 2012) otherwise known as Critical Care

Outreach Team (CCOT). Here in the UK, however, CCOT are unlikely to know either the patient or the family, thus limiting any continuity. This is because the CCOT role in the UK is largely confined to detecting deteriorating patients prior to AGCCU admission.

Challenges are not restricted to patients and family members; Haggstrom et al's (2012) grounded theory study utilised focus groups of critical care nurses and found that they were forced to compromise their care at the point of transition due to workload pressures. Whilst critical care nurses strove to "*be[ing] perceptive and adjustable*" in order to individualise care and promote recovery some staff felt inadequate in preparing relatives for the transfer and felt that written information might be helpful. Here in the UK, ICU Steps (a patient and relative founded charity) and the Intensive Care Society (a health care professional UK based charity) provide useful written information for both patients and family members but as discussed by Lin et al (2013) above they do not necessarily reach their target audience. Patients and family members in this study stated they received no written information regarding recovery from critical illness or around the transition from AGCCU to lower dependency areas of care.

Ward nurses consistently reported that they did not have the time to complete the amount of physical care needed in relation to patient dependency. Some ward nurses also appeared frustrated by the level of dependence some patients exhibited (Haggstrom et al 2012). The level of nursing presence in ward areas being a stark contrast to the very obvious presence of critical care nurses (Cutler 2013).

Many, but not all, patients and families experienced an important contradiction on discharge to ward areas. They are generally speaking '*making progress'* and yet patients consistently describe feelings of anxiety, vulnerability, and helplessness (Endacott 2011). A potentially key part of successful ward transition may lie in McKinney and Deeny's (2002) suggestion of empowerment to allow the patient to gain some sense of control. Johnson (2004) follows this up in her phenomenological study describing patients' need to know what is happening to them and that family

members and patients want, and need, relevant, and appropriate information and will seek this outside of critical care if not forthcoming. Current work around implementing user-centred critical care discharge information (Bench et al 2012) may be helpful in this respect.

The final critical juncture for patients and families is discharge to home. Deacon's (2012) qualitative study used an open ended questionnaire via two websites; namely 'ARDS Foundation' (Adult Respiratory Distress Syndrome) and 'ICU Steps' and received a global (first world) response (USA, UK, Canada and Australia). This revealed the need for further information so survivors can make sense of being critically ill, access to rehabilitation, both physical and psychological, and the need for some ongoing support or outlet. For some patients, the recognition of the significant burden that critical illness had placed on family members resulted in them requiring personal counselling.

Here in the UK, NICE Clinical Guideline 83 "Rehabilitation after critical illness" was published in March 2009. This guideline offers best practice advice on the care of adults with rehabilitation needs as a result of a period of in-patient treatment in critical care. Prior to this guideline, support only existed for clinical specialisms such as cardiac, burns and neuroscience. However, there is a general consensus that this has not been embedded or resourced effectively or consistently (Connolly et al 2014, Rattray 2014, Cotton 2013). This is despite studies reinforcing the requirement for early rehabilitation (Ohtake et al 2013). Needham et al (2012) and Hart (2014) go further to say that a model of survivorship is required in a similar fashion to that available to survivors of cancer, in order to address the long term effects of critical illness on both individuals and their families.

2.6.3 Physiological Sequelae

The physiological impact of critical illness has been well documented although there is limited consensus on how this should be addressed (Aitken and Marshall 2015, Needham et al 2012). Patients may experience a complex array of physical symptoms including pain, loss of mobility and loss of appetite and taste. Difficulties with speech, swallowing, eating and

sleeping are also commonly reported. In Strahan and Brown's (2005) phenomenological study patients reported significant sleep deprivation some of which linked to hallucinations and nightmares, and some to fear of actually going to sleep due to paranoia. Documentation of patients' sleep in AGCCUs is reported in the Ritmala-Castren et al (2014) quantitative study as being poor. This study found that nurses consistently overestimated the volume of sleep and were unable to assess sleep quality. Pain also prohibits sleep as evidenced by Strahan and Brown (2005). Sleep deprivation exacerbates the well-documented fatigue that patients experience post discharge from critical care (Cutler et al 2013, Rattray 2014, Misak 2014 and others) leading to a descending spiral of wellbeing.

Field et al's (2008) richly detailed narratives of '*One patient amongst many'* highlight the effects of profound muscle loss, and consequential weakness, that many patients experience. This qualitative study of forty critical care survivors provided accounts of the impact on patients of such physical weakness, enabling narration of their experiences and allowing health care professionals to learn from them. Patients articulated their vulnerability and inability to cope, in a ward environment, with staff not appreciating or understanding their inability to stand, or even lift a cup, when outwardly they may appear *normal*. Similarly, White (2013) and Misak (2014) published and presented widely their own experiences of critical illness. Misak's husband also provided an account of his own experience as a family member visiting critical care and living with the long term legacy of critical illness (Dyzenhaus 2014). Collectively they illustrate that the two journeys that may be experienced by a survivor and related family member. In addition, two sociologists have also published powerful narratives of their own individual critical care experiences. Rier articulated the value of a notebook (diary) which provided a concurrent record of his experience; a form of *inadvertent ethnography* (Rier 2000); (linking strongly with the development of Backman's work on Critical Illness diaries in Sweden (Jones et al 2015)). Richman (2000) was severely challenged by profound delirium which he described as "*dreams of affliction*" (p84) identifying himself as a *medical object* and *mechanical appendage* and recognising the power of technology.

He also acknowledged the support and kindness of nursing staff. He stated that nurses are in a strategic position to make patients' dream narratives an aid for understanding illness (Rier 2000, 2015, Richman 2000). These narratives are rich and insightful, and collectively may, and I suggest should, inform practice. What is evident is a difference in understanding the consequences of critical illness and the ability to support patients, and family members, both in the immediate aftermath of critical illness and the longer term.

An increased understanding of why muscle loss is so profound is slowly developing. The figure of muscle loss for patients in critical care being revised upwards to 2-4% per day (Rattray 2014). Intensive Care Unit – acquired muscle weakness (ICUAW) is described by Latronico et al (2014 pg. 259) however the pathophysiology is complex and still incompletely understood. Reported incidence depends upon the outcome measure used and can vary from 0.09% to 100%! (Latronico et al 2014). There is a well-documented need for agreed outcome measures in assessing all aspects of critical illness impact (Aitkin and Marshall 2015, Stevens et al 2014), a further demonstration of the research infancy of this subject area. The failure to consistently embed NICE clinical guideline 83 (2009) (Rehabilitation after Critical Illness) has already been alluded to. Rattray (2014), Connolly et al (2014) and Cotton (2013) confirm the lack of designated rehabilitation pathways for critical care patients and poor co-ordination across multi-disciplinary teams. However, there is consensus in the need for rehabilitation to start early and within the critical care unit (Needham 2012, Rattray 2014).

Patients receiving level three care in AGCCU require the presence of an endotracheal tube or tracheostomy. This is essential to maintaining a patent airway and therefore to patient survival. A significant contingent effect is the physical loss of voice; a key mode of communication for most people. Speech and Language Therapists (SLTs) undertook a mixed method study in the UK and reported patient frustration in losing their voice, leading to feelings of powerlessness and imprisonment. This was contrasted with the euphoria of regaining "*voice*" either naturally or artificially through a speaking valve (Magnus and Turkington 2006). Similarly, in Tembo et al's (2014)

phenomenological study of twelve critical care survivors, the theme of "*Being voiceless*" both literally and metaphorically pervaded. This exacerbated feelings of helplessness and evolved the theme of "*Being imprisoned*". Comparable findings are evident in Samuelson's (2011) larger qualitative study of two hundred and fifty critical care survivors. The inability to speak due to the presence of an artificial airway was a distressing bodily restriction for patients who were struggling, and failing, to communicate their needs. Once the breathing tube was removed patients still reported their struggle to communicate, unsuccessful attempts to formulate and pronounce words was a source of further distress and frustration.

Problems with appetite and taste are also frequently described (Strahan and Brown 2005, Samuelson 2011, Bench and Day 2010). Iatrogenic malnutrition in AGCCUs is acknowledged by Heyland and Mourtzakis (2014). Slowly an evidence base for feeding patients during critical illness is emerging, although a consensus is still lacking. Moreover, patients consistently report problems with re-establishing nutrition during the anabolic phase of recovery. Nutrition is, of course, explicitly linked with muscle activity; learning to breathe again, learning to move again all requiring muscle activity.

2.6.4 Psychological sequelae

A very high prevalence of psychological problems is reported in the literature for patients whilst in AGCCUs, on discharge to the ward, and during the recovery period in the community (Rattray 2014).

The incidence of delirium in patients during critical illness has been reported to be as high as 83% (Svenningsen et al 2014). The definition of delirium is drawn from NICE clinical guideline 103 as an *acute confusional state* of new onset. Delirium is a Latin word that translates to *going off the ploughed track* and has been described as "*brain failure*" (Ely and Page 2015). Ely and Page (2015), have researched and published extensively in this field and have highlighted different types of delirium prevalent in critical illness, namely;-

- *Hyperactive* - paranoid, agitated

  – Readily recognized, best prognosis

  – Purely hyperactive: 1.6% of delirium episodes

- *Hypoactive* - withdrawn, quiet, paranoid

  – "Quiet delirium"

  – Often not well recognized, misdiagnosed

  – Purely hypoactive episodes 43.5%

- *Mixed* - combination

  – Most common in critical care patients 54.9%

  – Worst prognosis

The literature contains many reports of critical care patients' transformation of perception, of unreal experiences, dreams and hallucinations (Belanger and Ducharme 2011, Bergom and Askwall 2000, Chaboyer and Grace 2003, Cutler at al 2013, Engstrom et al 2011, Hofhuis et al 2008, Johnson 2004, Jones 2003, Jones 2014a, Karlsson and Forsberg 2008, Williams 2009, Lof et al 2008, McKinney and Deeny 2002, Misak 2014, Olsen 2009, Pathanassoglou 2010, Ramsay et al 2014, Rattray 2014, Roberts and Chaboyer 2004, Rose et al 2014, Svennigsen et al 2014, Uhrenfeldt et al 2013, Wade et al 2012). Many patients reported on their inability to distinguish reality from hallucination or dream, consequentially this became the lens through which they remembered their critical illness. As we know from Storli et al (2008) these memories have both accuracy and longevity. The profound delusions and paranoia experienced by some patients have recurring patterns. The *capgras delusion* where patients believe all the people around them are identical is reported by Jones (2014a) and is evident within this study. Misak in her personal account (2014) describes the profound and terrifying delusions that related to her own safety. She highlighted the importance of making sense of these delusions as soon as possible, as often they did have a link with reality, a point confirmed by Jones

(2014a). Misak spoke of the relief in being able to place the memory in the '*correct box*'.

Wade et al's (2012) prospective cohort study revealed high levels of psychological morbidity; 55% of 157 mixed diagnosis critical care survivors demonstrated symptoms of which 27% had probable Post Traumatic Stress Disorder (PTSD). Wade and her colleagues were able to discern independent risk factors for both PTSD and depression. Polypharmacy including benzodiazepines, steroids, and use of inotropes together with the physiological changes associated with critical illness, in particular, infection, are known to be associated with delirium (NICE (CG 103) 2011, Cutler 2013,). The dilemma is, of course, balancing physiological need against psychological harm. Further necessary research is proceeding to refine practice in this area.

Roberts and Chaboyer (2004) conducted telephone interviews in Australia with 31 survivors of critical care between12 and18 months post AGCCU discharge. 74% of participants recalled dreams and hallucinations, somewhat higher than the 21% reported by Rundshagen et al (2002). This may be attributed to the latter study's inclusion of predominantly emergency admissions against the former inclusion of all critical care admissions (elective and emergency). This thesis relates solely to emergency admissions to adult general critical care. All patient participants (n=16) in this study, reported some form of delusion, hallucination or dreams.

The literature reveals two strategies that may assist patients in minimising the longer term psychological impact of critical illness. Both of these remain contentious in the literature and in practice. The construction of coherent narratives of the experience of critical illness is recommended by Williams (2009) who, as part of her doctoral research and with a background as a clinical counsellor, argued that story construction is central to a person's core identity processes. Memory loss and memory derangement are barriers to this process and the use of patient diaries is a hotly disputed intervention in AGCCUs. The recently-published Cochrane Review "*Diaries for recovery from critical illness*" (Ullman et al 2014) argues against routine use of patient

diaries until a body of evidence is developed - an argument developed further by Aitken et al (2013). By contrast Jones et al (2015) report from the Third International Intensive Aftercare Conference in Norrköping, Sweden states that diaries are an established and accepted practice in AGCCU. The inception and development of this intervention came from initial work by Carl Backman. This has been further developed across Scandinavia (Egerod et al 2011), Germany and Switzerland and (to a lesser extent) in the UK with tentative recommendations in the ICS "*Guidelines for Provision of Intensive Care Services"* 2015. Intuitively it confers several benefits to the patient but has perceived logistical and legal contentions by practitioners Nydahl et al (2014).

The second intervention relates to family presence and is discussed in 2.6.5.

2.6.5 Family Presence

The presence of family members in critical care and the role they play in relation to patient interaction has received some attention in the literature although much more is focused on meeting the needs of family members (see 2.5.6). There does appear to be consistent evidence that family members provide a "*lifeline to reality"* (Bergom and Askwall 2000, Eriksson et al 2011, Hupcey 1999) although some patients have no recollection of the presence of family members at all during their stay in critical care (Roberts and Chaboyer 2004).

For family members to be present, they obviously need to gain access to the critical care unit. This continues to be an area of contention and variable practice. As a member of a national guideline group I was involved in the publishing and presenting the recommendation for individualised, open visiting in AGCCUs (BACCN 2012) however, there continues to be much controversy and variation around the practice of open visiting (Stock 2004). Capellinie et al's (2013) global literature review revealed that 70% of Swedish critical care units favour open visiting, whilst in Italy the percentage is less than 1%. Indeed, visiting may be restricted to less than one hour a day in countries such as Greece, resulting in vigilant attendance outside of critical care and access denial leading to alternative strategies of coping

(Plakas 2014). Plakas' constructivist grounded theory study identified vigilant attendance outside the AGCCU in Athens due to highly restrictive visiting. In the Netherlands, a telephone survey (n=105) revealed 86% of Dutch Critical Care Units had restricted visiting (Spreen and Schuurmans 2011). In France, physicians argue for unrestricted visiting (Schnell et al 2013). Here, in the UK, Hunter et al (2010) undertook a postal questionnaire to 271 critical care units that revealed 19% of adult Critical Care Units had open visiting. One can only suggest that the volume of research from Sweden may have indeed, impacted positively in allowing families to be present at the bedside in adult critical care.

Vandall-Walker's grounded theory doctoral study from Canada identified "*work*" as the core category for family members; central to this "*work*" is gaining and maintaining access to their loved one (Vandall-Walker and Clark 2011). She exhorts registered nurses to support family members by removing barriers and developing partnering opportunities. However, this is an area of discord as illustrated in Agard and Maindal (2009), Agard and Lombard (2011), Buckley and Andrews (2011), Kean and Mitchell (2014). Some registered nurses feel unable to support family members in critical situations; particularly when the patient is deteriorating. Many spoke of the shifting context of critical care with the situation changing on a minute-by-minute basis (Agard and Lomborg 2011) and their attention changing between patient and family member. Similarly in Wong's (2015) grounded theory study in Australia, family needs became secondary to patient's primary physiological wellbeing. Perhaps, not surprisingly, Stayt's (2007) phenomenological study of registered nurses working within AGCCU reported conflict between their professional and personal self; essentially a disparity between professional ideals and being human. Much of the literature urges integration and active involvement of family members and yet less attention is given to the impact this may have on occupational stress working within AGCCUs.

Little attention has been paid to patients who have no visitors whatsoever. One study to discuss this phenomenon is Eriksson and Bergbom's (2007) prospective observational study, which found that 25% (n=198) of patients

did not receive visitors; however the study recruited both elective and emergency admissions. It is possible that as an elective admission there was a conscious decision not to visit, nevertheless, patients without visitors were significantly older, more likely to be female and live alone. As a quantitative research design, there was no opportunity to understand the experience but there was no increase in length of stay which was one of the measures used to determine impact of family presence.

2.6.6 Beyond meeting the needs of family members

There is a significant volume of literature which relates to the needs of family members in critical care. Initially, this was dominated by Nancy Molter's development of the quantitative research instrument Critical Care Family Needs Inventory (CCFNI) published in 1979 in the USA. This was further developed by Leske, during the 1980s, and continues in use today (Yang 2008). This quantitative research instrument was heavily criticised by me (Wilkinson 1995) and others (Burr 1998, Coulter 1989) because the series of need statements were derived, initially, from a survey of 23 graduate critical care nursing students (Berry 2010).   As a natural consequence of the replication of studies using this tool much research has focused on meeting the needs of family members.

There has been a slow realisation that family members are not just passive bystanders. They can contribute to the physiological and psychological well-being of their relative and, therefore, should be seen as partners in care. Moving away from this paternalistic stance is likely to take some time but there is growing body of work which is urging us to do so (Vandall-Walker and Clark 2011, Eldredge 2004, Davidson 2010, Williams 2005, McConnell and Moroney 2015). This new generation of literature is urging registered nurses to support a *"facilitated sensemaking";* identified as a core category in Davidson's (2010) grounded theory study. Davidson's study promotes the primary long term goal of preventing adverse psychological sequelae such as anxiety, depression and PTSD in family members, which may enhance satisfaction with care or provide comfort. The study also confirmed RN's discomfort in not knowing how to meet family members' needs or to work in

partnership with them. The core category of '*facilitated sensemaking*' is explained as a dynamic, reflective and iterative process, allowing an interpretation of the situation. It is more than just information provision. The ability of registered nurses to pick up on non-verbal cues is discussed by Wong (2015) but the questions raised by Stayt (2007) remain; in terms of staff resilience and their ability to maintain emotional literacy in a rapidly changing clinical context.

Evidence can be found in Mitchell et al's (2009) pragmatic clinical trial, (involving 99 family members in the intervention arm and 75 in the control group) that partnership working with patients' family members improves family-centred care, respect, and support. However, there were differences between groups in relation to patient age, and the severity illness scores of the patient, between the two groups which may limit reliability of results. Family members who were partners in care perceived the greatest overall improvement in family centred care, respect, and support. On a more cautionary note, there were also gender variances that were not explored and may be a further limiting factor. Similar results are however reflected in Vandall-Walker and Clark's grounded theory study where for most family members more involvement in care was preferred. Registered nurses were considered to be in the best position to advise which activities family members may be involved with and can support '*the work'* of providing care (Vandall-Walker and Clark 2011). They identified the significant workload shouldered by family members and the energy expended to complete their *work* which was categorized as; gaining access to their relative, needing to be present, patient related work, nurse/physician related work, and self – related work (Vandall-Walker and Clark 2011).

Eldredge's (2004) quantitative repeated-measures design indicates that closeness and helpfulness are integrated concepts in the partners of critically ill patients and are theoretically linked to Bowlby's attachment theory (Kaya 2012). Here the goal is to gain physical or emotional proximity with a partner when the need for security arises. Registered nurses are clearly key gatekeepers in this respect. This remains a contentious issue as highlighted

in 2.5.5 and in Riley et al (2014). Levy, an American intensivist who experienced visiting a critically ill relative claims;

> *"The environment in our ICUs often serves the convenience of the [ICU] staff... rather than the ...family unit, the objects of our care. Why is it that ICU professionals believe their presence by the bedside to be more important than that of the family member?" (Levy 2013)*

In addition to family presence or '*being there*' there is the need '*to know'*. Information flows between health care professionals and family members are highly valued and imperative to construction of understanding or '*sensemaking*' (Blom et al 2013, Davidson 2010, McKiernan and McCarthy 2010, Weick 2005). One barrier to effective communication is the consistently reported '*shock*', (Wilkinson 1995) that family members experience on receipt of the information that the loved one is critically ill, and again, on visiting their relative. This sense of confusion can initially be overwhelming, before coming to terms with critical illness referred to as the '*knowing and not knowing*' by Engstrom and Soderberg (2004) in their qualitative study and learning to live a *'changed everyday life'*. The alternation between hope and despair often referred to as an emotional roller-coaster is a common metaphor for the extremes of emotions experienced by family members.

Interruption or denial of information (perceived or actual) is a significant stressor for family members (McKiernan and McCarthy 2010). Morse (2001) discusses the suffering of family members in critical care and articulates a praxis theory of suffering, as illustrated in Figure 2.4.
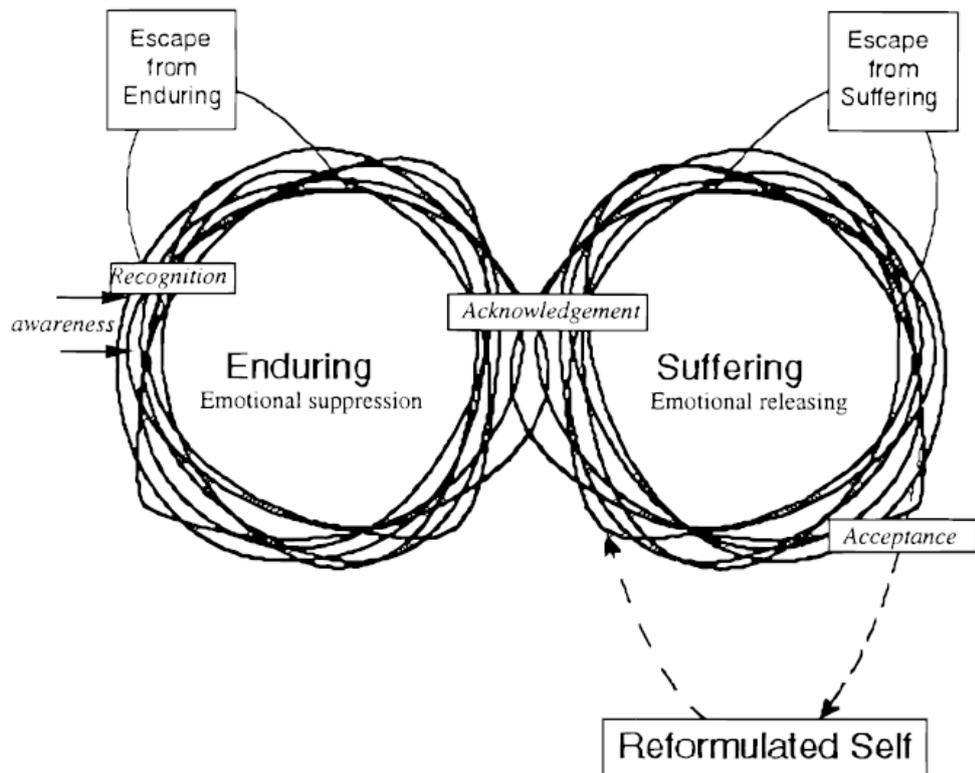
Figure 2.4 Model of Suffering (Morse 2001)

These two behavioural states may reflect the roller coaster of emotion so commonly referred to in practice by both registered nurses and family members. Endurance, Morse (2001) suggests, is a strategy that enables the person to do what must be done and provides control of the situation. In contrast, suffering manifests itself as emotional release. Ability to recognise the differing phases of suffering, and respond to them, is suggested to be an advanced nursing skill and may explain some of the discomfort experienced by registered nurses in critical care (Stayt 2007, Agard and Maindal 2009, Agard and Lomborg 2011). Further understanding of the emotional labour of caring, and supporting both family members and patients, in critical care is needed with much evidence that registered nurses feel unprepared for these roles (Williams 2005). Clearly, there are educational implications in understanding when and how comfort is offered to those who are suffering.

2.6.7 Technology v Humanity

Advanced life support requires highly technical equipment; this, in turn, necessitates skilled interpersonal interaction to ensure patient safety (Tunlind et al 2015). The debate around the art of nursing in a technological age is well articulated by both Henderson (1980) cited by Timmins (2011) and further by Sandelowski (1997) who considers the *"ir/reconcilable differences"* concerning nursing and technology. Technology seemingly progresses and provides both opportunities and threats to the critical care "*family*" (Cypress 2010); dehumanisation by technology is perhaps the greatest threat to the well-being of all members of the triad. To quote one of Stayt's patient participants in her interpretative phenomenology study;-

> "*I felt just separated from it; I didn't know what was going on and the person that they were discussing, the person attached to the machines wasn't me, like it was somebody else. It was like being in a world that wasn't real*" (Stayt 2012 p284).

A dualist view of the art and science of critical care nursing is called for by Tunlind et al (2015) and others. This approach is challenged in Chapter 7 and concurs with McGrath's (2008) qualitative study of ten registered nurses in critical care.   McGrath concluded that experienced critical care nurses were able to transcend the obtrusive nature of technology and deliver expert care to their patients. However, the journey to humanistic, technological proficiency was very demanding and novice nurses had difficulty in caring **with** technology. This raises the question of what happens to those nurses (and the patients and family members) who do not successfully complete that journey.

Tunlind et al (2015) interviewed eight experienced registered critical care nurses. This qualitative study revealed technology to be a security and utility but acknowledged that this sense of security can be false. It revealed that technology can be an obstacle to nursing work; a source of frustration and stress permitting a '*clinical gaze*' (Foucault 1980 cited by Adams et al 2015) enhancing the balance of power against the patient and novice registered

nurses. Reassuringly, experienced registered nurses were able to discern clinical reality from mechanical disconnect and were vigilant in determining patient status from their own experiences. However, Browne and Cook (2011) warn that experienced practitioners may display inappropriately high levels of trust in technology. This reiterates the question concerning less experienced registered nurses and their journey to develop such expertise.

The AGCCU has been described by survivors as '*incomprehensible and sometimes frightening'* with technology bringing about a '*forced dependence*' (Almerud 2007). The importance of (re) forging the bond between the science and the art of nursing is emphasised citing the Heideggerian belief that the two are not mutually exclusive and that they belong together given that technology is both *"a means to an end"* and *"a human activity"* (Almerud 2007)

The physicality of technology can literally become a barrier to caring. In Eriksson et al's (2010) observational study they noted the critical care setting was not welcoming and witnessed family members' being fearful of interfering with technology which was perceived as life sustaining. They claim that health care professionals may view the patient's body as a measurable object, with the focus being on the monitoring equipment and not the individual. Whilst this is not new knowledge, it does further illustrate a potential disconnect between relative and patient as technology obstructs the interplay between them with the potential for similar negative impact between RN and patient (Eriksson et al 2010). Strategies to address this include creating a healing atmosphere through '*spontaneous compassion*', described by Eriksson et al (2010) as nurses and relatives doing '*something out of consideration for the patient's condition and needs, without any wish for personal gain*' (p55).

2.7 Commentary

The diversity of literature reviewed indicates that this is not a unified and consistent body of knowledge. Nevertheless, there is an expansion of knowledge evident between 2000 and 2015 and ongoing. This review has allowed the commonalities and differences within this body of literature to

become explicit. In many instances though, the focus has been on the experience of healthcare rather than the experience of illness; Storli (2008) being the notable exception. Importantly, understanding an experience in terms of meaning does not necessarily rely on factual recall of the situation. As humans, we share ways in which we derive meaning, a core aspect of Symbolic Interactionism which is discussed in 3.5. It is argued throughout this thesis that personal meaning is not objective or rational but contextual and individual. There is clearly scope for further research in deepening what is known about the way people understand their critical care experiences through the personal meaning it has for them.

2.8 Summary and Conclusion from literature review

The preceding literature review has considered seven emerging themes and enhanced my theoretical sensitivity to issues for the triad of family members, critical care registered nurses and survivors of critical illness. As humans we do not live an isolated life, we are interdependent upon each other. Such dependence becomes more evident in critical illness. Patients are highly dependent upon registered nurses for their physical and psychological well-being. Family members are dependent on registered nurses for access to their loved ones and developing a construct of understanding for what life is like during, and following, illness. Departure and transition from the critical care unit, and the '*family*' (Cypress 2011) that has been established remains problematic for some patients and their families. The journey can be challenging for many of these families with no consensus on a rehabilitation pathway (Rattray 2014). For registered nurses in critical care the development of technical expertise in safely caring for patients, while sustaining emotional literacy to demonstrate compassion with family members, patients, and life, is challenging (Ball and McElligot 2003, Almerud et al 2007, McGrath 2008).

This inclusive review of the literature has highlighted lacunae (e.g. transitional care) and areas of disagreement (e.g. family presence and patient diaries) both in the literature and in clinical practice in relation to the critical illness trajectory as experienced by survivors of critical illness and

their families. Importantly, it has enhanced my theoretical sensitivity; this refers to a personal quality of the researcher. It indicates an awareness of the subtleties of the meaning of data. This activity allowed me to develop an enhanced sensitivity to data that assisted in theory generation (Glaser 1978).

Confirmation that caring for the patient and family members are intertwined has been established, but little is known about the patient and family member collective trajectory (Rattray 2014). Gaps in this knowledge have been addressed in this study using a grounded theory approach to explicate the journey that patients and their family members' experience. This study seeks to enrich existing knowledge and identify unique explanatory theory.

Features of the design of this research include the ability to explore complex human interactions in the real world of clinical practice and beyond. Understanding the phenomenon from a holistic perspective enhances the likelihood of revealing the complexity of the critical illness trajectory and the survivorship journey. Chapter three presents a detailed description of the methodology choice and underpinning theory of Symbolic Interactionism recognising that meaning arises out of social interaction with each other.

Chapter Three Methodology

3.1 Introduction

This chapter sets out methodological choices which I have made in order to address the research questions outlined in chapter one, namely; the critical illness trajectory as experienced by patients and family members, and critical care nurses' response to the needs of patients and their families. A brief introduction to qualitative research is followed by ontological and epistemological views of this research paradigm. Further detail around ontological and epistemological frames together with a descriptive account of Symbolic Interactionism can be found in appendix three. A historical perspective of grounded theory is located in appendix 4. Justification for the chosen theoretical framework together with the related research design is presented. The context and principles of constructivist grounded theory as offered by Charmaz (2014) are detailed concluding with strategies to ensure methodological rigour.

3.2 Qualitative research

At a simplistic level qualitative research constructs theory, quantitative research tests it (Morse and Field 1995). Therefore, qualitative research is not hypothesis led but is an examination of the 'what, why, when, how' of a phenomenon rather than 'how many' and 'how much'. The social constructs of reality together with the relationship between researcher and phenomenon shape the inquiry with no attempt to hold variables constant as this would deflect from the dynamic nature of human enquiry (Denzin and Lincoln 2011).

Consideration was given to different forms of qualitative inquiry but particular attention was paid to three main qualitative approaches which tend to address different types of questions. Phenomenology, derived primarily from philosophy and psychology, mainly looks at 'meaning' questions and tries to elicit the essential meaning of an experience for participants. By contrast, ethnography originating from anthropology is interested in answering

descriptive questions around issues such as values, beliefs, and practices of a particular cultural group within a given context (Denzin and Lincoln, 2005). Neither of these approaches seemed to address the central issue in the present study, that is, to understand the social processes during, and following, critical illness from the perspectives of multiple participants. Grounded theory, developed from sociology, is well suited since it primarily deals with 'process' questions and experiences over time and attempts to inductively and abductively develop a theory which is grounded in data and also has the potential to inform ways of generating action to, if necessary, alter the way that processes act in the social world (Glaser, 1998). Capturing the nature of human behaviour is clearly complex (Handberg et al 2015) and this holistic study is undertaken to develop a comprehensive depiction of the complexity of the critical illness trajectory.

A fundamental assumption of qualitative research is that the researcher is the instrument of the study and understanding the relationship between researcher, context, and participant is a central tenet (Paulus et al 2014). Engaging in the process of reflexivity makes this relationship more transparent. Reflexivity is deemed to be an intentional process attending to the perspectives, attitudes, and beliefs that shape research design and data collection and analysis. This adds transparency to the research process and in particular, helps address quality issues.

While Finlay (2003) highlights the contested nature of reflexivity, the following has been generally accepted as the definition adopted in this work. '... *reflexivity implies rendering explicit hidden agendas and half-formed intentions ... this should be a continuous endeavour'* (Gough 2003 p25).

Further, the view that qualitative research is interpretive and grounded in the lived experiences of people is well supported in the literature (Bryman 2008, Denzin and Lincoln 2011, Gelling 2015, Welford et al 2012). The main focus of this study to elicit the *social* processes surrounding the critical illness trajectory and to *describe* and *explain* not *evaluate.* Utilising an inductive, constructivist approach demonstrates philosophical congruence. Choices

relating to epistemology, methodology and methods in relation to this study are discussed in appendix three.

One of the main criticisms of qualitative research, in general, is the potential for the subjectivity of the researcher to influence the data. However rather than striving to enhance the validity and reliability so valued within quantitative research, the researcher needs to develop *theoretical sensitivity* (see 3.9*)*. In addition, prior to commencing the study, establishment of my personal philosophical position is vital (Birks and Mills 2011). Further, how I perceive myself and how I am perceived by others, matters and will impact on my ability to form relationships with research participants. Reinharz (1997) ask the question '*Who am I?*' and draws attention to the various 'selves' that we present in a research situation;-

- Research based selves: mature Ph.D. student, a nurse educator not directly attached to the AGCCU, being a listener, being a nurse with critical care experience.

- Brought selves: being a wife, mother, member of a family, female, white, British, 35 years' experience as a nurse and experience in teaching, management, and critical care nursing

- Situationally created selves: being an outsider, being a nurse, being a researcher, being a listener.

Positioned within this philosophical paradigm of constructivism, I, the researcher, strived to minimise the distance between researcher and researched (Denzin and Lincoln 2011). As a constructivist I reject the notion that there is objective truth waiting to be discovered; rather that meaning is co-constructed by both the researcher and the participant (Crotty 1998, Lincoln and Guba 1985). Therefore rather than a post-positivist approach to grounded theory, which suggests that there is an objective reality existing outside of human perception, a constructivist and post-modernist stance is assumed. This is a relativist position, where reality is understood as "*relative to a specific conceptual scheme, theoretical framework, paradigm, form of life, society or culture………there is a non-reducible plurality of such*

conceptual schemes" (Bernstein, 1983 p8). As the researcher, I am an active participant in data generation with participants, and the reality is one that is constantly reforming as a fluid construction of individual responses. This reflects the theoretical framework of Symbolic Interactionism which will be discussed further in section 3.3.

Within the context of this study, each participant may view and hold a different perspective on the critical illness trajectory. This may be influenced by context and time and with whom they share the journey. The nature of what is real to the researcher and the participants is context specific and dependent on multiple and possible conflicting realities. As the purpose of the study is to explore the critical illness trajectory from a holistic perspective, an ontological position that acknowledges and equally values perspectives is required. Qualities of the constructivist paradigm are outlined in Table 3.1.

Aim of inquiry	Understanding; reconstruction
Nature of Knowledge	Individual reconstructions, coalescing around consensus
Knowledge accumulation	More informed reconstructions; vicarious experience
Quality criteria	Trustworthiness and authenticity
Values	Influence accepted
Ethics	Intrinsic: process tilt towards revelation; special problems
Voice	Participant as facilitator of multi voice reconstruction

Table 3.1 Constructivist paradigm position on selected issues (adapted from Lincoln and Guba 2005)

Capturing the nature of human health behaviour is acknowledged as being complex (Handberg et al 2015). This study took a holistic attitude to obtain the most comprehensive depiction of the complexity of the critical illness trajectory. Symbolic Interactionism recognises that reality is seen as a social, developed interaction with others and provides the underpinning

framework for this study. The central tenets of Symbolic Interactionism are outlined in appendix three.

3.3 Application of Symbolic Interactionism

In the complex world of critical illness, survivors often struggle to make sense of their new world post critical care. In contrast, family members have often lived all too vividly through the time spent in AGCCU. From a symbolic interactionist perspective, I sought to describe and understand those experiences which may vary between survivor and family member. Meaning may be ascribed through the use of in-depth interviews but recognising that meanings are assigned and modified through a process of interpretation since the data is a construction between researcher and participant (Charmaz 2014, Crotty 1998). It is relevant to consider the social, cultural and historical contexts and the effects that this may have on the researcher – participant relationship. Examples include previous exposure to critical care by patients and family members. One survivor, Harry, had a previous critical care admission in a different AGCCU five years previously. He had intact memory of the profound dreams and hallucinations that he experienced on that admission. His partner, Sandra, as a consequence was less concerned about the obvious hallucinations he was experiencing whilst on AGCCU.   As previously acknowledged, meanings are not static but dynamic; there is recognition of the relativity of varied standpoints and the need to take into account the subjectivity of social actors as they engage with the world (Charmaz 2014, Handberg et al 2014).

Central to the concept of symbolic interactionism is the concept of the "I" and the "Me" where the "I" is spontaneous and more instinctual; less concerned with what other people think of you. In contrast, the "Me" is more socially aware, more deliberately and socially symbolic. There is, of course, no "Me" at birth; this is co-constructed through repeated social interaction with others. From a symbolic interactionist perspective, the "I" and the "Me" make up the "looking-glass self" which can reveal the multiple reflected images that we believe others hold (Charmaz 2014).

The participants in this study may have differing perceptions of themselves as a result of critical care experiences. Survivors can find themselves in a temporary liminal state between illness and health, family dynamics can change or reposition as family members can become protectors of their relative. Registered nurses are likely to conceive themselves as health professionals holding professional values but may be in conflict with their emotional self. Their own individual perceptions will have shaped their accounts and stories. Such is the complexity of the phenomenon under investigation that it would be impossible to hold the realities or systems involved in isolation whereas symbolic interactionism acknowledges that multiple realities exist and that meaning is socially constructed. As Blumer stresses, social interaction forms human conduct; it is dependent upon spoken and unspoken shared language and meanings. This further validates the use of in-depth interviewing as a suitable data collection method for this study.

Mead (1863-1931) and Blumer (1900-1987) were both affiliated to the sociology department at the University of Chicago and had a significant influence on Strauss who worked with Glaser to '*discover'* grounded theory (Heath and Cowley 2004, Charmaz 2014). The theoretical and historical background to grounded theory can be found in appendix four.

This study explores the critical illness trajectory from a holistic, dyadic perspective. A constructivist approach facilitates valuation of all perspectives and promotes development of shared meanings between participants. Thus, the constructivist approach is highly appropriate.

In summary, this section demonstrates familiarity with the three major approaches to grounded theory. The positivist interpretation espoused by Glaser lacks congruence with my constructivist philosophical perspectives articulated in section 3.2. Further, the concept of theory emerging from data in a detached way is at odds with my world view that multiple realities are co-constructed and interpreted in an interactive process (Crotty 1998). The pragmatic- symbolic interactionist predilections of Strauss and Corbin (1990) do demonstrate some philosophical congruence however the process of

analysis and coding is overly prescriptive, unlike Charmaz's constructivist interpretation which gives both focus and flexibility. The next section details further this latest variant of grounded theory.

3.4 Constructivist Grounded Theory

Constructivist Grounded Theory takes an epistemological position of subjectivism, meaning that we understand that researchers cannot be completely objective, rather it is acknowledged that an interrelationship exists between the researcher and the participant (Gardner et al 2012, Mills et al 2006). Ontologically a relativist position is assumed, meaning that we can only understand concepts such as reality and truth within a broader framework, which is contextually positioned within a certain time, place, and culture (Charmaz 2006).

Kathy Charmaz's constructivist approach is contended as a major redefinition of grounded theory (Higginbottom and Lauridsen 2014). A central tenet of constructivist grounded theory, and of this research study, is to give voice to participants (see table 3.2). Charmaz (2006) has encouraged grounded theorists to incorporate the multiple voices, views and visions of participants in rendering their experiences. In so doing, constructivist grounded theory has moved significantly from the original intent of the classic methodology (Breckenridge et al 2012, Cutcliffe 2005). Glaser (2012) is very critical of this approach claiming that "*Charmaz talks the talk of conceptualisation, but actually walks the talk of descriptive capture".* However to take an objectivist approach inherent within classic Glaserian approach I would need to '*get inside'* the heads of my participants to discover the truth. Given that the world of critical illness and families is both complex and involves multiple social interactions a constructivist rather than objectivist approach is justified.

The substantive differences between and objectivist and constructivist grounded theory are illustrated in table 3.2.

Version of grounded theory	Constructivist grounded theory (Charmaz 2006, 2014, Birks and Mills 2011)	Objectivist grounded theory (Glaser and Strauss 1967, Glaser 2012)
Research Paradigm	Interpretative	Positivist/Post-positivist
Role of researcher	Interactive, participatory and reflexive	Passive, objective and detached
Analysis	Codes and categories are actively **constructed** through an interpretative process	Codes, categories, and patterns passively **emerge** from the data
View of theory	Theory is **constructed** and represents a re-construction of multiple realities	Theory is there to be **discovered** and represents facts of a real and external reality

Table 3.2 Comparison of constructivist and objectivist grounded theory (adapted fromThomson 2014)

Having established the role of the researcher in this study as being participatory, it is appropriate to provide a reflexive account of the potential conflicts in being both a novice researcher and a professional registrant in the field of critical care nursing. These are referred to as the emic (insider) and etic (outsider) perspectives (Spiers 2000). As a critical care nurse investigating the critical illness trajectory I can be described as an '*insider*'; engaging and relating to a community of which I may be considered a member. I am at the same time an '*outsider*' to the truths and perceptions of family members visiting AGCCU and survivors experiencing critical illness. The insider- outsider or practitioner- researcher position has both advantages and disadvantages (Spiers 2000) and these are discussed in section 3.5.

3.5 Insider – Outsider perspectives

The art and science of nursing, as a whole, is oriented to supporting those who experience changes in health and well-being (Morse and Johnson 1991). This study is focused on the survivors of critical illness and family members who experience the full journey, or roller coaster ride, of critical illness. Subsequently, how this experience is understood by registered nurses in critical care is also explored and explained. These experiences cannot be captured in any depth by a biomedical or quantitative approach and justification for a qualitative approach and specifically a constructivist grounded theory approach has been made in sections 3.2, 3.3 and 3.6.

As a professional registrant for some thirty years, with a clinical background of both general and specialist intensive and critical care I have '*a priori'* knowledge that can both benefit and bias my thinking and interaction with participants. It is important that I both mitigate and account for the effects of such prior knowledge. The benefits include knowing and understanding how critical care units operate which indirectly, aided gaining access to research participants. Having gained formal ethical approval via the Integrated Research Application System and Research Ethics Committee (see section 4.2.1), I then sought to informally, negotiate my way into the field of research, referred to by Pope and Mays (2006) as '*getting in and getting out'* of the research field. Ethical approval alone does not facilitate access (Bailey 2007). Developing and building trust with a range of staff, from the outpatient manager to the team of critical care consultants, and, importantly, the secretary who arranged follow up appointments were all pivotal to the recruitment of participants in the study. Whilst effective communication skills are imperative for interviewing they are also essential for effectively negotiating the path to commence face-to-face interviews (McCallin 2003). There is also a requirement for resilience as gaining what may appear, at face value, to be a simple request for a room in an outpatients department required active pursuit and persistence!

In a similar vein, whilst formal ethical approval was effectively achieved, getting *'into the field'* required a more local negotiation by attending the weekly critical care meeting with critical care consultants and lead nurses. I should add that I sought to discuss the study at these meetings; it was not a prescribed prerequisite. This proved more challenging than formal ethical approval. Primarily this was due to an inherent lack of understanding of qualitative research methodology and the associated processes, particularly in relation to sampling and research bias. This is not an uncommon experience particular as medical colleagues have limited experience of qualitative research and similar challenges are reported in the literature (Bailey 2007). Despite some incoherent mutterings and raised eyebrows access was effectively negotiated. I did come away from the meeting feeling somewhat challenged but in many ways more resolved to give participants a voice. It is encouraging in 2016 to hear medical colleagues in the field of critical care acknowledge the limitations of their positivistic education and how this *'incites distrust'* (p 147) in qualitative research (Charlesworth and Foex 2016). On reflection, I believe it was important to navigate through this informal process of access negotiation to ensure maximum transparency and prevent any potential misunderstandings during the course of data collection and beyond.

My professional background also provides me with access to the language and terminology of critical care *'jargon'*. This was particularly apparent in the interviews with the staff who knew that I had a critical care nursing background and frequently sought to talk *'with me'* not *'to me'* about their nursing experiences in critical care. This can be a double edged sword as it undoubtedly provided rich data but, as a novice researcher, I was required to view the data with *'fresh eyes'* and avoid assumption making. There is also the contentious issue of power and trust in the relationship between researcher and participant (Hall and Callery 2001, Karnieli-Miller et al 2009, Johnson 2013). This will be discussed further in chapter 4.7.5. Whilst I did not work clinical shifts within the AGCCU in the study I was known to some of the nursing staff through my role as educator at the regional University. This may have influenced the relationship developed at interview.

As a researcher and educator (etic perspective) I have held a long term research interest in the social processes under investigation and have familiarity with the literature particularly from Scandinavia (Agard and Harder 2007; Blom et al 2013; Engstrom and Soderberg 2004; Engstrom et al 2011; and more see 2.3). Such research has provided rich descriptions of patient and relative experiences. The debate around engagement with the literature in the context of a constructivist grounded theory has been articulated in chapter two. The formal and more expansive literature review allowed theoretical sensitivity to be enhanced, and this concept is discussed further in the next section. Certainly the comparison between data and literature was helpful (a form of constant comparison, since '*data is everything*' (Glaser 2012)) in the generation of knowledge gaps and collating a summary of key themes (see appendix two). I entered the field having insight, but also carrying assumptions around the patient and relative experience of critical illness and the knowledge that staff had of these experiences. Such knowledge gave me an insider perspective that would have been missed by an '*outsider*'. Further, I was accustomed and familiar with the sights and sounds of a critical care unit. The challenge for me was to not allow my perspectives as a practitioner to impinge on the research and this required self-monitoring and support from supervisors. However whilst I may seek to achieve "*empathetic neutrality*" (Ritchie et al 2014) I recognise this can never truly be achieved – as indeed the transcripts reveal. Exposure to thick, rich, descriptive and at times, distressing data challenged me to remain in the '*etic*' or researcher role and there is evidence of taking on an '*emic*' or insider role in terms of signposting support to distressed patients and family members within transcripts. To have enough expertise in the field of enquiry to deeply understand what is being examined and the ability to analyse it non-judgementally is acknowledged as very challenging for a nurse-researcher (Deacon 2013). Hoare (2013) shares her own personal challenges of data collection in an open manner and argues emic and etic perspectives "*…are not binary opposites but rather sit along a philosophical continuum*" a statement I would endorse reflecting on data collection. The literature appears to portray emic/etic perspectives as being not only opposite but antagonistic rather than acknowledging the whole person

experiencing these tensions in a more fluid manner. I would suggest this latter view is more in keeping with a Symbolic Interactionist frame.   The position on this continuum depends on the role and relationship of the researcher in the social and cultural context of the area of inquiry (Hoare 2013).

Supervision was also helpful in discussing this dilemma with the guidance of reserving such signposting to the end of the interview and striking the careful balance of remaining engaged, empathetic and not dispassionate. Such qualities are representative of the fluid nature of reality defined by symbolic interactionism. It also demonstrates very clearly the co-construction of meaning as opposed to objectively viewing a "*window on reality*" (Charmaz 2000, p523). Nonetheless, strategies to both mitigate and account for my actions are required; these have taken the form of a reflective diary and memo writing as advocated by (Bailey 2007 and Clancy 2007). Such strategies provide an important audit trail of thought processes which ultimately influence the analytical export and potential development of substantive theory.

The concept of enhancing theoretical sensitivity, a core element of grounded theory, is linked with these strategies.

3.6 Developing and maintaining theoretical sensitivity

Theoretical sensitivity is the ability to recognise and extract from the data elements that have relevance for the emerging theory (Birks and Mills 2011). A key feature of theoretical sensitivity is developing the attitude of being '*open*' (Gibson and Hartman 2014 p109), that is, being open to a world of immense variability. It is an essential element of grounded theory and is influenced by the researcher's personal, professional and experiential history (Birks and Mills 2011). Four potential sources of theoretical sensitivity are identified by Glaser and Strauss (1967, p. 252-253). Firstly, personal experience prior to or outside the research may provide crucial insights. Secondly, insight may be gained from other people's experiences. Thirdly, existing theory may come as an insight about the researcher's own data and

lastly the research should continue to seek sustainable perceptiveness to the culmination of the study.

The following strategies were utilised to enhance and sustain theoretical sensitivity.

3.6.1 Personal and professional experience

There is general consensus that researchers do not enter the field as a *tabula rasa*. Glaser and Strauss (1967 p3.) recommend that researchers use their experience "*to help them see relevant data and abstract significant categories from their scrutiny of the data"*. Striking a balance between being theoretically open and sensitive, yet minimising and recognising one's own biases and theoretical positioning can be challenging. Equally, attempting to repress past experiences is neither desirable nor possible (Schatzman and Strauss1973). When I commenced this study I had over ten years' experience of working directly in AGCCUs and twenty years in acute and critical care post registration education. During this time I have always maintained strong clinical links with practice to sustain and grow my knowledge for teaching purposes. In addition, I have both recent and earlier personal exposure to critical illness; my younger daughter was admitted to the resuscitation room at the age of seven months and whilst undertaking this study my husband was involved in a cycling accident resulting in admission to the resuscitation room and subsequently required level two care in a high dependency care unit (ICS 2015). This has undoubtedly sensitised me to crisis theory (Woolley 1990) experienced by family members; in particular the shock of admission and the coming to terms with unexpectedly critical illness. Both strong themes within the literature and the data collected from family members, as evidenced in Chapter 5.

Undoubtedly, this insider perspective has enhanced my sensitivity to the experiences of family members but I still need to remain reflexively vigilant as one individual's experience can be so very different to another's.

3.6.2 Sustained immersion in the data

Prolonged engagement with the data and asking questions of the data are central to enhancing theoretical sensitivity. Repeated reading of transcripts together with listening to the audio files whilst correcting verbatim written transcripts in Word™ effectively facilitated this. Listening to the recorded interviews evoked a more powerful response to the data as the nuances and emotion can be lost in written transcript. This allowed for annotation of transcripts (to include audible nuances) and writing of memos. Listening to the files would transport me back to the interview and allowed a re-visioning of the experience. This was particularly useful when reviewing the patient data as interviews were on occasion undertaken successively with limited time for immediate reflection. Awareness that transcriptions are not a literal representation of participants narrative became very obvious on re-listening to the audio files and Hewitt (2007) warns that loss of pace, tone and intonation can have a sanitizing effect, arguing that they represent *a* version of the truth.

Initial line by line coding of the data commenced with the first interview and was initially undertaken in Word™. Subsequently, transcripts were uploaded into Atlas Ti™ (version 7.5.6) and recoded; whilst this may be seen as repetitive it provided an opportunity for additional insights that I had missed on initial coding and confirmation of original codes. As a novice researcher, this was an important learning curve as was the constructive feedback on both data and coding from supervisors.

Additional immersion came from patients' insights of surviving critical illness which were actively sought to enhance my teaching in this subject area. I obtained transcripts from the lay members of NICE CG 83 Rehabilitation after Critical Illness from the guideline lead. In addition, I invited survivors to come and speak to groups of pre and post registration adult nurses about their own and family experience during and after critical illness. Patient experiences in critical illness have only started to be heard in the last fifteen years as the focus within adult critical care has moved from physical survival to understanding the physical, psychological and cognitive effects of critical

illness beyond discharge from critical care. These narratives never cease to sensitise me to the very significant impact that critical illness has on both the individual and their families. Mitigation and support against the negative effects, which are complex, and individual are actively being sought in the ongoing POPPI trial (Provision of Psychological support to People in Intensive Care). Research prioritisation by the James Lind Alliance has also occurred (Reay et al 2014).

3.6.3 Theoretical insights from the literature

Literature is used consistently and iteratively throughout this research study as outlined in appendix one. Given the documented personal and professional experiences, and the requirements for both acceptance to doctoral study and ethical approval, forays into the literature have been frequent although expansive literature searches were reserved to the latter part of data collection (section 2.3). The debate around reviewing the literature in the context of grounded theory has been discussed in chapter 2.2 and will not be repeated here other than the addition that Glaser and Strauss' (1967 pg. 253) exact words are that "*there is no ready formula*" with regard to engagement with theoretical literature. Indeed, Urquhart (2013, p 29) argues that the contentious debate has become something of a myth and can distract the researcher from the simple premise you do not start with a theory and that initial literature reviews should not disrupt emerging theory.

The literature was particularly helpful during the process of data analysis. Sociological concepts such as '*sense making*' were explored more widely. In particular, I actively engaged with a wider range of sociological literature, including reaching into anthropological papers. This took me away from *my* subject area and my professional self (critical care nurse and educator) and gave me insights that could otherwise have remained uncovered. Two papers published by medical sociologists (Rier 2000 and Richman 2000) provide individual and personal narratives of the "*missing voice of the critically ill*" highlighting two separate, but emergent themes, from the literature. Firstly the use of a *notebook* akin to critical care diaries advocated

by Jones et al (2015) and secondly the support needed to make sense of the "*dreams of affliction*" (Richman 2000 p84) so commonly reported by patients both in the literature and in this study. Both supervision and wider engagement with literature and theories can act as '*conceptual levers*' (Schatzman and Strauss 1973) helping to view data in different ways and assist in the *construction* (Charmaz 2014) or *discovery* (Glaser and Strauss 1967) of core categories and theory.

3.6.4 Sustaining and developing theoretical insights

In drafting the findings of the study, new and detailed literature searches were undertaken as indicated in appendix one. According to Glaser and Strauss (1967), new insights can occur late in the inquiry. Therefore comparing and contrasting emerging theory with existing substantive and formal theory is encouraged to aid and enhance conceptualising. In this element of engagement with the literature there does at least seem to be consensus (Glaser and Strauss 1967, Urquhart 2013).

3.7 Ensuring quality and rigour

Developing strategies to ensure and demonstrate the quality of research data and their findings is a central issue particularly in the context of delivering evidence based patient care. However, in common with other areas of qualitative research, this appears to be an area of dissension (Rolfe 2006, Elliott and Lazenbatt 2005) an example of '*Smoke and Mirrors*' as discussed in Schmuttermaier and Schmitt's (2001) '*Modernist Illusions in the Quantitative versus Qualitative Research Debate*'. They like Rolfe (2006) claim that the quantitative-qualitative dichotomy is redundant and should be recognised as a continuum with an associated continuum of quality control. Although Schmuttermaier and Schmitt (2001) go further in suggesting that '*researchers are inclined to see what they want to see*' which may or may not correspond with what *is* there. In addition, they state that claims about methodological purity are a '*form of self-delusion*' with Morse et al (2002 p.4) concluding that the '*literature on validity has become muddled to the point of making it unrecognisable*'. Against this backdrop, I aim to illustrate and

justify strategies used to enhance the quality of this constructivist grounded theory study.

Glaser and Strauss (1967) identified four quality indicators for '*Classic*' grounded theory research. Firstly that the theory has *fit* to the substantive field. Secondly that the theory is *understandable* and makes sense as a basic social process in the relevant field. Thirdly that the theory is *modifiable* to be applicable to everyday changing situations and finally that users (survivors, family members, and health professionals) can *control* or work the theory. These can be contrasted with the quantitative terms of validity and reliability, which some authors (Morse et al 2002) argue are overarching constructs in all scientific paradigms. This is evidently also a much debated area and a summary is provided in Table 3.3.

Quantitative Criteria	Qualitative Criteria	Universal Criteria	Classic GT Criteria	GT Criteria	Constructivist GT
Validity	Credibility	Validity	Fit	Research process	Credibility
Reliability	Transferability	Relevance	Work		Originality
	Dependability		Relevance	Empirical grounding of findings	Resonance
	Confirmability		Modifiable		Usefulness
(Polit and Beck 2010)	*(Lincoln and Guba 1985)*	*(Hammersley 2007)*	*(Glaser and Strauss 1967)*	*(Corbin and Strauss 1990)*	*(Charmaz 2006, Allen 2010)*

Table 3.3 Criteria for assessing quality of research (adapted from Elliott and Lazenbarr 2005)

As this study has adopted a constructivist approach rather than a classic Glasserian one, the positivist assumptions are rejected in favour of the interpretative assessment of '*trustworthiness*'. This is supported by Sandelowski (1993), Chiovitti and Piran (2003) who argued that issues of validity in qualitative studies should be linked not to 'truth' or 'value' as they related to objectivity and positivism, but rather to '*trustworthiness*'. Trustworthiness has been further divided into *credibility* and may correlate to the positivist concept of internal validity; dependability, which relates more to reliability; *transferability* or *fittingness* (Cooney 2011) which is a form of

external validity; and *confirmability* which relates the degree to which data represent the participants' views. Each of these criteria will be discussed in relation to the study.

3.7.1 Credibility

The measure of credibility refers to the authenticity of the data or how representative the data are of the participants' experience of the phenomenon under review (Chiviotti and Piran 2003). Several strategies were used to enhance the credibility of the study. Namely; allowing participants to guide the inquiry process through reflexive, in-depth interviews where issues raised by participants were further explored with subsequent participants. Clearly the only people with authority to comment on phenomenon are the research participants. During interviews of all three participant groups, I actively sought to develop trustful, researcher-participant relationships to construct rich, meaningful data of the critical illness experience. Further discussion of the use of in-depth interviews within qualitative enquiry is provided in Chapter 4.7.1. The topic areas of the interview changing and becoming more focused through constant comparison of data is a key characteristic of this method. This allowed for emerging theoretical concepts to be explored further, checking data with data and data with codes (Elliot and Lazenbatt 2005, Charmaz 2014). This can be illustrated by the change in project title early in data collection when it became clear that some survivors of critical illness had little or no recollection of family members visiting. A broader working title was therefore agreed with supervisors which was far more in keeping with the grounded theory method. This is a common issue reported by Cutcliffe (2005) and is partly driven by the need to identify a research question to initially register on to a doctoral programme and to gain ethical approval as opposed to entering the research field with the notion of '*general wonderment'* (Cutcliffe 2005).

Use of participants' actual words is a central tenet of the grounded theory method at all levels of coding which adds to the credibility of the study findings (Chiovitti and Piran 2003). Care needs to be taken that meaning is

not distorted by the extrapolation of single words and the researcher being alert to misinterpretation. This can be mitigated against by reflective interview skills, using techniques such as "*can you explain what you mean by ...*" Using data to check data also assists in confirmation and therefore credibility.

The process of '*member checking'* advocated by Bryman (2008) was discussed at supervision. The literature was also consulted on this topic (Cutcliffe 2005, Elliott and Lazenbatt 2005, Guba and Lincoln 1989, Sandelowski 1993). Despite being advocated by Guba and Lincoln (1989) this strategy was ultimately rejected for the following reasons; the progressive nature of constant comparative analysis infers that the focus of the research will evolve and change through increasing theoretical sensitivity and therefore member checking no longer becomes a valid method of countering researcher bias and subjective interpretation (Elliott and Lazenbatt 2005, Sandelowski 1993). In a constructivist view of the world, credibility is ensured through application of the grounded theory method where constant comparative analysis and theoretical sampling act as a credibility check rather than returning transcripts to participants.

Credibility can be enhanced by articulation of the researcher's personal views and insights into the phenomenon (Chiovitti and Piran 2003) demonstrating and engaging in reflexivity. Specific strategies included, a post comment interview sheet, reflective journal and monitoring and discussing engagement with the literature. These are all heuristic devices to support credibility.   Professional and personal perspectives are made explicit throughout the thesis as I attempt to engage in critical self-scrutiny. The following extract is taken from a reflective memo after patient and relative interview PR09.

This was a long (60 minutes), rich and detailed interview with a 54 year sepsis survivor and her partner. I was particularly struck by the emotion of abandonment expressed by the patient "*you are own your own, you are definitely on your own*". The tremendous support of her partner who had an all too vivid memory of critical care that his partner had not, is further evidence of the growing concept of '*dualistic worlds'*. The details of her journey brought into question again (for me) my role as a critical care nurse and the lack of knowledge I had (when in clinical practice full

time) around the delirium experienced by patients. The profound delirium experienced by so many of the patients interviewed is frequently being disclosed for the first time at interview such is the fear that they are or were "*going mad*". I can only imagine how that must feel. The onward journey from critical care is clearly so challenging and the preparation so poor I feel a real sense of failure as a critical care nurse and question what my role had achieved during all those years in clinical practice. Latterly my teaching has overtly and explicitly used patient and relative experiences to enhance insight in to the patient and relative experience – I believe generally to good effect, but I wish I could turn back the clock to change my clinical practice. Such feelings continue to challenge me to move into practitioner rather than researcher mode in terms of offering support and explanation.

At the end of the interview we visited the critical care unit at their request, the patient struggled with '*walking through'* the doors of the unit and could only withstand the sights and sounds of the critical care unit for a few moments such was the intensity of the emotion they invoked. As I thanked them for their participation and said goodbye I recognised that recovery was still a long way off. In her own words "*I am just not the person I was, I've got no patience with anybody, I don't like myself for that, I really dislike myself".* I was saddened that whilst physical survival had been secured well-being was still a distant ambition.

Reflective Memo

Box 3.1 Reflective memo following interview PR09.

Peer review is an additional strategy for establishing credibility. Submission of peer reviewed abstracts for conference presentation and journal publication allows reviewers who are unrelated to the study to comment and challenge. Details of conference papers and publications are provided on page 15. Colloquium presentations at City University London also provided the opportunity for challenge and critique of the data and study as a whole. Supervisory meetings with joint review of coded transcripts, reflective comments, and chapter extracts helped provide guidance and assurances around my ability to code in addition to challenging the analysis and developing theory. My supervisors' methodological knowledge and clinical knowledge in psychological health was particularly fitting.

3.7.2 Dependability

Dependability is concerned with transparency and refers to the degree to which the reader can evaluate how the findings of the study were realised.

An audit trail that contains detailed descriptions of research methods (chapter four) and associated documents (Appendices 3-14) demonstrates dependability. Data collection was undertaken between Sept 2013 and January 2015 and during this time there were minimal contextual changes to the AGCCU or Trust status. The increased pressure on hospital beds across England during the winter of 2014/15 is noteworthy with the hospital being frequently on '*black alert'* meaning there were no beds available for admission in the hospital. It is also worth noting, that whilst the research findings may be dependable, they are not directly reproducible as the context and data are unique, however, Corbin and Strauss (1990 p.15) argue that a "*grounded theory is reproducible in the limited sense that it is verifiable*".

3.7.3 Confirmability

This term relates to confirmation that the data does offer a faithful interpretation of the views held by the participants and does not reflect the biases, beliefs and assumptions of the researcher (Lincoln and Guba 1985). Recording and transcribing interviews, together with providing an audit trail of processes, was central to ensuring confirmability. Verification of the emerging theory was sought through supervision and sharing with '*critical friends'*. In addition resonance with fellow researchers at colloquium presentations helped promote critical self-reflection.

3.7.4 Transferability

Transferability, sometimes referred to as '*fittingness'* (Chiovitti and Piran 2003) is the degree to which research findings can be generalised or applied to other situations and may be referred to as *theoretical generalisability* (Bryman 2008). By providing detailed descriptions of the research context (chapter one) together with rich, thick descriptions of data (chapter five and six) readers may be able to determine the applicability to other contexts (Lincoln and Guba 1985). Similarly, delineation of the sample (detailed in chapter four) is a further strategy to assist in assessing transferability (Chiovitti and Piran 2003). The extent to which the emergent substantive theory can be applied may be affected by regional and national variations.

Presentation at national and international conferences also assisted in assessing the transferability of the findings.

A further strategy advocated by (Chiovitti and Piran 2003), and employed in this study, is to return to the literature relating to each category of the theory described. Such interplay between data and literature is methodologically congruent and highlighting similarities between data and theoretical constructs in the literature may further assist in transferability, although the final decision must rest with the reader (Glaser and Strauss 1967, p230).

A summary of strategies used to enhance rigour throughout the study is contained within box 3.2.

• Data collection from three participant groups to achieve multiple views of phenomenon
• Iterative and concurrent data collection and analysis
• Constant comparative analysis
• Methodological congruence
• In depth interviews yielding rich descriptive data
• Using conceptual levers to abstract and conceptualise theory
• Reflexivity – transparency of personal and professional experience, recording reaction to data, attempting to engage in self-criticality
• Peer debriefing – academic supervision, reviewer feedback from abstract submissions
Rigour enhancement in qualitative research

Box 3.2 Summary of strategies used to enhance rigour

3.8 Chapter conclusion

In summary, this chapter provides the epistemological frame for this study as one of social constructionism with a relativist ontology. The theoretical perspective is drawn from Symbolic Interactionism and the methodology or research design is constructivist grounded theory (Charmaz 2014) and is illustrated in figure 3.1. The chapter has sought to explain and justify these

decisions noting the insider perspective. Measures taken to ensure the quality of the study have also been articulated. The next chapter discusses how these methodological decisions have been put into practice and details gaining access to the field of research, recruitment, sampling and data analysis culminating in the analytical processes of this research.

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│         Epistemology            │
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│     (Social Constructivism)     │
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              ▽

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│      Theoretical Perspective    │
│                                 │
│    (Symbolic Interactionism)    │
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┌─────────────────────────────────┐
│          Methodology            │
│                                 │
│  (Constructivist Grounded Theory)│
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│            Methods              │
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│  (Interviews & comparative analysis)│
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┌─────────────────────────────────┐
│          Data Analysis          │
│                                 │
│(Initial coding, focus coding, selective coding│
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│        Theory generation)       │
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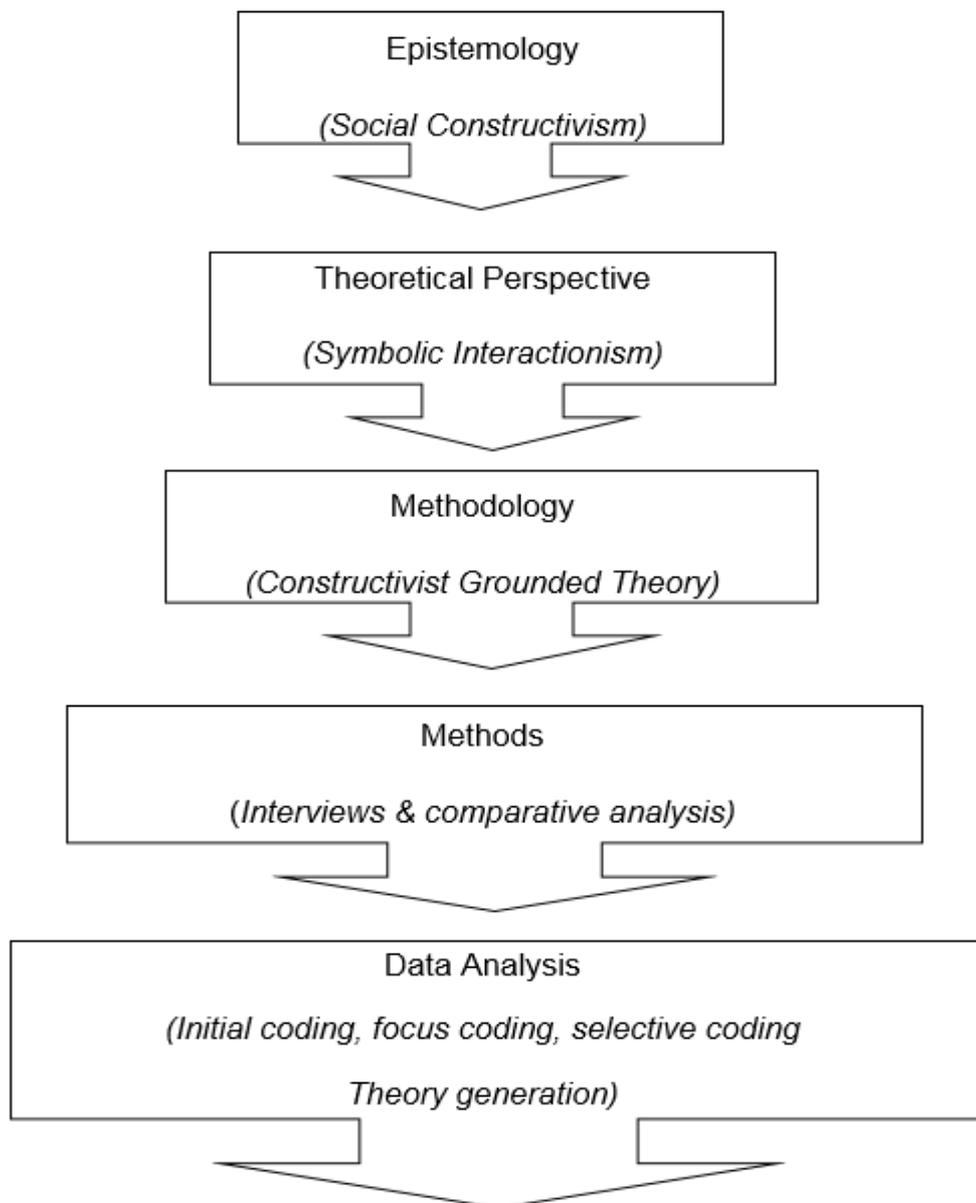
Figure 3.1 Theoretical and Methodological underpinning

Identification of these five key elements may ensure theoretical and methodological congruence and highlights related assumptions in an explicit and transparent manner (Crotty p 4 1998)

Chapter Four Methods

4.1 Introduction

This chapter discusses how the epistemological and methodological principles identified in chapter three were applied to the research study. The ethical considerations and formal processes used to protect the well-being of research participants are detailed. Subsequently, procedures and techniques for gathering data and moving from purposive sampling to theoretical sampling are presented. The iterative process of data generation through co-construction and constant comparative analysis is discussed with evidence of methodological, reflexive and analytical memos. The chapter concludes with details of data analysis.

4.2 Ethical considerations

This section describes the formal processes of seeking and obtaining ethical approval. It then considers the ethical deliberations in relation to the study and how they were managed; namely obtaining informed consent, coercion avoidance during recruitment, confidentiality and anonymity and, importantly, striving to ensure the psychological and emotional well-being of participants.

4.2.1 Formal ethical approval

Ethical approval for this research was applied for and granted via the Integrated Research Application System (IRAS) administered by the National Research Ethics Services as part of the NHS [13/LO/0798] (appendix five). Evidence of indemnity was provided by City University London, and following a formal application to the Research and Development department of Mid Essex Hospitals Services, (MEHS) a Letter of Access was issued (appendix 8). Integral to this latter process was a Disclosure and Barring clearance together with evidence of completion of Good Clinical Practice training; an e-learning course administered by the National Institute for Health Research. Such formal strategies are central to protecting the well-being of participants, however, this is just the starting point since good ethical practices should be

at the heart of design processes, through reporting and beyond (Webster et al 2014). There appears to be broad consensus of the constituents of ethical research as highlighted in box 4.1 (Webster et al 2014).

Constituents of ethical research (Webster et al 2014)
Research should be worthwhile and should not make unreasonable demands on participants
Participation in research should be based on informed consent
Participation should be voluntary and free from coercion or pressure
Adverse consequences of participation should be avoided and risks of harm known
Confidentiality and anonymity should be respected

Box 4.1 Constituents of ethical research

Whilst the rigorous process of ethical approval may limit the risk to participants I am also working from an established ethical framework by Beauchamp and Childress (2013) namely:

- Respect for autonomy through informed consent, confidentiality, and anonymity

- Beneficence – "*do good*".

- Non-maleficence – "*do no harm*"

- Justice, distribute the burdens and benefits of research equally.

Although these are well accepted principles they do not provide explicit contextual guidance for qualitative researchers (Hewitt 2007). Arguably, such guidance is more important in qualitative research, where there is increased vulnerability to bias through the attitudes and qualities of the researcher, and potentially the more intrusive nature of the qualitative interview (Hewitt 2007). The foundational assumptions of the study discussed in chapter three accept the researcher's inherent subjectivities. Rejecting the notion of objectivity further predicates against checklists and guidelines being effective. Moreover, as the principle method of data

collection was through interviewing it is difficult to absolutely predict moral questions or sensitivities that may arise during the course of the interview.

As a researcher I had a moral obligation to ensure the research had a sound justification since qualitative interviews should exhibit more than intrusive curiosity and as such should achieve more than '*telling of sad stories*' or the achievement of an academic award (Thorne and Darbyshire 2005, Hewitt 2007). Sensitivity of the risk to participants was a concern from conception of the study to the conclusion and this is discussed in more detail in 4.2.3 and 4.3.

4.2.2 Gaining access

Whilst the formal element of acquiring access to research participants is articulated in 4.2.1 and manifests as a 'Letter of Access' (Appendix 8), actually gaining access to sites and people was a complex multi-layered process with both formal and informal components. In parallel to seeking Research and Development (R&D) departmental approval I gained the support of the lead nurse for AGCCU and the lead consultant for critical care follow up. Initially, this was in writing and followed up with an informal discussion providing an opportunity to 'walk through' practical details such as the location of rooms for interviews. By mutual agreement I arranged to attend the monthly team meeting where all consultant intensivists, lead nurse, band seven registered nurses, research nurses, and allied health professionals gather. Whilst this was not a formal requirement it was a sensible approach to informing and engaging staff with the study particularly as some staff acted as 'gate keepers' to research participants. Gaining the support of the lead for follow up (intensivist) and the senior nurses on the AGCCU was crucial to gaining access and further detail of this interface is available in 3.8.

I was privileged to have the assistance and support of not only the lead nurse (identified in the Letter of Access) and intensivist for critical care but the support of the Out Patient Department manager and the critical care clinic secretary. Gaining their support was central to the operational success of gaining both access to the field and data collection. As highlighted by

McCallin (2003) effective communication and organisational skills are imperative to being an effective researcher with the additional thinking and creative skills needed for constructivist grounded theory development.

4.2.3 Addressing ethical concerns

The ethical concerns around this research centred on informed consent, anonymity, confidentiality, and harm or benefit to participants. Undertaking this study has the potential to confer an academic award to the principal investigator and may be considered as a latent ethical conflict. A fundamental aspect of demonstrating respect for others is to gain their consent to actions that will impact on them. A definition of informed consent is provided by Holloway and Wheeler (2002 p286) as "*a voluntary agreement made by participants after having been informed of the nature and the aims of the study*". In this study, all participants; patients, family members and registered nurses, gave written consent, having had the opportunity to read relevant participant information sheets (appendix seven, eight and nine).

The participant information sheets detailed the nature and purpose of the study in addition to providing full contact details of the lead researcher and the supervisory team. These documents were sent, or given to, participants at least 24 hours in advance of potential interviews. In the case of patients, this information was sent out four to six weeks in advance of their outpatient clinic appointment (appendix nine). Formal written consent was taken at the outset of the interview with the ongoing option to withdraw at any point during the course of the interview. This element is item two on the consent form; each item was discussed with participants as part of the formal consent process in an effort to confer protection and to balance any power imbalances in the researcher - participant relationship (see section 4.7.5).

In recognition that sensitive issues were likely to be discussed and explored, consideration was given to the availability of further support mechanisms for participants. Informing the General Practitioner of patient participation in the research study was one strategy, highlighting the availability of the Patient Advice Liaison Service (PALS) to both patient and family members on the participant information sheet was another agreed and verified by IRAS. For

all three participant groups, the option to refer to the psychotherapy team within the hospital was available via the lead nurse for critical care. As highlighted by Tee and Lathlean (2004) identifying such support mechanisms for qualitative interviews is good practice.

4.3 Avoiding power relations and coercion

Avoidance of coercion during the recruitment process was largely ensured by the processes outlined in 4.2.3. In particular, at no point did the researcher make the first direct approach to the potential participants who were provided with written information (participant information sheets and covering letter). Such strategies can help mitigate against participants feeling coerced into undertaking research; however Hammersley and Atkinson (1993) claim there is an inevitable power imbalance in the research relationship despite commitment to ethical positioning. The potential for further blurring of professional roles is discussed in 4.4. The Participant Information Sheet for patient, nurses and family members clearly states that I am not a member of the clinical team and gives assurances around confidentiality but with the disclaimer that evidence of harm or malpractice requires disclosure. It was clear in some patient transcripts that there was an initial hesitancy in disclosure of negative experiences, but the disclosure was nevertheless made, illustrating a high degree of psychological comfort within the interview as evident in Jane's transcript;-

> *"... maybe I shouldn't... I am going to say it, I thought people on X Ward were really bad, I mean there were other people in there that were ill pressing their buzzers and you could hear the nurses laughing and joking, they didn't come" (PR09).*

4.4 Professional Accountability

Hewitt (2007) highlights the need for the researcher to clearly define the remit of the research interview to participants when the researcher has a clinical background. However, the reality is, according to Kean (2007) and my own experience, that there is a very fine line between maintaining a detached research attitude and making a contribution to alleviate suffering.

There is a real danger of muddling the roles of researcher and professional thereby confusing both researcher and participants. As a professional registrant, I also have a professional code to follow (NMC 2015) which requires me to prioritise people, practise effectively, preserve safety, and promote professionalism and trust. Silverman (2000) and Atkinson (1997) have argued that research agendas should not be muddled with emotionalism and therapeutic outcomes but focus on rigour and validity. But Hewitt (2007) and I would argue from an ethical perspective that rigour and validity must be balanced with moral concerns. The ethical framework highlighted in 4.2.1 was adhered to as far as humanely possible in the context of a novice researcher.

4.5 Recruitment

This research project was undertaken within an 800 bed district general hospital (DGH) in the United Kingdom. The DGH operates as a NHS Trust providing elective and emergency services to 380,000 people from rural, semi-rural and urban areas. The AGCCU had fourteen Critical Care beds; ten level three beds, four level two (see table 1.1) but able to "flex" between the two levels. The survivor population was heterogeneous with the causation for admission being varied (see table 5.1). The age range of survivors was 42-75 years (mean 61 years). The AGCCU typically saw more emergency than elective admissions with retrospective data from December 2014 showed there had been 700 admissions of which 490 were emergency in nature; accounting for 70% of all admissions to AGCCU.

At the time of data collection there were 71 Registered Nurses working within the AGCCU (January 2015 data). Eleven nurses were recruited for interview having a range of clinical experience in AGCCU from 1.5 to 27 years (mean 12.5 years).

The study was undertaken in two overlapping phases. Phase one involved the recruitment of critical care survivors and family members to answer the first research question;-

- How do patients and family members experience their critical illness trajectory?

Phase two involved the recruitment of registered nurses working in AGCCU to answer the second research question;-

- How do registered nurses in AGCCU respond to the survivorship needs of patients and family members?

Given the iterative nature of grounded theory, it is methodologically congruent that these phases overlapped given the need to check theory against further data.

The study required the recruitment of three participant groups; survivors of critical illness, family members and registered nurses working within AGCCUs. To ensure that participation was voluntary, I, as the researcher did not make the initial approach to potential participants. The following arrangements were agreed by IRAS and the local Research and Development department via both a Trust Approval Letter (appendix seven) and an associated Letter of Access (appendix eight).

4.5.1 Family Members

The lead nurse for AGCCU and band seven nursing staff assisted in recruitment of family members. They made an initial approach, provided written information about the research (appendix 10 and appendix 13), with contact details of the researcher. If the family member was interested in participating in the research, I made contact at least 24 hours later and arranged a convenient time to conduct the interview. Written consent was obtained immediately prior to commencement of the interview (appendix 16).

4.5.2 Patients

Patients were identified in liaison with the identified consultant intensivist, as part of the follow up process established by the NHS Trust's AGCCU. Regular (monthly) clinics were held in the out-patient department where some patients were followed up post discharge from critical care at between three to six months. The secretary to the AGCCU arranged outpatient appointments for survivors of critical illness and sent written information (appendix nine and appendix twelve) detailing the research together with contact details of the researcher and the supervisory team to prospective attendees. A stamped addressed envelope and form to indicate whether they were or were not willing to participant in the research was included. If the patient was interested in participating the researcher made contact prior to the clinic date and arranged a convenient time to conduct the interview, this coincided with their outpatient clinic appointment for all but one participant. Written consent was requested and in all cases obtained immediately prior to interview (appendix 15).

Thirty six letters of invitation were sent out, sixteen patients indicated that they were happy to be interviewed. Five actively responded stating they did not want to participate, four of them kindly detailed the reasons why they had declined. There were no responses received from the remaining fifteen patients and it is not known why they did not respond to the invitation letter. The reasons provided by non-participants revealed a desire not to revisit a painful episode in life. These responses sensitised me further to the vulnerability of survivors of critical illness. Although Glaser (2012) states '*everything is data'*, and as such the written responses provided an inadvertent source of data I did not have explicit consent for inclusion of this information albeit that survivors disclosed this information freely. As such the content is summarised rather than directly quoted.

- Recollection was linked to a troubled episode in the survivor's life span
- No memory of being in critical care

- Explicit wish not to recall the emotion pain that this life event implicated.

4.5.3 Registered nurses

The AGCCU is divided into seven nursing teams and at the time of undertaking the interviews, there were 71 registered nurses working on AGCCU. Each team leader was asked to give registered nurses the option of participating in this research. Letters of invitation (appendix 14) together with information sheets (appendix 11) with contact details of the researcher were provided to all band seven team leaders. For interested nurses, I arranged a convenient time to conduct the interview. Written consent was requested and in all cases obtained immediately prior to interview (appendix 17).

4.5.4 Inclusion criteria

The study focused on the impact of unexpected critical illness and not the consequences of major elective surgery, so all patients admitted electively to AGCCU were excluded. In addition, a minimum 72 hour stay in AGCCU was deemed to be a substantive period of time to fully experience the AGCCU. This was largely a pragmatic decision but is a figure that has been applied in other studies (Stayt 2012). Definition of family member was taken from the European Federation of Critical Care Nurses and is broad and inclusive;-

"…*those people who are most important to the patient. This includes patient's family, loved ones and close friends*" (Fulbrook et al 2008).

In reality, this transposed to partners (11/15), son (1/15), mother (2/15) and daughter (1/15).

Registered nurses who had worked within AGCCU for more than one year were invited to discuss their experiences. This period of time ensured regular exposure to both critically ill patients and family members and completion of initial clinical competencies. It was noted whether or not a post registration qualification in critical care nursing had been completed, but this was not applied as an inclusion or exclusion criterion.

In summary;-

- Patients; - Admitted to AGCCU as an emergency for greater than 72 hours e.g. post cardiac arrest, medical and surgical emergencies.

- Family Members of patients admitted in the above categories. As defined by the European Federation of Critical Care Nurses (Fulbrook et al 2008)

- Registered nurses (NMC registrants) working in AGCCU for greater than one year.

4.5.6 Exclusion criteria

- Patients admitted electively (and associated family members).

- Explicitly at end of life (patients and associated family members).

- Inability of potential participants to speak English (although those for whom English is not their first language were purposefully included).

- Patient or Family members considered by the lead nurse or intensivist to lack capacity to consent, or the cognitive ability to engage in discussion.

- Registered nurses who had worked in AGCCUs for less than one year.

Defining purposive selection criteria is a central strategy to purposive sampling; the key factors in this study relate to a particular experience or role. Participants are selected on the basis of these known characteristics and reflect sample units of *symbolic representation* (Ritchie et al 2014)

4.6 Sampling procedures

The preceding section 4.5, discussed recruitment and selection criteria that demonstrate methodological congruence and strategies to protect participants. This section will discuss the participant characteristics, sampling and interview procedures

4.6.1 Participant characteristics

Descriptive detail of participant characteristics; gender, age, medical diagnosis, length of stay in AGCCU and, in the case of RN participants, length of critical care experience and qualification were recorded. These are detailed in Chapter 5 (table 5.1, 5.2a & 5.2b) for patient and family members and Chapter 6 (table 6.1) for staff participants. Pseudonyms were identified in preference to research codes to assist in developing the storyline and generating a more humanistic perspective to the study (Birks and Mills 2011.

4.6.2 Purposive sampling and Theoretical sampling

As stated in 4.5 this study required a sample of participants who have experienced AGCCUs as either a patient, family member or RN; constituting purposeful sampling. Whilst such sampling has been criticised as a major source of bias from a quantitative perspective it is imperative that participants are identified at a particular stage which is context bound in order to obtain good data (Morse 2007). A further definition of purposive sampling is provided by Patton (2002 p230) namely the "*intentional selection of information-rich cases whose study will illuminate the central questions of the research"*. All participants within each of the three categories met the inclusion criteria identified in 4.5.4; participants were all "*good informants*", that is they were able to articulate their experiences and were willing to share with the interviewer (Morse 1991).

Sampling then progressed to theoretical sampling where participants related their story adding to the existing data set about a particular category or concept. Progressive interviews thus moved from open, in-depth, to semi-structured as themes emerged and developed to reveal concepts or constructs which could be used to support theory generation (Birks and Mills 2011, Charmaz 2014). Criteria for purposive sampling can be defined prior to entering the research field but criteria for theoretical sampling can, and were, only elucidated following concurrent gathering and analysis of initial data. Here the purpose was to develop and refine the construct of the emerging theory and not to achieve representativeness (Charmaz 2014). In one of my first interviews Annie spoke of how her family could not

understand what she had been through and "*that they were the same person*" in contrast *"I am not the same person" (P01)* following critical illness*.* This early insight into the change in relational self as a consequence of surviving critical illness lead me to initially code for change in self and prompt and probe more specifically about relational selves in subsequent interviews. Thus purposeful sampling is superseded by theoretical sampling as the data and emerging theory highlight the direction to follow (Cutcliffe 2000). Importantly there can be no a-priori specification of the theoretical sample as it data driven. The theory should be grounded in the data, not driven by procedure (Breckenridge and Jones 2009). Data was constantly checked against codes and more data; the focus being on sufficiency and significance of the selective code.

A helpful distinction between purposeful and theoretical sampling is further provided by Breckenridge and Jones (2009):

> "*While a purposeful sample is selected at the outset of the study for a predetermined purpose, theoretical sampling progressively and systematically tailors data collection to serve the emergent theory. Theoretical sampling is thus always purpose-driven; the sample is selected for the purpose of explicating and refining the emerging theory*".

In addition, constant self-awareness and reflexivity was maintained throughout the interview process to minimise potential bias. This was achieved through reflective, analytical and theoretical memo writing and maintaining a reflective diary. Supervision was also an important part of this evolving process; allowing emerging concepts to be discussed, and challenged, helping the researcher to accept or reject developing theories. A sample memo written following supervision is provided in Box 4.2. The crucial role of memoing in facilitating theoretical sampling is emphasised by Holton (2007) and Chiovitti and Piran (2003) and discussed further in 4.8.3.

Box 4.3 Reflective memo (supervision)
At supervision (24th March 2015) we discussed the theoretical memo I had written around a possible emergent core category to explain the experiences of survivors of critical illness and the family members. One of the conceptual levers for this abstract leap has been literature around

survivorship in cancer patients (Blows et al 2012, McKenzie 2010) and some of the social work literature (Johnston 2011) and of course, centrally, the coded data from interviews. The concept of survivorship may, I suggest, equally be applied to critical care survivors since they are literally moving from survival along a journey hopefully to thriving. In addition, a paper provided by one of my supervisors entitled *Parallel lives*: Younger stroke survivors and their partners coping with crisis had some influence although the disease pathology was more distinctive than the more generalised physical and psychological sequelae of critical illness seen in the patients interviewed. The discussion section does provide useful insights into the impact of unexpected illness on the "*family machine*".

Charmaz supports conceptual leaps which can demonstrate the process of abduction. Of course, CGT allows you to go back and check out the category with more data.

On reflection, I believe some of the discussion around the label of "*dualistic worlds*" became rather too literal. I had not intended this to be the case, I see the term as a metaphor for the **dual realities** that both parties experience – both real to the individual. I have read around the use of metaphors as theoretical codes (core categories) (Birks and Mills 2011) and am aware of their pitfalls. The transcripts reveal profound realities in the form of subliminal (out-of-body experiences) and the reality of delirium for all survivors interviewed contrasts with the world of making sense of having a relative who is critically ill experienced by family members. The ongoing journey is reflected in the table in the memo. I have (naturally) been questioning myself about this and have gone back to the data. I have relooked at the open coding and the subsequent focus codes that capture these – I have manually diagrammed these out to check for '*fit*' and have shown them as simple relationship diagrams in Atlas Ti. A category is defined by Gray 2014 "*A classification of concepts*" and categories are defined by their *properties* (attributes or characteristics pertaining to a category) and their *dimensions* (location of properties along a continuum). I need to do further work around the properties and dimensions….. as Charmaz says this is an ongoing process of focus coding and categorizing where incomplete understanding raises questions; the answers to which may help to fill properties of the categories.

The commentary around better reflecting the ontological perspective set out in the methodology is spot on – on re-reading my memo it appears much more as a "*discovered*" category (sitting with objectivist GT rather than CGT) rather than one that is constructed between the researcher and the participant. It is, of course, constructed in a more abstract way between the survivor and the family member.

Box 4.2 Supervisory memo around evolving theory

Sampling ceased once *theoretical saturation* had been reached; identification of saturation can also be problematic however I was looking for data that no longer revealed new theoretical insights rather than merely looking for repeating patterns (Charmaz 2014). As such, sample size "*is a function of theoretical completeness*" (Sutcliffe 2000 p 1447).

The required number of interviews which need be undertaken is a problematic question as detailed by the National Centre for Research Methods report (NCRM 2012) and conflicts with the foundational assumptions of qualitative research. However, the reality is that a number does have to be identified for the purposes of ethical approval by IRAS. As an approximation, a figure of 20-30 participants has been cited as a typical number for grounded theory (Smith et al 2011). Given the evidence from the

literature (Ritchie at al 2014, Smith et al 2011), and with the support of supervisors, IRAS submission sought approval for a total of 45 interviews, with approximately 15 interviews in each participant category.

There are several reasons why sample sizes are comparatively small in relation to quantitative research.   Incidence or prevalence are not the concern of qualitative research; there is no requirement to determine statistical significance. Further, the data yielded in qualitative studies are rich in detail and gathering vast quantities could be ethically inappropriate, and certainly unmanageable, to analyse (Ritchie et al 2014). Equally, it is important that samples are not too small, since they may fail to capture the diversity of the population and experience that is being sought. Good purposive and theoretical sampling ensure that the sample will be rich in terms of the constituents, characteristics, and diversity and address the research question.

Theoretical saturation is defined by Urquhart (2013) when "*the researcher finds no new concepts are emerging from the data – all that is happening is that there are more instances of existing categories*" (p. 9). Birks and Mills (2011 p115) break this down further by stating that it is when the emerging "*theory makes sense to the researcher*". This is in keeping with the underpinning constructivist perspective of this study. The researcher needs to be convinced that they understand what they see (Morse 2007). However, as a novice researcher and grounded theorist, I am aware that theoretical saturation is likely to only be reached to "*a matter of degree*" and that there is always the possibility of something "*new to emerge*" (Strauss and Corbin 1990 p136). The term *theoretical sufficiency* originally coined by Dey (1999 p. 257) and endorsed by Charmaz (2014) may be more appropriate; not just to the novice researcher, but in terms of reflecting the fluid nature of reality, and being open to what is happening in the field and not foreclosing analytical options.

4.7 Data collection

In this section, the use of in-depth interviewing in the context of constructivist grounded theory will be discussed. Strategies to develop and enhance the

skilled activity of actively questioning and listening, reflecting and probing will be considered together with procedural issues such as data recording and data storage.

4.7.1 Interviews

Interviewing has, in many ways, become synonymous with qualitative research (Wimpenny and Gass 2000) although the interview has been criticised by Silverman (2011) as an overused strategy referring to an emotionalist research method born out of the '*interview society*'. He argues that the uncritical adoption of interviews provides little more that anecdotal insights and conveys a false sense of authenticity. Silverman (2011) does not dismiss the value of interviewing outright but argues for robust analytical thought for their use and relevance to the research question; this is further supported by Charmaz (2014). However within the context of this study successful interviews may have discerned thoughts, feelings, and experiences that would not have been revealed by any other method (Cresswell 2013, Yeo et al 2014). Qualitative interviewing starts with the premise that the participants' perspective is meaningful (Brayda and Boyce 2014).

In the context of an inductive and constructivist paradigm, the researcher becomes the research instrument through which data are collected. Some concerns have already been articulated around the problem of method slurring with Baker et al (1992) highlighting the importance of specificity in methodology and distinguishing particularly between phenomenology and grounded theory, two frequently misused terms in the description of qualitative methodology. Whilst commonalties in the interviewing process exist at the outset there is a point where divergence occurs; the phenomenologist remains centred on eliciting the experience of respondents whist the grounded theorist is seeking to develop theory and as such the nature of the interviews changes to a more structured approach to achieve theoretical saturation (Wimpenny and Gass 2000).

Initially, I sought to gather the narrative of the experience of patients and families utilising loosely structured, in-depth or intensive interviews which

lasted from 45 minutes to one hour and a quarter. This approach allowed exploration of feelings and attitudes and provided an opportunity to make explicit, tacit perceptions. Such a method is an acknowledgement that the participants are experts in their own experience (Brayda and Boyce 2014). Whilst face-to-face interviews may be considered to be time consuming, laborious and challenging to analyse, they are likely to be the best method to generate data on sensitive issues and experiences (Darlington and Scott 2002). Face-to-face interviewing, as opposed to telephone interviews, had the added advantage of being able to pick up on non-verbal cues and this may enhance the well-being of participants (Birks and Mills 2011). The subjective nature of the interview and the active co-construction of data and knowledge is congruent with both the chosen paradigm and the methodology.

As an experienced clinician and educator I have developed skills in establishing rapport and communicating effectively, however Birks and Mills (2011) caution novice grounded theorists that developing theoretical sensitivity and applying this within an interview context is demanding. Several transcripts were reviewed and commented on by both first and second supervisors which helped to hone my skills as a novice interviewer in the context of constructivist grounded theory method.

Interviews with survivors and family members commenced with a loose structure, although a beginning, middle and end can be discerned within most transcripts as the researcher does need to be able to move through the interview (Birks and Mills 2011, Yeo et al 2014). The interview process is regarded by some as a "*lengthy conversation*" (Schatzman and Strauss 1973 p.73) who identify that early interviews may be less "*economical*" (p.71) as the precise information needed has yet to be established. In the case of this study, early interviews revealed that survivors had limited and sometimes no recollection of visiting family members whilst in AGCCU but highlighted more significant and sometimes longer lasting sequelae of critical illness. These areas then became the focus of subsequent interviews and were explored with both survivors and family members. Explanatory theory to elucidate the

differing experiences and social processes was co-constructed with data and literature in an on-going and iterative manner.

4.7.2 Dyadic and triadic interviews

During the course of data collection, I was presented with the opportunity, and the methodological threat of undertaking dyadic and triadic interviews. This is an acknowledged underexposed dilemma between ethics and methodology in nursing research (Norlyk et al 2016). Whilst anticipating individual interviews I was presented with the presence of partners and/or son (RO1) daughter (PR11) at the point of interview with some survivors (see table 5.1 and 5.2a and 5.2b). Given that participant information sheets had been provided in advance and that initial approaches had been made by senior nurses or consultant intensivists and verbal agreement given, I was left with the decision to include or exclude the partner at the point of interview. The research question '*How do patients and family members experience the critical illness trajectory*?' demonstrated clear congruence with dyadic and triadic interviews which aided decision making. Further, there is epistemological congruence with interviewing relational selves as Mead (cited by Bjornholt and Farstead (2014)) views the self as '*inherently relational'* (p4). Sakellariou et al (2013) highlighted that illness is an intersubjective experience; referring to how humans share experiences and how they depend on each other to both construct and make sense such experiences. A more intuitive and overriding factor was my own ethical stance; I drew heavily on my own sensitivity, clinical wisdom, and moral competence together with an element of pragmatism. In some situations (PR03, PR09, PR13) participants needed their partners, who were also their carers, to provide some element of physical support and probably psychological support too. Therefore, from both my professional perspective, as a registered nurse and as a researcher, I was ethically led to include their partners in the interview process. Indeed, it felt intrusive and ethically difficult to ask a partner who was there in support, not to stay during the interview. Norlyk (2016) identifies identical emotions in her study of patients post-surgery.

Notwithstanding the methodological dilemmas of dyadic interviews, there is evidence in the literature that such an approach provides rich and valid data related to both couples and individuals (Bjornholt and Farstad 2014). Indeed, illness is experienced, lived and understood within a particular social context and as such, joint interviews of illness experience are supported by Sakellariou et al (2013). As interviews of survivors progressed and the initial emergent theory of '*dualistic worlds'* emerged, there was a real strength (from a researcher's perspective) for dyadic interviews to explore and check this theory. Listening to the voices of people living with survivors provided further insights into how people experienced living post critical illness. It is clear from the data that perspectives of survivors and their partners do not always coincide but that they can have access to each other's life world and can perhaps start to understand it. This understanding may never be complete but this may not deny reconciliation; *'…it has been hard to reconcile the two separate lives that we lived during this time, and neither of us will ever be able to fully comprehend what the other went through'.* Jane (PR09).

As the data in chapter five illustrates, and supported by Norlyk et al (2016), Bjornholt and Farstad (2014), the presence of the survivor's partner helped the patient recall and in some cases reorient memories of the critical illness journey. Cognitive impairment and, in particular, memory loss is a well-documented complication after critical illness (Stevens et al 2014). It is acknowledged that interviewing participants separately may have offered a different understanding and produced differing storylines however the aim of this section of the study was to explore how survivors and family members experience critical illness and to explore life post critical illness in their own relational context. As a novice researcher, this became an opportunity rather than a threat and a focus for reflection on the challenges researchers face in the concrete world of data collection. My learning from this reflection relates to the need to apply constant attention to ethical principles of beneficence, non-maleficence, and justice.

4.7.3 Interview stages

Identification of the stages of an in-depth interview are provided by Yeo et al (2014) and illustrated in table 4.4.   This provides some practical advice and guidance of moving through the "*opening, narrative and finale*" (Yeo et al p.186). I probably struggled most with developing thinking time during stage 4 as some participants disclosed quite distressing experiences in relation to their critical illness to which the "I" responded as an instinctively compassionate nurse wanting to offer support rather than the situated "me" which was the novice researcher. When Kevin (PR13) disclosed the physical, cognitive and psychological sequelae of his critical illness he was tearful and emotional; I did not feel able to probe further as this felt (to me) to be too intrusive, instead, I made the rather obvious but grounded comment "…*but you are here.*" The direction of the interview went on to discuss confronting mortality. Facilitating the narrative of a sensitive and personal experience within a humanistic and ethical framework appears to akin to walking a tight rope at times. Charmaz (2014 p. 68) confirms the importance of reading participants' non-verbal as well as verbal cues to check for intrusion and includes strategies for opening spaces for participants to decline to answer; - *"I don't know if this is an appropriate question but…".* She argues that softening a question can reduce its potential invasiveness.

Stages of an in-depth interview
Stage 1: arrival and introductions   • Establish an initial rapport   • 'host' the interaction by taking responsibility for making if friendly and positive
Stage 2: introducing the research   • Seeking informed consent: aims, objectives, voluntary, confidential   • Scope of the interview: the participant is in control of what they disclose   • No right or wrong answers, hearing their perspective in their own words
Stage 3: beginning the interview   • Contextual background information: for reference in interview and to set the tone
Stage 4: during the interview   • Breadth and depth of coverage
Stage 5: ending the interview   • Give some advance notice

• End on a positive note: suggestions and recommendations
Stage 6: after the interview
• Thanks for participation: value of their contribution
• How the information will be treated and used
• Be prepared to stay to help change the mode back to the everyday
• Listen out for 'doorstep data'

Table 4.4 Stages of the in-depth interview (Yeo et al 2014)

Interviewing is undoubtedly a complex act as illustrated above. Interviews can, and do, lay open thoughts, feelings, and emotions that create emotional discomfort and distress. In addition to the above, strategies advocated by Brayda and Boyce (2014) such as building trust, active listening, understanding where there is subtext, and showing empathy were employed. It is noted by Bryant (2009) that active listening involves giving free and undivided attention to the interviewee which is a difficult discipline requiring intense concentration and incorporating both non-verbal and verbal communication. As an interviewer in this context, I aimed to adopt a body posture that demonstrated listening; sitting slightly forward, hands still. I also maintained appropriate eye contact to convey engagement but not intrusion as advised by Bryant (2009) together with non-verbal nods as a means to maintain the flow of conversation. Additional specific strategies to directly support participants are detailed in 4.2.3.

The choice of in-depth interviews permitted the generation of rich data that had breadth and depth; participants were able to narrate their experience without being anchored to specific questions as evident in structured interviews (Schatzman and Strauss 1973). A list of prompts and probes were used to support and guide the interview (appendix 18), however, these evolved following constant comparative analysis of initial interview data. Prompts are ideas introduced in to the conversation and the views of the interviewee sought. They can be used to clarify a question or stimulate a response if the interviewee is struggling or when the interviewer senses that part of the narrative may be missing. For example in PR15 Barry was describing a surreal experience and I sought clarification as to whether it was part of a hallucination or dream. Probes are responsive follow up questions

which elicit more information, description or explanation; examples include P04 when I asked Linda *"How does that feel*?"* in relation to the preceding description of the changed relationship with her son. Probing seeks to amplify or expand, explore, clarify and explain; allowing understanding of the experience to grow. There may also be the need to clarify inconsistencies (Yeo et al 2014).

Interviews with patients and family members were undertaken prior to interviews with registered nurses. The research questions effectively steered this order:

1. How do patients and family members experience their critical illness trajectory?

2. How do registered nurses in AGCCU respond to the survivorship needs of patients and family members?

Staff interviews (phase two) were more structured as the questions or discussion points had been developed directly from the patient and family member interview data; nevertheless, they too evolved over the course of interviews as a result of constant comparative analysis. In addition to the skills required to undertake in-depth interviewing or intensive interviewing (Charmaz 2014) there are a number of practical considerations that underpin the success or otherwise of data collection.

4.7.4 In-depth interview – practical considerations

Practical measures such as scheduling appointments, punctuality and ensuring the physical comfort of both interviewer and interviewee are important together with ensuring paperwork and recording equipment are in order. I always made sure that I had water, glasses and tissues available; all of which were used over the course of different interviews. Venues for interviews were negotiated and arranged in advance. All patients and some family members (with the exception of one) were interviewed in a private room in the outpatient department within the district general hospital where they had been originally treated. Family members whose relatives were in-patients on AGCCU were interviewed in a room designated for family

discussions. This was located on the AGCCU and is a non-clinical room containing soft furnishings, paintings and soft lighting. Staff members were also interviewed in this room. Whilst the location of the room (on AGCCU) may have affected respondents in terms of its proximity to critical illness it was largely a pragmatic decision since family members were visiting and would not wish to be far from their relatives. Equally, staff were interviewed during their clinical shifts and would not wish to be any great distance from the unit. Availability of the room was also a key factor. Appropriate signage on the door prevented any interruptions and, together with the absence of any 'phones or computer equipment, helped to create a conducive environment for an in-depth interview. Achieving privacy, quietness and physical comfort were clearly important (Yeo et al 2014). One patient was unable to stay to meet with me in the outpatient department but invited me to her home in order for the interview to go ahead (P04 Linda).

All interviews were digitally recorded with the participant's permission. A discrete, high quality digital recorder was utilised recording data as MP3 files. Gray (2014) claims the recording of interviews is vital; this is in contrast with Glaser's contention that skill development will be hindered by taping and does little more than generate superficial data (Birks and Mills 2011). However recording data does allow it to remain '*live*' as any hesitancy, inflection and emotion can be captured together with the textual content. Whilst video recording would have helped capture the interview more completely it is likely to be viewed as intrusive and may have limited the responses of participants and indeed the performance of the researcher (Birks and Mills 2011).

Following interviews, field notes were recorded to capture non-verbal cues along with thoughts, insights, and reflections. Interview recordings were listened to post-interview and transcribed into Word™ documents within three to five working days; this process was critical for me to become immersed in the data. Transcriptions were checked against audio files to verify accurate transcription and anonymised to ensure confidentiality.

A well conducted interview can and has yielded rich insights and helped to develop theoretical constructs. It is undoubtedly a privilege to have been given access to the participant's social world and their experience.

4.7.5 Researcher –participant relationship

Traditionally the interviewer holds the balance of power in an interview situation; they own the project and generally set the parameters for discussion. However, the participants own the knowledge the researcher is in pursuit of and have the power to withhold or disclose (Darlington and Scott 2002, Charmaz 2014, Yeo et al 2014). This further determines the requirement to build trust and develop a collaborative relationship. As a matter of ethical principle, and cultural courtesy, politeness and respect prevailed throughout the whole interview process; from informed consent to closure of the interview. The strategies outlined in 4.7.2 indicate the skills needed for participants to feel relaxed and enabled to speak freely, on their own terms about their experiences and their interactions.

I sought to develop a style of '*responsive interviewing'* (Yeo et al 2014 p 181) that '*emphasises the importance of building a relationship of trust between the interviewer and interviewee'.* To a greater extent, I believe this was achieved and evidence for this can be found within the transcripts. Sarah (PR13) in our conversation said "*Thank-you for letting me talk so openly…*" and Charles (P02) appreciated information that was a by-product of our conversation "*I'm pleased I came to see you just for that information…"* Charmaz (2014 p. 73) however warns that gender, age, status, and experience may result in *interactional power differences.* The transcript from family member John (R02) reveals a conversation that had an additional agenda;-*"I was ignored as a union steward of 18 years. Now I see it from the perspective as a relative and as a nurse and as a trade union activist of 18 years and 28 years in nursing, and I know where the problems are in the health service, but nobody wants to listen because it costs money to fix".* As a trade unionist within health care he shared with me many additional experiences much broader than his experience of being a family member in AGCCU; undoubtedly though this shaped his experience and

provided different insights that were not evident from other participants. A clear example of where understanding the context of data collection is central to understanding the data. Yeo et al (2014) acknowledge that achieving the delicate balance between ensuring the participant can speak freely and guiding the interview to ensure the research question is answered is very difficult. I would suggest that interview R02 did go somewhat '*off topic'* in several places, however, I was fortunate to not have any time pressures on this occasion and continued as an active listener steering John to the research question when I was able. I accept that a more skilled qualitative interviewer may have achieved a better interview focus but I sought at all times to maintain a sensitive and non-confrontational approach to the changing interview dynamics as advocated by Yeo et al (2014).

Clearly the personality of both interviewee and interviewer will also have an impact on the co-construction of data – this is methodologically congruent with constructivist grounded theory development with Symbolic Interactionism as the underpinning theoretical perspective (Yeo et al 2014).

As I embarked on the interviews with registered nurses (phase 2 interviews) I became aware (through active reflection) that my style of interviewing was subtly different from when I interviewed patients and family members. Whilst still paying attention to the same physical and psychological requirements of achieving comfort to support honest and comprehensive responses, I felt more able to probe participants. I believe this is related to my perception that they were less "vulnerable" than survivors of critical illness and family members. Of course I afforded them professional and emotional respect but it revealed to me that I had not "probed" other participants in the same way. I am certain that this was due to my own anxiety that potentially intrusive probing may cause more psychological distress. This is despite evidence in the transcripts that interviews, particularly with survivors, may have conferred unexpected benefits. This latter disclosure reveals the fine line between a detached research attitude and the contributions of a researcher with a professional registration, but as suggested in section 3.8, should this line be considered as a continuum rather than a perspective that is diametrically opposed? (Hoare et al 2013). It does also reveal something more

fundamental; what it is to be human. Humans are the most emotional animals on earth. According to Turner (2007) emotions are responsible for both the formation of social structures and the fuel for destructing them.

Certainly during and following interviews with survivors who had quite harrowing stories to tell I experienced an emotional response. Empathetic engagement can lead to internalising of participants' suffering and the development of compassion stress may be evident (Hewitt 2007). Access to supervision and mentor support was helpful in mitigating against this, although it would be almost impossible not to have had an emotional response to the suffering experienced and articulated by some survivors. A similar experience has been articulated by other researchers such as Magarey and McCutcheon in their qualitative study "*Fishing with the dead – recall of memories from the ICU*" (2005).

4.7.6 Data storage & CAQDAS

Secure data management is central to high quality, ethical research. All participant data were stored electronically on a password protected computer. Any transcripts discussed at supervision were anonymised and coded to protect confidentiality. Once transcripts had been verified for accuracy against audio files and anonymised they were uploaded to Atlas ti™. Computer-assisted qualitative data analysis software packages (CAQDAS) allow data storage and are particularly helpful when handling large amounts of data (Spencer et al 2014). There has been much debate about the role of CAQDAS expressing both hope and fear. Many authors including Strauss (Barry 1998) have expressed concerns around the use of computer software for qualitative research. However, it does have a range of benefits beyond storage of data; the ability to cross cut quotations and develop nodes or sub-categories that can be diagrammed to show relationships. The additional reassurance that the underpinning verbatim data remain linked and in situ, all supports the process of data analysis (Paulus et al 2014). It should be emphasised that software can only be used to support analysis and not carry out the analysis and interpretation (Flick 2009, McNaughton Nicholls et al 2014). However, it does undoubtedly aid the iterative movement between the original data and the subsequent

conceptualisation, abstraction, and interpretation that is integral to constructivist grounded theory and other qualitative analysis.

As I undertook interviews prior to receiving training in the use of Atlas ti™ I completed line by line coding in Word™, using highlighting and other text tools for several interviews. I also undertook manual coding with coloured highlighters to achieve initial insights into the data as part of data immersion. This process did allow me to feel "closer" to the data – whilst possibly an illogical observation from a reductionist perspective it is well recognised and reported in the literature. This manual approach is used by both novice and experienced qualitative researchers' alike (Thomson 2013, Barry 1998, Charmaz 2014).

All anonymised transcripts were uploaded to Atlas ti ™ and initial coding completed. Focus codes were co-constructed through mapping to initial codes knowing that the underpinning verbatim quotations remained in situ for checking as illustrated in figure 4.1.   The next stage continued the constant comparison between focus codes or sub categories; asking questions of the relationships between data. An example of this process is shown in the screen shot figure 4.1. Such diagramming or mapping can help show positions and processes more clearly (Clarke 2003).
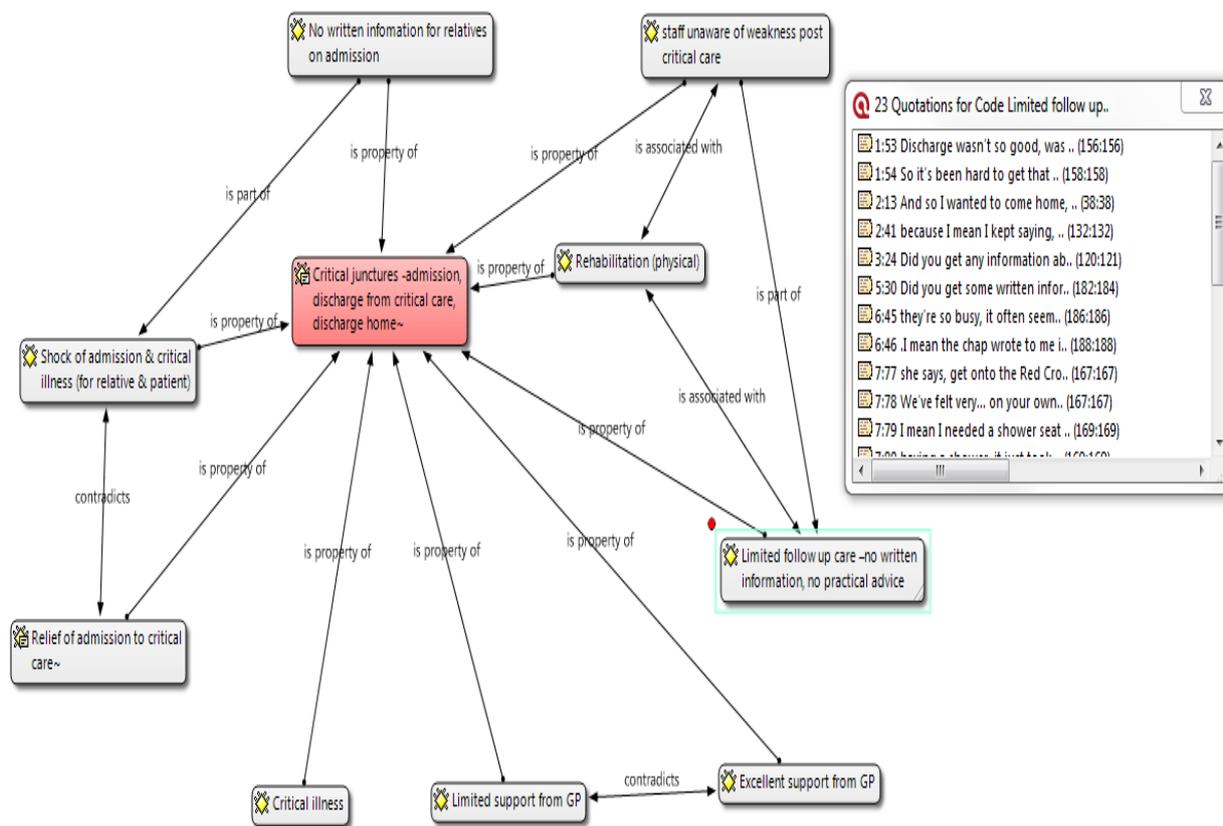
Figure 4.1 Initial codes linked with the focus code Critical Junctures

CAQDAS Atlas ti ™ has proved to be a useful tool in the handling and management of large amounts of textual data. The steps taken in data analysis will be further detailed in the next section (4.8).

4.8 Data analysis

Constructivist grounded theory generation is an iterative process with data collection and data analysis occurring concurrently. The next section details the processes of data analysis and the steps taken to construct explanatory theory as espoused by Charmaz (2014). Analysis in grounded theory research is not without contention; lack of adherence to the method has been highlighted by Stern (1994). Further evidence of this is cited by Benoliel (1996) who analysed 146 grounded theory publications by nurses and identified three categories of research; grounded theory approach (used interview data), grounded theory methods and grounded theory research. She concluded that the distinguishing features of grounded theory research are the constant comparative method, theoretical sampling, further multiple

comparison and theoretical coding. In an effort to avoid methodological transgression these steps will be outlined further.

4.8.1 Constant comparative method of analysis

Constant comparison has been a standard method of analysis in social science for many years and certainly prior to the '*discovery*' of grounded theory in 1967. It is a key part of constructivist grounded theory and grounded theory methods (Urquhart 2013). The concurrent nature of data collection and analysis are distinguishing methods of grounded theory permitting the initial generation of codes (Birks and Mills 2011). The process involves comparing data with data, data with codes, and codes with categories which are also compared with new codes. It is this iterative method of comparison at differing conceptual levels that can drive "*abstract categories rich with meaning*" (Birks and Mills pg. 94). The non-linear, iterative nature of this process and in particular the current study is outlined in figure 4.2. The decision making process when undertaking constant comparison is considered to be one of induction and abduction. Inductive thinking can be defined as;-

> "*a type of reasoning that begins with a study of a range of individual cases and extrapolates patterns from them to form a conceptual category*" (Bryant and Charmaz 2007, pg. 608).

Whereas abduction is defined as;-

> "*a type of reasoning that begins by examining data and after scrutiny of these data, entertains all possible explanations for the observed data, and then forms hypotheses to confirm or disconfirm until the researcher arrives at the most plausible interpretation of the observed data*" (Bryant and Charmaz, 2007 pg. 603).

It is this latter process that permits abstraction and creativity which is a hallmark of constructivist grounded theory (CGT). Critically, the focus in CGT is on a mutual construction of knowledge, by the researcher and the participant, and the aptitude to develop subjective understandings of participants meaning (Fram 2013).

Figure 4.2 Diagram illustrating non-linear process of constant comparative analysis and theory generation (Page 2013)

There are several aids to support the principle of constant comparison including; close reading and rereading, coding, diagrams and memo writing (Boeije 2002, Fram 2013), all of which were adopted within this study. Boeije (2002) supported by Fram (2013) recommend the following constant comparative analysis steps in qualitative research:

- Comparison within a single interview
- Comparison between interviews within the same group
- Comparison of interviews from different groups
- Comparison within dyads
- Comparing couples.

Whilst this list may appear prescriptive and linear the output is determined by creativity and theoretical sensitivity, in a non-linear and iterative manner. There is no procedure or prescription for this process, comparisons go hand-in hand with interpretation. This process of *purposeful comparison'* (Boeije 2002 p409) directly links to the theoretical sensitivity of the researcher and allows interpretation of social phenomenon. Central to data analysis is the use of memos as a vehicle for conceptual abstraction (see 4.8.2).

4.8.2 Memo writing

Memo writing is a central tenet of grounded theory; proving a record of thoughts, insights, and ideas (Birks and Mills 2011, Charmaz 2014, Urquhart 2013). Memos are central tools to reflexivity as discussed in 3.10.1 and have been referred to as the lubricant to the grounded theory machine as illustrated in figure 4.4. An additional metaphor provided by Stern (2007) is the mortar holding together the building blocks of data.
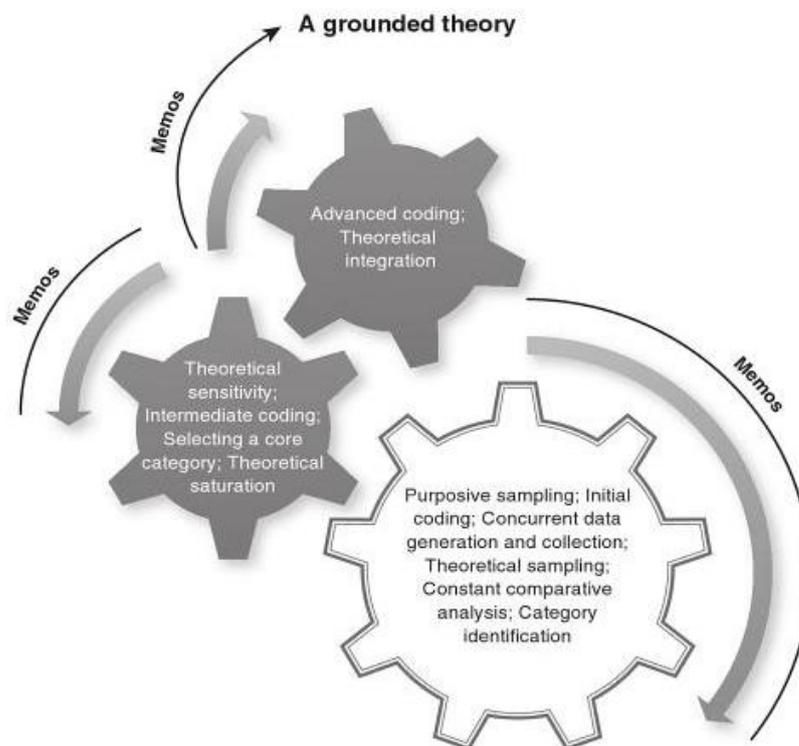
Figure 4.3 The role of memos in conceptual ordering – (Birks and Mills 2011, p37)

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The function of a memo in the context of grounded theory is broadly outlined by Birks and Mills (2011) in the pneumonic:

- M – Mapping research activities
- E – Extracting meaning from the data
- M – Maintaining momentum
- O – Opening communication

Memo writing allowed me to freely consider and explicate patterns and relationships in the data; this helped in code definition and groupings to form categories and permitted greater levels of conceptual abstraction. Being challenged on my developing concepts and abstraction was an important part of supervision as my preconceptions might only become evident when my taken-for-granted standpoints are questioned (Charmaz 2014). An example of a reflexive memo in relation to considering conceptual abstraction is shown in box 4.4.

Theoretical memo around constructed theoretical code (patients and family member interviews) '*dualistic worlds*'

Through interviews with patient and relatives the notion of *dualistic worlds* between the two groups is being constructed and emerging as a theoretical code and needs to be checked. Initial and focus codes have led me to consider this as a possible theoretical code and I need to consider how the categories relate to one another as this is a key element of theorising. How have I got here?

Data reveal the many losses that patient experiences; - time, voice, identity, memory, limbs, mobility, independence (dignity and self-esteem) cognitive function a form of **ambiguous** loss or **living** loss (Kelly 2008) perhaps. **(Ambiguous loss** is a loss that occurs without closure or understanding Pauline Boss 2006). This is contrasted by family members' experiences who live through the critical illness episode in a state of heightened anxiety and emotional shock. Experiencing the shock of admission to critical care and starting the process of making sense of critical illness is evident in both the data and the literature. They (FMs) may have to "*work*" at gaining access and being with their relative, they are very likely to have been confronted with the possibility that their relative may die. A commonly used metaphor is the roller coaster of emotions that this experience brings; one day may see improvement, the next a major deterioration (*it's just like a rollercoaster, one day, you know, you come in and you can cope, and another day you feel very down, but then when you get here, amongst everybody else, you feel, you know, more lifted again and... Yes, it is like a rollercoaster R04*) and (*it was two steps forward, three steps back.* (PR06)).

The table below attempts to compare and contrast the experiences of the two participant groups. They are frequent seen to be at differing stages in the survivorship trajectory. Patients reporting conflict with FMs that they (FMs) do not understand the experience, because they have not been through it (*"Because I say to me daughter, I say, you don't know – oh, I do know what you've been*

through, she goes, because I've been through it too, I don't want to know all of that now, and I don't want to see this... oh, don't mention that, ...but it feels better for me to talk about it, because I didn't see the things that was going on, even though I was having it done to myself…. Because they sort of like, they try to shield you". e.g. P01). Equally, patients say that the FMs have suffered more in the initial phase because they (patients) have no recollection "*In a way I suppose that was a worse nightmare for them two (partner and daughter), than it was for me, because I didn't know too much, did I? It was a nightmare for me trying to get better because it was hard but that must have been a terrible nightmare for the family….Two different nightmares*". (PR10).

Family members may believe that "*you're well out of it really, you know, you don't want to be remembering too much of it" PR05.* This can be seen as a protective approach which may ultimately cause conflict as according to Morse and Johnson's model of Understanding the Illness Experience (1991) and the work of Christina Jones (2014a) there is a need for patients to construct the illness narrative in order to complete the transition from stage III to IV, the final stage of survivorship which is either complete recovery or acceptance of a lower level of functioning. (Survivorship being the concept of moving from surviving to thriving)

Critical illness - Two different nightmares.

Patient	Family member
Critical illness (Critical juncture)	Critical illness- (Critical juncture)
- limited or absent recollection of admission and stay in AGCCU - Dreams and hallucinations - Sleep deprivation - No or limited insight into critical illness Stage I-stage of uncertainty Stage II – stage of disruption (Morse and Johnson 1991)	- shock and anxiety of admission - confrontation with mortality of relative - Coming to terms with critical illness "*sensemaking*" - Doing the "*work*" of a relative – gaining access, getting information, balancing life.
Discharge to ward (Critical juncture)	Discharge to ward (Critical juncture)
- Physical sequelae (muscle loss, reduced mobility) - Psychological sequelae (ongoing delirium, flash backs/dreams) - Lack of insight into critical illness - Awareness of loss of dignity and independence - Conflict between "*getting better*" and reduced level of care - May start to come to terms with critical illness "*sense making*" - Confrontation with own mortality Stage III –stage of striving to regain self (initial phase)	- Conflict between "*getting better*" and reduced level of care - Coming to terms with critical illness "*sense making*" - Relative at risk of deterioration - Doing the "*work*" of a relative – gaining access, getting information, balancing life. - Protective towards family member (relationship change)
Discharge to home (Critical juncture)	Discharge to home (Critical juncture)
- Desire to be at home conflicting with fear and anxiety (physical and psychological sequelae) - Abandonment (by health workers) - May start to come to terms with critical illness "*sense making*" - Enhanced emotions and emotional instability (anger, guilt, frustration, fear)	- Discharge welcomed but "*hard work*" - Lack of appropriate support in the community - Coming to terms with the aftermath of critical illness "*sense making*" - Change in relationship dynamic

• Change in relationship dynamic Working towards Stage IV-stage of regaining wellness	

Looking at the literature around "*survivorship*" which is a concept generally applied to cancer survivors (Blows et al 2012) it struck me that there were similarities in the processes surrounding critical care survivors. That is the process of moving from surviving to thriving. For some of the participants interviewed this journey is near completion but for the majority they were still on that journey to regaining "*wellness*" (Morse and Johnson 1991). So what explains that world that the survivor inhabits? What is that journey like for both the survivor and their family? What are the longer term effects? Some are reported in the literature particularly the physical weakness and the ongoing psychological challenges which in the worst case can result in PTSD, with the FM member being susceptible as well as the survivor (Wong and Brett 2013, Ilse van Beusekom et al 2016). Is there an explanation of the social process of moving from survival to thriving (which may not be achieved by all)?

Could the anthropological theory of 131 be helpful in scaling up the proposed category of parallel realties? The word limen is Latin for threshold. One definition of liminalty is provided by Johnston (2011) drawing on Turner's work (1969) as some-one "*who is in-between, who is standing at the threshold, who occupies the margins, or is going through a rite of passage*". The shock of critical illness can force both patient and family member in to a (different) transitional situation. They can each find themselves in liminality, that is, in limbo or being on the fringes of "here and there". Patients literally exist on the threshold of death and reality with one patient describing what it was like to step across that threshold in an out of body experience (Cant 2012).

"... I wouldn't say they were unpleasant, in fact, well, I wouldn't say I enjoyed them, but I mean my wife had just come in, ...but I was having real trouble breathing, and then all of a sudden it was almost as if I had stopped breathing, I felt fine. And then I went all cold and tingly, but not an unpleasant sensation and I was up on the ceiling looking down. And this happened twice within a short space of time, because I said to my wife afterwards, I said, you know, I was up there thinking, you know, this is it. And then I thought, well, you're here. I'm a bit lonely (laughs)."

Living in a liminal space can be extremely stressful, the person may not accept the liminal role assigned to them by critical illness and this can cause conflict between the patient and family members (see P01 and Barnett 2006b). But prior to this within the critical care unit it is clear that patients hallucinations create a unique illness narrative and can take them to a subliminal world which can have a profound effect on the onward survivorship journey. There is evidence from the table above of two different illness narratives. Looking at the data for a few patients and family members this can bring a new zest for life;-

"*We do things, we don't put anything off anymore. I'm not saying it's done us good, I wouldn't go... because we were very happily married before, but the impact is so great when someone is that ill that I've never... I don't think I'll ever forget it...and it does make you appreciate so much more than what you normally do. You don't take things for granted because, as I say, A went to bed that night completely healthy, within X amount of hours he was more or less fighting for his life*".PR06.

But for the majority, there is a sense of disconnect in understanding the experience. Understanding of the various liminal states that both survivor and family member progress through, almost certainly at differing rates because of the nature of critical illness may be helpful in supporting survivors and their families to stage IV of Morse and Johnson's model of the Illness Experience (1991). Constructing an illness narrative seems important for most survivors – strategies to achieve this are being hotly debated in the literature.

Box 4.3 Reflexive memo around developing theoretical code

As evidenced above memos can serve as catalysts in data analysis and ultimately form the foundation of an explanatory theory.

4.8.3 Coding

Data collected via in-depth interviews were analysed using constructivist grounded theory coding, namely; initial coding, focused coding and theoretical coding employing the constant comparative method (Charmaz 2014).

During initial coding fragments of data were studied and coded; it may be appropriate to adopt participants language as an initial code e.g. '*losing control'* (PR09). Initial coding is an interactive and analytical process where the researcher responds to the data. An example of initial coding of PR09 is provided in Box 4.4.

Dismissing how poorly she has been **Travelling the cancer journey – 5 year survival.** **Promise of new beginnings developed into nightmare**	F: And how poorly I've been. **I think I dismissed the fact of how poorly I have been,** you know, I'm very much, you know, obviously I've been through the cancer, I've been... get on with it now. I think in my mind my breast reconstruction, I was so... to me I know, you've got to go through it, five years and what have you, but to me, breast reconstruction, because I had to have delayed reconstruction, after that it would have been closure on everything, a new beginning, a new, you know. I was changing locations with my job, I was going to be moving to X, so it was all going to be like a new beginning and it turned out to be an **absolute nightmare**, you know...
	I: Can you tell me why?
Changing self **Losing patience. Dislike of self** **Frustration**	F: ...I obviously don't feel as well as I did even when I was having my treatment, I mean all my joints have affected, **I'm just not the person I was**, **I've got no patience with anybody. I don't like myself for that, I really dislike myself,** because at work I was saying, I work for the NHS and I'm very much with patients, what have you, and they worry about the trivialest thing, and I feel like saying, do you want to know, do you really want to know, and I get really... But I don't obviously say that, but that's how I'm feeling, and I have to calm that down a bit. But I'm not.**.. I don't feel sorry for myself, I really don't, but I am angry that everything has happened,** you know, it went from having breast

| Angry at the whole cancer and critical care experience

Long and challenging journey

Not sorry for myself (repeated from above)

Very angry

Blaming herself

Incredulous at reality | cancer and just had a lumpectomy and having radiotherapy to… well actually it's spread, it's, you know, there's two, we've found two lumps, two lots of cancer, you need to have your breast removed, you need to have chemotherapy, you need radiotherapy, you need to wait for a year, and you're thinking, whoa, and I've gone through all that and you think, OK, let's go through it, let's go through it. **The reconstruction was going to be it, and all through that I didn't… I do not feel sorry for myself, but now I feel very angry.** I think, I must have done something really terrible for all these things to have happened, because if you tell somebody they think really? Is she making it up as she goes along, because, you know, all these things have happened? |

Box 4.4 Example of initial coding (PR09)

Initial coding allows categorising segments of data with a short name that both summarises and accounts for the data. If analytical ideas occur during this process memos are written so that ideas can be developed and checked against more data or literature.

Coding is the central link between data and developing an emergent theory (Charmaz 2014). As coding develops elements of a budding or nascent theory will direct further data collection; this is theoretical sampling. Charmaz (2014 pg. 113) describes coding as the "*bones of your analysis*", the "*working skeleton*" is developed through theoretical integration.

When initial coding is completed, the second phase involves categorising significant initial codes to a smaller number of focused codes. Figure 4.1 illustrates "Critical junctures" as an example of a focused code with several open codes scaffolding the concept and the underpinning quotations for one of the initial codes '*limited follow up*'. The third phase is to relate the focused codes together with theoretical relationships; this process of identifying the characteristics, properties and dimensions allows the naming of a selective or theoretical code. These theoretical codes are few in number and form the core concepts of the account in relation to the body of data (Charmaz 2014, Woolf 2014, Eaves 2001).

It is pertinent to recall that the researcher is actively naming data and therefore constructing codes. As Charmaz states (2014 pg. 115);

> *"We may think our codes capture empirical reality. Yet it is **our** view: we choose the words that constitute our codes."*

She urges researchers to excavate data for tacit meanings – close attention to coding may permit this. Charmaz also urges us to pay attention to language when coding; in vivo codes can provide symbolic markers. One example is from Sharon who refers to "*Two different nightmares*" to put this into context;-

> "*In a way I suppose that was a worse nightmare for them two (partner and daughter), than it was for me, because I didn't know too much, did I? It was a nightmare for me trying to get better because it was hard but that must have been a terrible nightmare for the family….Two different nightmares*". (PR10).

For me, this was an example of a participant's innovative term that captured both her and her family's experience. I sought to "*unpack*" (Charmaz 2014) this term; to understand the implicit meaning and to compare with further data. Hearing this phrase was a further trigger that helped crystallise my muddled and cluttered thoughts; providing a focus for comparison with data and literature as part of the constant comparative process. Remaining open to the data is a further key message given by Charmaz.

4.8.4 Theoretical coding

Engaging in initial and focused coding in conjunction with memo writing allows for rapid analytical development to the latter stage of coding which is theoretical or abstracted. Glaser explains theoretical codes as conceptualising "*how substantive [focused] codes may relate to one another as hypotheses to be integrated into a theory*" (Glaser 1978, pg. 5). A further definition is provided by Stern (1980, pg.23) stating it "*simply means applying a variety of analytic schemes to the data to enhance their abstraction*". Theoretical codes can bring lucidity and precision to the analysis if they '*fit*' the data and analysis (Charmaz 2014) and may take into account several

focus codes. Urquhart (2011) highlights the permeable boundaries between selective and theoretical coding and I would suggest diagrams such as 4.4 are heuristic devices to conceptualise coding in constructivist grounded theory.

An area of contention here is that of prior knowledge. In the book *Theoretical Sensitivity* (Glaser 1978) provides 18 coding families and a further 23 in his later book (2005); this may lead to forcing '*theory*' development which Urquhart (2011) and Charmaz (2014) warn against. There is then, a tension between emergence and application of theoretical codes which has yet to be resolved. We can, however, and arguably should, be generating our own theoretical codes. The purpose of coding was to breakdown and then re-integrate the analytical story back together and helped identify relationships between categories (Charmaz 2014). This process allowed the storyline to develop; again an iterative process of moving back and forth between writing theoretical memos and engagement with data and literature.

The stages of theory building and scaling up theory are integrated within the discussion Chapter 7. Suffice to say that there was a significant period of "*drowning*" in data and codes before I started to "*swim*". By this, I mean starting to move away from describing and make sense of the data to constructing a conceptual theory (Cutcliffe 2005).

4.9 Chapter conclusion

This chapter has justified and documented the rationale behind the methods selected in the data collection and data analysis stage of the study and detailed the iterative, non-linear process of constructivist grounded theory method. Ethical considerations and strategies were considered and applied to ensure the well-being of participants including an awareness of the relationship between researcher and participant, particularly in the context of a nurse researcher have been considered.

Details of the stages of data collection and analysis in the study have been explored, justified and contextualised.

The aim of this chapter and the preceding chapter has been to provide the reader with a clear audit trail of process and thinking in relation to both data analysis and the early stages of theory construction. An overview of the research timeline of data collection and analytical processes is detailed in figure 4.4.
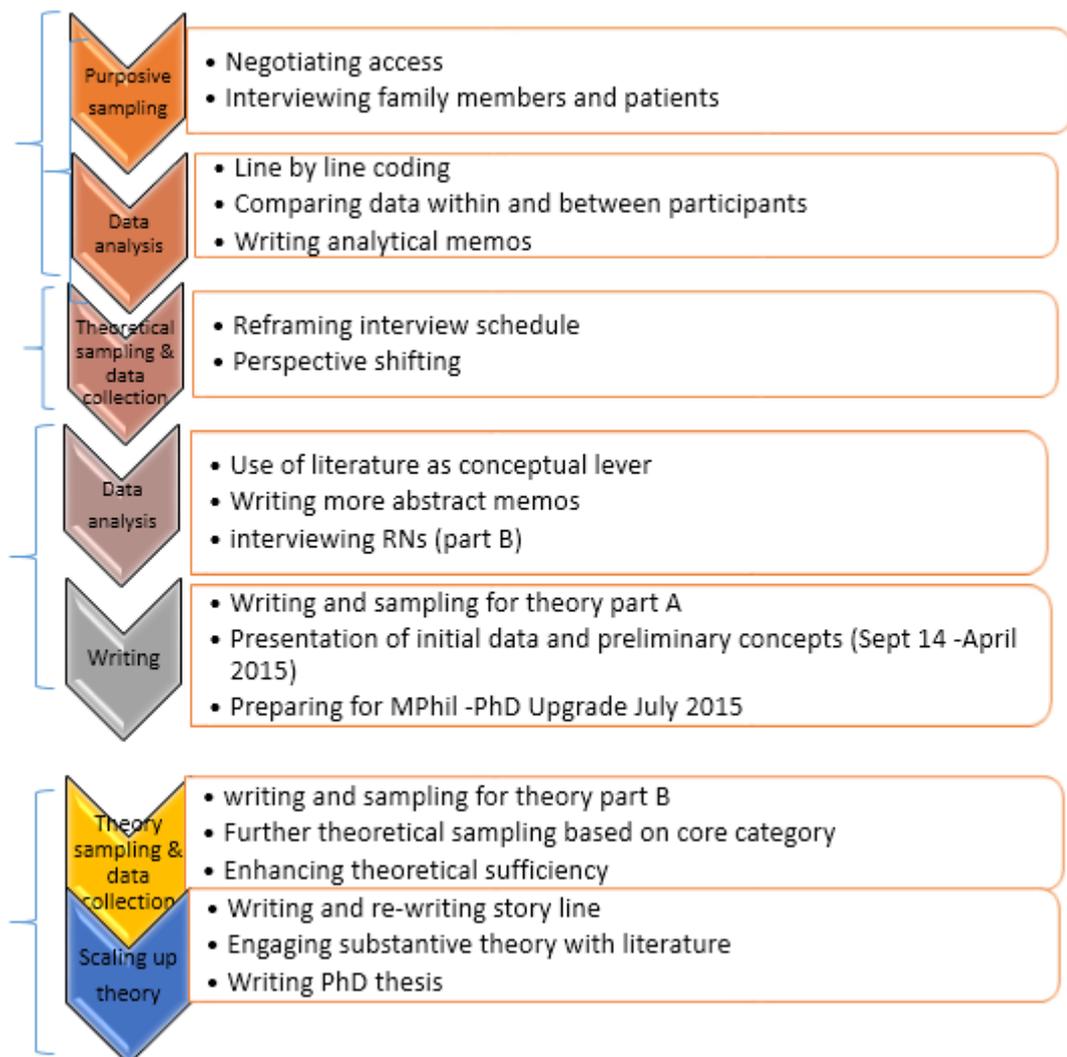
Figure 4.4 Research timeline – data collection and analysis

Chapter Five Findings (Survivors and Family Members)

5.1 Introduction

The next two chapters present the main findings of the study. This chapter is dedicated to constructs from the patient and family member interviews whilst Chapter 6 presents constructs from interviews with RNs.

The chapter commences by introducing the participant characteristics to give context to the findings of the research. The five focus codes of the patient and family interviews are explored in detail through the use of quotations from participants. This illustrates selective codes in a transparent and grounded manner. Network views taken from Atlas ti™ are provided to aid limpidity. Although the focus codes are introduced in discrete sections, they are intertwined and convoluted with fluidity and interaction that is difficult to convey. Efforts are made to cross reference and rebuild the whole experience for the reader. The focus codes have no particular hierarchy as they contribute equally, but differently, to the understanding of the critical illness trajectory. Illumination of the core category and the developing theory is introduced and will be fully discussed in Chapter 7.

Participant quotations are used to both support and illustrate deviations from core categories in an effort to ensure adequate representation of the participants' voice. Similarly Atlas ti™ network views indicate the dimensions and relationships of initial and focus codes. Where necessary lengthy quotations have been included to ensure contextual information is included to maintain authenticity to the participant's account and guard against misrepresentation (Hewitt 2007). Equally some quotations have been edited to only include relevant text to support the discussion. This is indicated by the presence of a triple dot ellipsis (…). All details that may compromise the confidentiality and anonymity of the participants and their geographical location have been removed. These details have been replaced with a generic description placed within square brackets e.g. ([mental health centre]). Pseudonyms are used throughout.

Chapter six reveals five focus codes in relation to RNs interviews. These are explored in an identical manner, concluding with the study's contribution to the knowledge base of critical illness experience and related nursing care.

Synthesis of the findings and subsequent discussion in relation to existing literature and theories are provided in chapter seven.

5.2 Participant's characteristics

Tables 5.1, 5.2a and 5.2b[2] provide biographical details of survivors and family members.
For survivors, details of their length of stay in AGCCU are provided together with duration from AGCCU discharge to date of interview.

For family members interviewed in AGCCU the duration of stay of their relative at the time of the interview is detailed. Descriptive detail of participant characteristics; gender, age, medical diagnosis are included. These data afford the reader added contextual detail.

Pseudonyms were identified in addition to research codes to assist in developing the storyline and generating a more humanistic perspective to the study (Birks and Mills 2011).

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[2] Key to table 5.1, 5.2a and 5.2b – P = Patient, R=Relative; PR =Patient+Relative

Research code	Gender	Age (yrs)	Pseudonym	Medical diagnosis	Length of time in AGCCU (days)	Duration from discharge to interview (months)
P01	F	65	Annie	'flu and pneumonia	17	6
P02	M	75	Charles	#humerus, GI bleed, respiratory failure	(3 AGCCU admissions) 40	9
PR03	M	59	Andy	Emergency GI surgery	10	5
P04	F	52	Linda	Pneumonia and respiratory failure	4	5
PR05	M	55	David	Pancreatitis and rupture of biliary tract	17	10
PR06	M	58	Mark	Pancreatitis	29	6
P07	F	61	Judith	GI bleed and rheumatoid arthritis	6	6
P08	M	72	Richard	Anaphylaxis	4	6
PR09	F	54	Jane	Sepsis and breast reconstruction	16	6
PR10	F	72	Sharon	Sepsis and GI surgery	24	7
P11	F	46	Joy	Crohns disease and GI surgery	5	7
PR12	M	69	James	Emergency bowel cancer surgery and sepsis	16	11
PR13	M	42	Kevin	Necrotising fasciitis and L arm amputation	13	4
PR14	M	63	Alan	Emergency aortic aneurysm repair and cardiac arrest	10	8
PR15	M	70	Barry	Peritonitis and cardiac arrest	6	8
PR16	M	69	Harry	Biliary peritonitis	15	8

Table 5.1 Patient participant characteristics

Key to table 5.1, 5.2a and 5.2b – P = Patient, R=Relative; PR =Patient+Relative

Research code	Gender	Pseudonym	Relationship	Medical diagnosis of patient and demographics	Admission time within AGCCU
R01	F	Wendy	Partner	Bowel obstruction and sepsis, male aged 82	72hrs
R02	M	John	Son		
R03	F	Susan	Mother	Pneumonia, male aged 24	72hrs
R04	F	Penny	Partner	Respiratory failure, bronchiectasis, male aged 68	10 days
R07	F	Anthea	Mother	Status epilepticus, cardiac arrest, aspiration pneumonia, male 24	7 days

Table 5.2a Family member characteristics interviewed on AGCCU.

Research code	Gender	Pseudonym of family member	Relationship	Medical diagnosis of patient and demographics	Duration from discharge to interview (months)
PR03*	F	Lucy	Partner (Andy)	Emergency GI surgery, male aged 59	5
PR05*	F	Jenny	Partner (David)	Pancreatitis and rupture of biliary tract, male aged 55	10
PR06*	F	Hazel	Partner (Mark)	Pancreatitis, male aged 58	6
PR09*	M	Gary	Partner (Jane)	Sepsis and breast reconstruction, female aged 54	6
PR10 +11* (PRR)	M F	Arthur Gill	Partner (Sharon) Daughter (Sharon)	Sepsis and GI surgery, female 72	7
PR12*	F	Carol	Partner (James)	Emergency bowel cancer and sepsis, male, 69	11
PR13*	F	Sarah	Partner (Kevin)	Necrotising fasciitis and L arm amputation, male 42	4
PR15*	F	Emily	Partner (Barry)	Peritonitis, heart failure and diabetes, male 70	8
PR16*	F	Sandra	Partner (Harry)	Biliary peritonitis male 69	8

Table 5.2b Family member characteristics *interviewed with patient at clinic Key to table 5.1, 5.2a and 5.2b – P = Patient, R=Relative; PR =Patient+Relative

5.3 Findings Patient and Family Member interviews

The five focus codes presented in figure 5.6 are constructed from the 68 initial codes identified via line by line coding of 16 patient interviews and 15 family member interviews. This process has also enhanced the construction, conceptualisation and abstraction of the selective code or core category. The five focus codes are;-

- Ambiguous loss (5.3.1)
- Dreams and hallucinations (5.3.2)
- Physical and cognitive sequelae (5.3.3)
- Sensemaking (5.3.4)
- Critical junctures (5.3.5)

Codes were supported with memos to define what they meant to the researcher. Some initial codes have been placed in two categories as they can have multiple effects e.g. loss of identity was associated with both an *ambiguous loss* and as part of the *physical and psychological sequelae* of critical illness. The focus codes reflect the complex and convoluted experiences of participants. Ultimately, data is brought back together again as the developing, coalescing theory seeks to explain the phenomenon. Such co-constructed, middle range theory can contribute to advancing the discipline of critical care nursing and provide a much needed lens through which to view and comprehend critical care survivorship (Iwashyna 2010). In summary, such empirical research can lead to the development of middle range theory which may inform and advance more abstract grand theory (Jakimowicz and Perry 2015).

5.3.1 Ambiguous Loss

The premise that ambiguity combined with loss can create a powerful barrier to coping and can bring conflict to human relationships has been explored by Boss (2006). Ambiguous loss is a loss that occurs without closure or understanding. This type of loss can leave a person searching for answers, and thus complicates recovery and can reduce resilience (Boss 2006, Oakley 2007). The relationships of initial codes to the focus code of

ambiguous loss that makes up this section are illustrated in figure 5.1. Participants' spoke of "*loss*" in many differing ways; physical, temporal and relational. Survivors, in particular, revealed a loss of identity. According to Boss (2006) persistent ambiguity defies resolution and can cause serious relational disorders. The naming of this focus code was driven by the initial codes from the data and influenced by researching literature around "*loss*". The following vignettes exemplify the initial codes and collectively build to the overarching focus code.
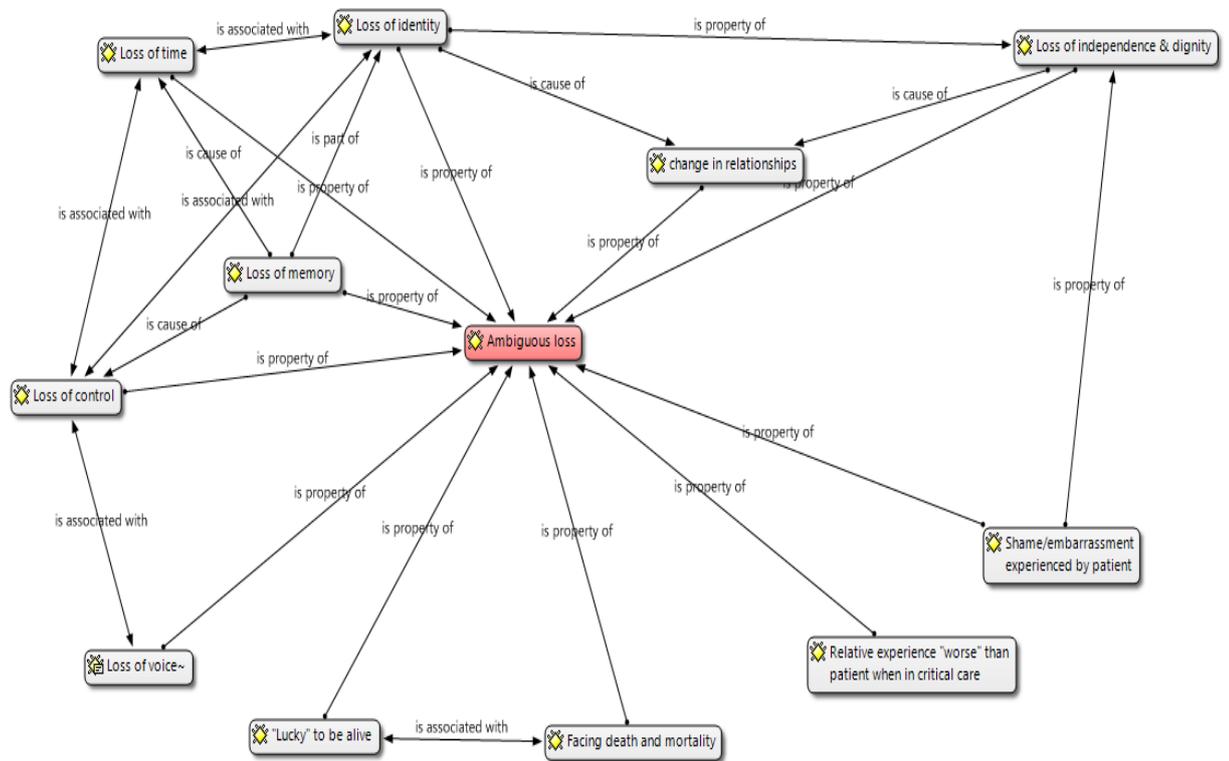
Figure 5.1 Network view ambiguous loss (focus code)

Loss of time was a recurring feature in patient interviews. Annie spoke of her disbelief regarding the passage of time saying:

Annie: *'I can't believe it is Christmas in three months, when as far as I'm concerned it's still February, it's just after Christmas, I'm still waiting for spring and summer.'* (P01)

She later stated:

Annie: '*Even though it's only like a month in hospital it seems the six months has gone, I can't remember the six months, I think, oh blimey, I've been out like six months now.*' (P01).

Time had become distorted. Such distortion can add to the sense of 'lost' time in critical care.

This loss of time frequently caused a disconnect with reality, particularly when associated with delirium. Andy was in hospital for 3 months most of which he had no recollection:

Andy: '*Yeah, three months, and most of it I can't remember*' later he stated: …' *it was such a blur and the moments of sanity were not many...*' (P02).

James articulated a similar experience over a shorter period of time:

James: '*I have no recollection at all. I know I was in the living room one minute and the next I was on a trolley or something being taken to a ward, so that two weeks, in my mind, is a complete blank to me.*

Pam[3]: *Blank, yes.*

James: *But as far as Xs [wife] concerned it's totally different...because she was there all the time. She says that she had conversations with me I don't recall, I had conversations with Dr this and Dr that and Dr thing and Dr who. The visual was that I didn't know where I was. (PR12)*

This was an early indicator of two different experiences of one individual's critical illness experience.

The combination of delirium and memory loss undoubtedly enhanced the concept of ambiguous loss; since the time lost may be related to unreal memories.

Hazel (partner to Mark) also spoke of her incredulity at the passage of time: '*You went in on 18th May and you had five weeks in ICU. I don't know where the time went.*' (PR06)

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[3] Pam refers to the researcher and author – Pamela Page

Andy revealed his hazy and complex memories following emergency gastro-intestinal surgery:

> **Andy:** *'the next thing I really honestly remember, I've got some fuzzy, fuzzy odd bits and pieces, there was basically a nurse leaning over me and saying, don't panic, you know, you're in the ICU room, you've been here for six days and, you know, you're over the worst of it.*
>
> **Pam***: You said there were some hazy bits, did you have any hallucinations or dreams or anything like that?*
>
> **Andy***: Yeah, yeah, I did, yeah, yeah. This is why I'm saying they're hazy, because they don't make a lot of sense, but... I remember seeing the heart machine and thinking I remember seeing it flat line, and I don't know if it actually did or not, but I remember there was a bit of a panic, that's what I think anyway...and I can remember somebody discussing something about whether I lived or... not that I lived or died, but .. I don't know, but it was like very sort of all mixed and muddled.' (PR03)*

These complex and complicated 'memories' again augment the notion of ambiguous loss as they may mitigate against making sense of what actually happened.

Jane also experienced a profound sense of time loss, believing she had just woken up from her surgery when in fact she had been unconscious for two weeks:

> **Jane:** *'My family came to visit and everyone kept saying, oh, you've woke up, you've woke up! And I'm thinking, I've only been asleep 40 minutes or so, you know, because to me, I didn't know I'd been asleep all that time, everyone was so happy, and I felt a little bit, well, I am in hospital, I am entitled to have a little bit of a sleep, you know, not realising I'd been asleep about a fortnight. So I was confused, I didn't understand anything that was going on' (PR09).*

The effect of lost time, whilst quantifiable, relates more to loss of time as viewed in the context of their life. For some it appeared as losing a bit of life, particularly when confronting death, time had become more precious.

Loss of memory is of course interlinked with loss of time, (as illustrated in the network view figure 5.1), which contributed to the inability to make sense of what had happened as Jane continued to illustrate:

> **Jane:** *"So I was just so confused, I don't know what happened, I don't know how I got from the X ward to ICU and what I was doing with a tube down me and why I had nurses on a one to one and everyone's looking after me and I'm thinking,...what's happened, and everyone – well you woke up, you woke up, everyone's so happy. I'm thinking, I don't know why you're so happy... I've only been asleep. No recollection' (PR09).*

Sharon spoke of her prolonged stay in critical care, which included readmission to AGCCU. She also had very little recollection of her stay however her family member filled in some of the gaps:

> **Pam:** *And you said your daughter and your husband have filled in some of the gaps...*
>
> **Sharon:** *Oh yes. I wouldn't know if they hadn't told me because I wasn't here. Well, I was, but I weren't, was I?*

Sharon effectively summarised the notion of *'being there, but not'*. Being alive in the real word but living in an unreal world of dreams, delirium or simply unable to recall any memory of real events. She went on to say:

> **Sharon:** *It feels weird because you often think about, well, what happened, and you have to sort it out in your mind by what my husband and my daughter's told me. **But you just think it don't seem true, you know, because you weren't there to know'** (PR10). (my emphasis)*

The notion of '*being there, but not*' contributed and helped construct the core category (or selective code) of '*parallel realties*' where the critical illness

experience can be very different between family member and survivor. Relatives experienced acutely the emotional trauma of admission to the AGCCU and the subsequent days were tortuous and yet the survivor frequently had little or no recollection of this period of illness.

This loss of time was linked by some participants to a sense of loss of control. Jane referred to critical illness causing loss of control within the present tense; '*I don't like the fact that I'm losing control.' (PR09).* An indication of the longer term effects of critical illness.

Physical loss of control in relation to bodily functions caused distress, embarrassment and loss of dignity. For Sharon the worst part of her critical illness experience was the incontinence she experienced and recalled after discharge from critical care:

> *Pam: So what would you say was the most stressful time for you, during that whole episode of illness?*
>
> *Sharon: Being sick every day and going to the toilet.*
>
> *Gill (daughter): The incontinence.*
>
> *Sharon: I'd got the diarrhoea and I just lay there just having to go to the toilet,*

Joy shared a similar experience when she was on the general ward following discharge from AGCCU;-

> *Joy: '...the first few days on the ward I was very weak. I remember one night I tried... I couldn't get out of bed, I needed to go to the bathroom, and obviously my legs wouldn't move and that ....well I panicked then because I couldn't really get out of bed. I personally felt a bit disgusted with myself,..I was embarrassed because I had a bit of an accident...so to me that was horrible. For me personally I thought it was awful and I just wanted to get in the shower, and I had all these things connected to me, so that was traumatic. I had a little cry in the bathroom by myself'.* (P11).

Both participants felt they had been cared for compassionately by nursing staff, as Sharon said *'they [nurses] had to keep coming and seeing to me, bless them, they never moaned, really good.* (PR10). Nevertheless, both Sharon and Joy experienced profound shame and embarrassment. As Sharon's daughter Gill highlighted the rapid transition from independence to dependence was a shock:

> **Gill:** *But it is, it's a shock to the system...you wake up and suddenly you can't do anything [laughs], and because she's so independent as well, by being incontinent is a big thing to someone, isn't it?* (PRR11).

Loss of voice, was closely interlinked with loss of identify; an integral part of ambiguous loss which can result in lack of resilience according to Boss (2006). Loss of voice with subsequent re-establishment of verbal communication had clear relational impact, as well as being a source of frustration and anxiety as shown in the vignettes below. Due to his loss of voice, Charles was reluctant to receive visitors in AGCCU but eventually welcomed the presence of his son:

> **Charles:** *"I didn't want visitors because when I had the tracheotomy I couldn't talk, that was terrible if anybody ever came. My sisters wanted to come and I said no, I've got two elderly sisters, and my brother. But strangely enough, as time went on, I'd look forward to my son coming, even if we didn't talk. It was a pleasure to see that face I knew (*P02).

Andy spoke of his frustration at his lack of voice due to the presence of an endotracheal tube:

> **Andy:** *I couldn't communicate, that was the biggest problem…..I couldn't communicate with anybody else, literally I'd basically vegetated...and it was one of the worst things I could hear but not talk* (PR03).

He, like Charles expressed some anxiety about having family members present but being unable to communicate with them;-

> ***Lucy:*** *There was somebody there all the time.*

> **Andy:** *Yeah. But the thing is I … couldn't communicate'* (PR03).

Some patients spoke of their attempts to use communication aids to replace the spoken word but this often led to further frustration;-

Alan spoke of trying to write responses but frequently muscle weakness precluded this;-

> **Alan:** *A bit frustrating actually, yeah, especially when your wife's chatting away to you and you can't really... and because I was so weak I couldn't really write either, I mean I tried to write and it was like a spider crawling in an ink pot, you know, so... No, it was frustrating apart from anything else really* (P14).

Jane attempted to point to an alphabet board but this was also too strenuous.

> **Jane:** *'I couldn't talk obviously, because I had a tube, and they gave me like a children's ABC thing to just try and spell out the word, and I couldn't even... it was just total rubbish, I was trying to spell out water and I couldn't even do that, I couldn't even hold the pen sort of to do it, very frustrated.* (PR09).

Even when Jane's voice was returned to her there was some aspects of her experience she was reluctant to utter:

> **Jane:** *'Even when I had my tube out I felt a bit too stupid because thinking that these people are going to think I'm a bit silly, I might end up in the X [mental health] Centre or something, because I'm saying all these things'* (PR09).

Returning an audible voice either by removal of an artificial airway or the use of a speaking valve was a poignant moment for staff, family members, and patients alike as Alan reveals:

> **Alan:** *'I mean my wife, when she came in I just had to nod or shake my head or whatever, and then one day they said, we'll put in a speaking one for when she comes in. And they didn't tell her, and the nurse who'd done it she said, I want to wait and see what happens.*

> *And my wife came in and she said, I love you, and I said, I love you too [laughs and tears]……. And the nurse was over the moon, she said, oh, that's wonderful'* (P14).

However, it can take some considerable time for the physical voice to return to normal and on occasion may require intervention. For Barry it was weeks after discharge before he could hold a conversation*; -'I can hold a conversation now, weeks after discharge, I couldn't.....cracked up, broke.'* He did not recall receiving any explanation as to why this happened.

Information was also lacking for Harry and his wife. When I asked *'once the tube was out were you able to talk?'* His wife responded*:*

> **Sandra:** *Yes, but you didn't make sense much, did you?*

> **Harry:** *I don't know.*

> **Sandra:** *[laughs]*

> **Pam:** *And did anyone explain to you why what he was saying didn't make sense?*

> **Sandra:** *No, not really, but then he'd done it before and he got better, so he knew that it was a process, but they didn't tell us in X hospital either'* (PR16).

Harry had experience of a previous elective admission five years previous to this emergency admission. He experienced profound delirium which despite being five years ago, was vividly remembered; "*And they're still vivid today, even five years ago I can still recall them, yeah, five years ago today".(PR16).* Such vividness was also found by Barnet (2009) who states that the dreams and hallucinations experienced in AGCCU are far greater than any dream in ordinary life. They can be so real that they are the first thing shared with their family member which can enhance anxiety and distress further.

The repartee (evidenced above) between husband and wife was an illustration of a dyadic interview in process; with one partner supporting and prompting the other in a natural manner.

Experiencing profound and acute losses (temporal, relational, physical and more) can culminate in a loss of identity. Andy explains how as a result of his prolonged critical illness and profound muscle loss he could neither communicate nor move:

> **Andy:** *I couldn't communicate, that was the biggest problem. I couldn't communicate with anybody else, literally I'd basically vegetated......and it was one of the worst things I could hear but not talk, I couldn't talk but yeah, I'd listen... just like a... I don't know, a pet I suppose, really... you can't... yeah.*
>
> **Pam:** *Did you feel trapped in the bed then?*
>
> **Andy:** *Yeah, I did, yeah. When I woke up and just couldn't move. You know, the really strange thing I think was when I finally did try and move that it was like going back to being a baby. (PR03)*

Using the simile of a *pet* implies loss of autonomy and referring to himself as *being a baby* indicated the inability to function as a male adult who was previous fit and running a successful business. The sudden onset of dependence was clearly a challenge for both patients and family members.

From a relative's perspective Kevin's wife Sarah described the shock of seeing her previously fit 42 year old husband and father of their three children.

> **Sarah:** *"a few times when I went to see him he was very helpless, he was extremely weak in the beginning, he had to have the cot sides up, he was very confused, a little bit – not aggressive, but just because of his confusion he was very frustrated. One arm was up, obviously this arm was gone, and because he was wriggling a little bit quite often I would walk in and he's half way down the bed and the sheets weren't changed and he was calling out and nobody was with him. And I know everyone is really, really busy, but it was a shock to me to see my husband in that helpless state and that upset me more than anything really" (PR09).*

Having lost his left arm to necrotizing fasciitis[4] and experienced severe sepsis, Kevin and his wife found the transition to the ward difficult. As a couple and indeed as a family, they were having to make sense of the delirium as well as come to terms with the loss of a limb. Sarah spoke of Kevin's denial in relation to the amputation:

> **Sarah:** *'So it did take him a good week, I would say, to really get back to some kind of normality where he could have a conversation and acknowledge what I was saying, but he never acknowledged the arm; he wouldn't talk to us about it at all' (PR13).*

Unsurprisingly, such loss impacted on relationships with and between family members; largely in a negative way although one couple surviving critical illness found the experience gave them a new zest for life. Jenny spoke of an added '*appreciation*' of the time with her husband.

> **Jenny:** '*It does make you appreciate so much more than what you normally do. You don't take things for granted because, as I say, David went to bed that night completely healthy, within hours he was more or less fighting for his life, so it's... that's the hardest thing, you know, it happened so quickly (PR05).'*

Later in the interview Jenny again returned to the subject of their new appreciation of life and living it to the full:

> **Jenny:** *'The things that you take for granted you appreciate them, and I hope that will never leave us, because it is a big wide world out there and we do things... We've always been active and done things, but we do even more, and we appreciate things a lot more, and it's only because of what happened to him. Drastic measures! (PR05).'*

They also spoke of the change in relationship with their two sons who had been immensely supportive during the whole critical illness journey. However the majority of the participants spoke of tensions that had arisen as a consequence of critical illness. Annie spoke of her daily struggle to

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[4] A flesh-eating disease caused by bacterial infection.

perform basic tasks in the home and how she perceived her family as being unable to understand why she struggled:

> **Annie:** *"But people don't under... people can't understand. Though they've seen me go through it, they can't understand what it is like to go through it...because at the end of the day they're still the same person, even though I've caused all this rigmarole in the family, they are the same person as they was what happened before, except I suppose they've had a lot of upset, what have you, I'm not the same person"* (P01).

Although her family had witnessed and supported her through the critical illness there is evidence from this study that the experience is very different for survivors and their family members. The repetition of "*same person*" by Annie seems to emphasise the fact that she is not the same person by virtue of having survived a critical illness. Further evidence of consequential change in relationships.   Annie, like many survivors, wanted to talk about her experiences; in particular to somebody who understood or who had insight in to the critical illness trajectory. The in-depth interview provided a vehicle for such discussion:

> **Annie:** '*But it's nice to speak to someone that understands, because I try to speak to the family and I say to them, you don't know how... oh yes, we do know how you feel, but you know they don't*' (P01).

Life after critical illness affected the whole family, not just the survivor; the level of dependence before and after critical illness can be a sharp contrast as Gill above highlights. Annie noted the physical sequelae and the psychological effects of surviving critical illness with loss of independence changing the relationship she had with her daughter pre-critical care admission;-

> **Annie:** '*…because my eye sight's not as good as what it used to be. ..I've lost a lot of my hair. I can't do things that I used to do so I have to rely on... because my daughter's moved back in, so I have to rely on her to do things, and then I'm a very independent person, I don't*

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> *like asking people to do things, so that's what I've got to do now, so I*
> *get really short tempered (P01).*

Such changes in relational identity typify ambiguous loss and according to Boss (2006) participants may benefit from family therapy to aid mutual understanding of the experience and develop resilience.

The physical, cognitive and psychological impact of critical illness is well documented in the literature (see 2.6.3 and 2.6.4) although it was very clear from the interviews that both patients and family members were unaware that many of the challenges they were experiencing were commonly experienced in this population. Further evidence of the physical, cognitive and psychological impact is provided in sections 5.3.2 and 5.3.3, however there is an acknowledged gap in the literature with regard to the social and relational aspects of recovery from critical illness (Rattray 2014).

Some family members struggled with supporting rehabilitation and appeared very alone on the rehabilitation journey. Mark, 58 years old, who previously played three rounds of golf a week spoke in an understated manner how he tried to '*get going*' following a four month hospital stay, with no contact from his General Practitioner on discharge home. He presented at the interview in a wheelchair and with evident foot drop[5]. He had survived a prolonged episode of pancreatitis due to gall stones and still had a long journey ahead before he would be '*thriving*'.

> **Mark:** *'I was struggling a little bit to get going, you know, get going,*
> *get myself...'*
>
> **Hazel (wife):** *'Yeah, I think he wanted to, but he can't, we try to push*
> *him and the family would say, come on dad, you must, you know, do a*
> *bit more, you must walk a bit more, and I pushed him a bit too far this*
> *week and he kind of collapsed' (PR06).*

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[5] Foot drop is a gait abnormality in which the dropping of the forefoot happens due to weakness, irritation or damage to the common fibular nerve including the sciatic nerve, or paralysis of the muscles in the anterior portion of the lower leg.

Hazel went on to talk about the change in her husband following critical illness; it was evident from both observation and interaction that she had become his main carer with a consequential change in relationship post critical illness:

> **Hazel:** *"He just sounds a bit different, from our point of view, you know, coming home, he looks different, he sounds different and he behaves a bit different, so it's almost like there's a bit of him that's not the same anywhere."* (PR06).

Again, further evidence of a sense of loss of identify or loss of familiarity in addition to a change in their relationship.

The heterogeneity of the population studied was evident in Linda's account and revealed individual responses to having a relative who is critically ill. This reflects the need for an individualised patient and family centred approach to care:

> **Linda:** *"I had three family members that came to visit me on a regular basis and they all, they were all different, and they all reacted differently to it. My dad was obviously quite upset about it, he was the one that actually took me in when I was admitted and he found it all extremely stressful and upsetting. My son hasn't really talked about it that much, I think he, it probably affected him more than the others, so... even now he'll swerve the subject if I, you know, if I try and talk to him about it, so he found it very difficult to cope with. My brother was in pieces [laughs] my brother was, you know, well he thought they were going to lose me, so he was the worrier".* (P04)

Linda went on to talk about the effect her critical illness had on her family members but in particular her teenage son and how the dynamic of their relationship had changed following her critical illness:

> **Linda***: "...there's only my son and myself that live here, so yeah, it was... I mean we were very lucky that my father actually was visiting from X when it happened and my brother, who lives in X, came down immediately when I was taken in, I think my son, it hit him harder than*

everybody else....he's matured an awful lot over the last few months and he now thinks, you know, he needs to take care of me, so [laughs] yes. He's stepped up, I suppose..." (P04)

Linda experienced profound delirium in Critical Care and this worsened on transfer to the general ward. She spoke in the present tense how she still struggled to believe her son's account of her own critical illness.

> **Linda:** *"And even now I find that really difficult to accept that he's telling me the truth, because I was convinced or am convinced that there was, you know, this huge room behind me with all the equipment in it," (P04)*

Feelings of guilt were expressed by both survivors and family members and are characteristic of ambiguous loss; keeping people 'in the moment' and inhibiting them from moving on (Boss 2006). Joy spoke of the guilt she experienced in being unable to fulfil her role as a mother post critical illness.

> **Joy:** *"I suppose because not being able, just being a mother you're used to multi-tasking and things, aren't you? Obviously I couldn't cook, then I felt guilty because of my youngest son, and I couldn't cook him dinners and things, so I felt quite bad then." (P11)*

Many survivors spoke of facing death and their own mortality with some explaining the effect that this has on them:

> **Joy***: It freaks me out a little because obviously I didn't think I was going to have an operation and not wake up until Friday, I didn't realise how bad I was, that sort of freaked me out. And then your mind works overtime, you think, oh, I could have died, and my children, and I wouldn't have known nothing about it, would I. I sort of quite happily went down for this operation and I could have not returned, you know,*

> **Pam***: And do you still think about that now?*

> **Joy***: Sometimes, it just freaks me out, it's just quite... I don't know, it freaks me out, but I'm glad I'm here. (P11)*

Facing death and confronting one's own mortality frequently prompted the phrase "*lucky*" to be alive. This was heard recurrently but, at the same time, there was acknowledgement that life was not the same as prior to critical illness. This combined *grief and gratitude*, expressed simultaneously, was evident in several interviews.

Jenny spoke openly and honestly about the enormous pressures of living with and through critical illness as a family member and provided a further insight in to the different worlds experienced by patients and family members in critical care;-

> **Jenny***: "I will be honest, because I have spoken about this to David, our two kids were superb and very supportive and the eldest son said, I've got to say something to you mum, and I knew what he was going to say, if Dad's going to die, let it happen now, don't keep putting us through... So from that side of it, I don't know if David to this day, will ever know what the family goes through, but there he is sitting there, (PR05)".*

Such insights provided by family members enhanced my theoretical sensitivity to the developing theory of *dualistic worlds* experienced by survivor and family members. There is also a sense of temporality; that is being bounded by time. The temporal processes of adaptation in response to (chronic) illness are well documented by Bury (1982), Charmaz (1995) and others but not so within acute and critical illness.

Survivors and family members spoke openly of their confrontation with either their own mortality or that of their loved one. Kevin's wife Sarah, recounted being taken into recovery room of the operating theatre;-

> **Sarah:** *"They identified that the infection was necrotizing fasciitis, there was a curtained off area at the bottom of the recovery room and I thought he was dead, I thought, he's behind that curtain….. Three surgeons [who] explained to me that he was very poorly and they needed to stop the infection and the only thing they could do was to amputate, because it had gone to there [points to arm] in the bone, but further up in the flesh. If it got to here [points to top of arm] then*

they wouldn't stop it. So he went for five hours and they brought him back to ITU and started to recover him and …the surgeon came in and said, I'm really sorry... and I thought Oh no not the other arm too, and I just thought, oh my God! Don't, I want him to live, please God, but if he does live don't take both arms," (PR13).

The tension of surviving critical illness with the potential loss of both arms was too much for Sarah to bear or comprehend. Her world as a wife and mother had been totally disrupted; confronting both mortality and disability concurrently. The expression that physical survival alone may not be enough was evident in other transcriptions, with ongoing morbidity of critical illness impacting on participants several months following hospital discharge. As Jane said *"People think, oh, you should be happy because you're alive. It doesn't quite work like that, you know, it doesn't.*" (PR09). Jane acknowledged that she still had not accepted that she had been critically ill; "*I still try and dismiss the fact that I've been that ill. I've not come to terms with the fact I was at death's door basically, and I think I have the problem there.*" (PR09)

Other participants discussed their confrontation with death in a more factual, procedural manner;-

> **Richard**: "….*they put this pipe down my throat, because there wasn't sufficient oxygen getting to my lungs, my ticker stopped for two minutes. They started me going again and the first thing I remember, or got told about this, is when I woke up in Intensive Care, and they said oh, you've been here for four days."* (P08)

Richard had experienced anaphylactic shock following a change in his prescription medication for hypertension by his general practitioner. He acknowledged the role of his wife in saving his life; - "*If my wife hadn't been behind me I'd have been dead, because I would have choked"* and how "*it made me appreciate life a bit more*". There is consistent evidence of the opposing dimensions of being *lucky* to be alive (above) and *facing mortality.* Further evidence of gratitude and grief. Anthea, spoke of the challenges of living with her son who had been admitted to Critical Care for the second

time and the dawning realisation of what admission to critical care could mean;-

> **Anthea:** *"...it is tough going, and ending up in here [AGCCU] is really tough, because obviously you see Intensive Care as being what it is, and they're only in here because they're really, really poorly. And last time it wasn't 'til I spoke to somebody, they actually said to us, you do realise he's extremely ill, and I didn't think you could be extremely ill just having epilepsy, but of course now I've Googled it, so of course this time that's when you think the worst". (R07)*

Alan's confrontation with his own mortality was very real to him. Alan had experienced an emergency aortic aneurysm repair and had been discharged home, in his view too early and required readmission

> **Alan:** *"I basically think I was probably discharged too early because within two weeks I was back in again, virtually with the same problems, I couldn't breathe, my heart was going like the clappers, in fact I actually had a heart attack at home which I didn't realise, it took them about half an hour to get me stabilised at home and then they rushed me in. Once I was in, which unfortunately was over the bank holiday Easter weekend, so there wasn't a lot of doctors around. I had another heart attack and they called my wife in because they said they didn't think... [tearful]". PR14*

He went on to explain two out of body experiences during this period of deterioration and cardio-respiratory arrest. This was perhaps the most extreme version of a differing reality or dualistic world, certainly to the one experienced by his wife. Despite being described on paper in a sequential and factorial manner he was tearful and emotional in his articulation;-

> **Alan**: *"...and I actually had two out of body experiences...*
> **Pam**: *Can you tell me what they were like?*
>
> **Alan**: *...well they weren't... I wouldn't say they were unpleasant, in fact, well, I wouldn't say I enjoyed them, but I mean my wife had just come in...I was obviously really having trouble breathing because they*

kept on putting this huge mask on me, which I couldn't cope with, and I had to... but I was having real trouble breathing, and then all of a sudden it was almost as if I had stopped breathing, I felt fine.   And then I went all cold and tingly, but not an unpleasant sensation and I was up on the ceiling…..

Pam: Looking down?

Alan: Looking down. And this happened twice within a short space of time, because I said to my wife afterwards, I said, you know, I was up there thinking, you know, this is it. And then I thought, well, you're here. I want to be with you... [laughs]" (PR14)"

Laughter was frequently apparent at some of the most poignant points of interviews across all participants. The proximity of both tears and laughter seemed very close for many participants. To me this emphasised the strength of emotions such experiences generated and the conflicting dichotomy between 'lucky' to be alive and facing one's own mortality. There is also some debate around the two sides of survival; survival from death and survival for life (Barnett 2008). Alan had clearly survived for life. Confrontation with mortality undoubtedly changes the world view of both survivors and family members with both grief and gratitude being a common dialectic. However physical survival alone may not be enough, as a member of ICU Steps blogged:

> *Bill: "Unfortunately many people never get the psychological support they need and are left not knowing why they feel so bad, when they've just survived a near death experience and everyone tells them how happy they should be, if only it could be like that." (ICU Steps blog 2016)*

The next section presents the findings in relation to dreams and hallucinations experienced by survivors and witnessed by family members.

5.3.2 Dreams and Hallucinations
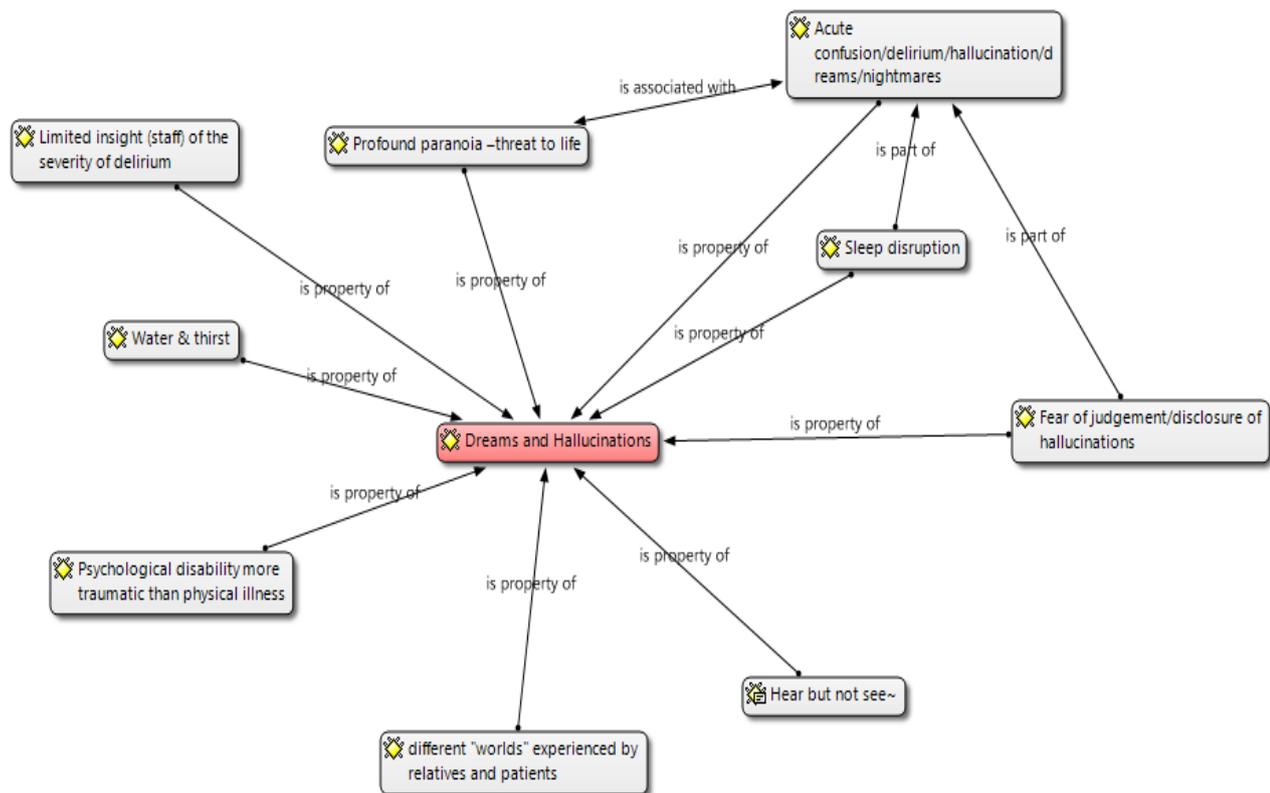
Figure 5.2 Network view Dreams and Hallucinations (focus code)

All sixteen survivors of critical illness experienced either unusual, recurring dreams and/or hallucinations or nightmares. This study adds to the growing body of knowledge around the psychological problems experienced by patients both during their stay in critical care and following discharge. Figure 5.2 illustrates a network view of initial codes leading to the focus code of dreams and hallucinations.

For Linda the psychological impact of critical illness, mainly in the form of paranoia, was more disabling than the physiological critical illness. She was desperate to be discharged home from the ward;-

> **Linda:** *"I literally begged them to let me out, every couple of hours everybody was trying to kill me, and then I'd sit there and think, oh this is ridiculous, you know, it can't possibly be true, there's all these people here, and eventually I decided that I needed... I knew I was ill,*

mentally ill at the time, and I knew I needed to get away and get home, and once I got home then things started, you know. I mean I can look back and laugh now, but at the time it was horrendous, you know, sort of the first 24 hours of getting home I was still convinced that someone was trying to kill me". (P04)

Whilst in the AGCCU Linda recalled her conviction that all staff were trying to kill her;-

"*I remember that – I think – I had a tussle with one of the nurses, and I think I may have hurt her arm holding on to her, I thought she was trying to tamper with the machinery...and after then I was convinced that they were all trying to kill me, because I'd hurt one of their nurses, so it was quite traumatic, I think is probably the best way of putting it."* (P04).

Linda was desperate to leave AGCCU but unfortunately her psychological well-being deteriorated further:

Linda: "*I couldn't wait to get out of intensive care, because I thought once I got onto the ward I'd be safe, and unfortunately it followed me through, so once I got onto the... I think I... I actually felt safer in intensive care than I did once I got onto the ward because there was a lot more coming and going on the ward and it's... the psychosis seemed to really take a hold once I got onto the ward. So that was worse, I think, than the intensive care experience."* (P04)

All patient participants experienced dreams or hallucinations and some had previously been reluctant to share them with either family or health care professionals. Some participants shared them for the first time as part of the study; one example is from Charles:

Charles: *'I had very nasty, very nasty hallucinations, I was a drug runner, I was a booze runner, I was involved in money laundering, I was... all these criminal activities. Is that odd? Is it me that's odd?'* (P02).

When I responded that it was not at all uncommon, a sense of both amazement and relief was evident.

James explained how the dreams and hallucinations he experienced caused him to lose touch with reality:

> **James:** *'I was – God knows where I was, but if you remember from your childhood, Kaleidoscope with the six, seven, eight lenses, whatever they are, nurses used to get into lens nine and they walked, dum, dum, and all the time this music's going, de, de, de, de, that irritating music at Disneyland? De, de, de – that kind of thing was going on and so forth. And it got to the point where I had no idea where I was, I didn't know what I was looking at, I wished it would stop, but it didn't, and then eventually it just faded, so I must have gone to sleep, that must have been subliminal, whatever they call it'.(PR12)*

Many clinical staff are unaware of the prevalence of delirium, both in AGCCU and following discharge to ward areas or the community. This is confirmed in the literature (Elliott 2014, Darbyshire et al 2016) and in this study (Chapter 6). In this study survivors and their families had received little, if any information on delirium as a result of critical illness. The distress of hallucinations was also felt and expressed by family members. Susan witnessed her son (aged 24 and admitted with pneumonia) hallucinating during a brief period of self-ventilation prior to re-intubation;-

> **Susan**: "*Actually yesterday evening was really horrible as well because when he was woken up, he was woken up gradually and then he was taken off the respirator, he was hallucinating so badly and because he's had some mental health issues five years ago when he was at that point hallucinating and hearing voices, I thought, oh no, he's gone back five years to that, and that was the most horrific experience for us, that's the worst experience of my life really*". (R03)

Here we see the impact of a family member observing a loved one in a world that is unreal to them but real to the patient. Two different realities or worlds or as Sharon previously said "*two different nightmares*".

Profound paranoia (delusions of persecution) were frequently articulated and, again, add to the growing corpus of knowledge of the psychological

impact of being critically ill. Survivors commonly reported that nurses were trying to harm or kill them. When asked what the hallucinations were like Alan replied *"not nice because I was convinced one of the nurses was trying to kill me"*. This was not an isolated episode but went on for a period of days;-

> **Alan:** "*I was convinced she was trying to kill me and as I say, it was really, really vivid, and it went on, it wasn't just a one off thing, it went on for a couple of days, and I was convinced, because I think one day I actually hit one of the nurses because I thought she was joining in, you know.*"(P14).

It is hard, if not impossible, to imagine that your life is in constant danger and you are lying, probably naked, in a hospital bed, with tubes and lines 'tying you down' but this is the physical reality of being critically ill and necessary for physical survival. It is perhaps not surprising that connections have been made with the experiences of survivors of war and other atrocities and that post-traumatic stress symptoms or disorder can and does develop as a consequence (Parker et al 2015). The combative behaviour described by Alan (above) is a daily event for most critical care nurses, and indeed ward nurses, yet it is far from normal for the individual patient concerned. A point highlighted by the lay member of NICE clinical guideline 103 (Delirium: Diagnosis, prevention and management) who experienced profound, paranoid delirium but the only health care professional that had noted and recorded this important diagnosis in her medical notes was the physiotherapist (personal communication Dr Ian Bullock 2012). When the patient challenged this at her follow-up appointment the staff stated that her behaviour was 'normal' given how ill she had been, however from her perspective it was anything but normal for staff and her family to be trying to kill her.

For some survivors their hallucinations were more pronounced or memorable post discharge from critical care; Barry had experienced biliary peritonitis complicated by heart failure, diabetes and acute kidney injury. Whilst on an

acute medical ward (post AGCCU) he described how he felt he was being kept in hospital against his will and the overwhelming desire to escape.

> **Barry**: "*I could see that trolley and that table there and I was hallucinating about what the people were doing and what was behind it. I could see through walls! And as an ex-engineer my feet are clearly grounded [laughs] and, you know, never taken hard drugs, but if I hadn't realised what it was... But at the time, that was the interesting thing, I hadn't made the connection between my treatment, the infection and the antibiotics and the hallucinations, I firmly believed the first two or three of them, episodes, were real, absolutely real, and that I was being kept from going home. All my mind was focused on was escaping.*"

Barry had reflected on the hallucinations and sought to make sense of them, making the following observation; "*retrospectively I'm thinking, wonder if people who are losing their mind, becoming insane, I wonder if that's how they think, that they are normal, but everyone else around them isn't*". It is clear that such experiences had a profound and long lasting impact; in some cases greater than the physiological illness.

Family members were aware of their relative's paranoid delirium. Hazel (wife of Mark) spoke of the care that he received from critical care nurses and in particular how they had really listened to what he was saying whilst being in a delirious state.

> **Hazel**: *A couple of the nurses came and spoke to him, you know, and they were really listening to him as if he was making a lot of sense, and I was kind of thinking, why are you, you know, why are you... he's just... but they were like really listening to him, because he accused one of the boys of putting bananas down his tube and trying to kill him, and this particular ICU lad was special, he was lovely, he did an awful lot for you, and, yeah, he's trying to kill me! He's trying to kill me!*

Hazel as a relative was acutely aware of her husband's confrontation with mortality and recalled when "*he was on 100% oxygen, you know, I remember one night it was 100% oxygen. There was actually nowhere to go from*

there". In contrast, Mark had little if any recollection of his critical care stay, his wife Hazel saying that "*when I talk to him about it he doesn't really remember".*

Difficulty in distinguishing between what was real and what was unreal was a recurring theme in the interviews. Kevin believed he was in Great Yarmouth for the duration of his critical care stay and that it was Christmas; *"…on the nurses' station for some reason I just thought it was Christmas and they were having a party, like a little party, there was like hot chocolate, whether they were really drinking hot chocolate I don't know."* He was acutely confused on discharge to the ward according to his wife Sarah. Kevin stated that "*Apparently I was quite rude to family members, telling nurses to get rid of them because they were useless...*" Family members have to contend with making sense of behavioural changes as well as the physiological consequences of critical illness. Equally, survivors were challenged if and when they learnt of their altered behaviour to make sense of it.

Annie (P01) in common with other survivors spoke of "*…weird recollections".* She went on to describe classic *capgras delusion*[6], which may be related to an inability to recognise emotional significance in the face. Sedation and delirium inhibit such interpretation (Jones 2014a). Patients are consequentially unable to link different memories over the time of their critical illness.

> "*I remember seeing doors with people standing, like little midgets, hobbit things, standing, curtains with all like stars and moons on, and people doing things to me that I didn't want done.. but they're all faceless people..."* (P01).

When I asked whether she had received any explanation for the hallucinations that she experienced she said not, but stated that she had used the internet as a resource;-

> **Pam**: "*And has anyone explained to you why you had hallucinations"*

---

[6] Capgras delusion is a disorder where a person holds a delusion that someone has been replaced by an imposter

> **Annie**: "*I've looked it up on the internet, it's all to do with the medication they gave me to keep me under, and my daughter, Y, said, she said like, because one of her friends is a doctor and she was looking after me, Y said to me one day, she was laughing, and I wondered what was wrong. She said, it's taken three times as much sedation to knock your mum out than it does for a normal bloke*".

Annie was still struggling to come to terms with life after critical illness and she made the following recommendation to help patients such as herself; "*you could have someone come round who'd been through a similar experience … just like to explain all the sorts of the hallucinations...*". Annie explained how the hallucinations she experienced created a sense of disconnect between her and her family.

> "*..because I kept saying to her [daughter], I saw this over there, she said, no, you couldn't have mum, I said, but I did, I saw that, I know I saw... you know, you're so adamant*".(P01)

Similarly, Charles (P02) spoke of conversations with his son around hallucinations that seemed so real to him "*I used to say, is that boat your wife's uncle or something? He said, what boat? I said, that boat. He said, we haven't got a boat. Like I was going down the Thames and I was being left on my own. But it was so real*". Charles spent a total of three months in critical care, much of that time was lost to him in terms of reality "*it was such a blur and the moments of sanity were not many...*"

The long road from survival to regaining an acceptable quality of life had made Charles reflect on his critical illness experience and questioned his physiological survival "*what can I do? Would it be better if I died? That's... I suppose a lot of people get like that, don't they? And you think, do I want to be like this for the rest of my life?*" He experienced suicidal thoughts during his episode of critical illness which he had not shared previously "*…[laughs] I had had enough. I hadn't thought about this when I was talking next door, but there were a couple of times when I was thinking, how can I die?*" A further example of laughter being evident at the most poignant of disclosures. The interview had followed discussion with the consultant intensivist yet it was

only during the course of the research interview that this disclosure was made. This may indicate enhanced psychological security on the part of the interviewee but can confer greater responsibilities to the interviewer. Later in the interview he returned to this subject "*I was thinking, how can I commit suicide without hurting myself too much, because I just felt that life was a bit worthless*".

Six months post discharge Annie was still experiencing nightmares and irritability which was causing conflict within her family;-

> **Annie**: *No, I still get nightmares...*
>
> **Pam**: *What do they involve?*
>
> **Annie** *...like with blue curtains and stuff, and I do get a lot... I do get very irritable and I shout a lot at people, and then they shout back at me, and then it makes me shout even more, ..What it is, I think it is, is they saw me come in at like 7 stone, that's what I was when I come home, and now they've seen me like this, so as far as outward appearances, I look fine, but inwardly I'm still, I think, recovering from it...*

This vignette furthers the argument that physical recovery, for some survivors, can be more rapid that the psychological recovery post critical illness. Such lack of visible ill health is a well-documented struggle within the field of mental health. As Linda (P04) stated the experience of paranoid delirium on the ward and at the point of discharge "*was worse than the intensive care bit, I must admit*".

Jane (PR09) and her partner Gary also spoke of the blur between unreal and real worlds as perceived by Jane. This contrasted with the real world experienced by Gary and a sense of two different worlds and possibly some tension being evident;-

> **Gary**: "*It was a blur between reality and the dreams of course, so you would tell us, oh this happened and this happened as if it was real and we'd like, right, OK, you know...*"

Jane: "*It was real to me*".

Gary: "*Yes, of course it was, absolutely*".

Jane: "*It was real to me, it was very, very real to me what was happening was real and...*"

Gary: "*But it took a while, perhaps a few days, for you to realise, oh, maybe I am having dreams then, maybe, you know, for you to take on board*". (PR09)

Jane, like other patient participants, didn't share her hallucinations with staff but did with her family. Gary spoke of how he would "*play along for a little bit, don't you, but you say, well actually, no, you're here in hospital, there is a roof, everything's OK...*" During the interview Jane disclosed that she was fearful that she was going 'mad';

Jane: "*I'm going mad, I mean I kept saying... I said oh, there's drips coming through the ceiling, didn't I? I kept saying to you, oh, they had to move my bed; they did move my bed, I remember them moving my bed, but they've had to move my bed because the ceiling's all dripping, I was obsessed with this water coming through the ceiling and me being in this shack. Sorry...*" (PR09).

The inclusion of an apology may be indicative that Jane felt she had done something 'wrong'; a lack of congruence with normal behaviour and feeling an associated stigma. The in-distinction between what was real and unreal from a survivor's perspective was a recurring theme. Harry (PR16) had a critical care admission five years previously and experienced vivid and memorable dreams but had no recollection of his actual stay in critical care on either occasion. Similarly, on his recent admission to critical care he stated:

Harry: "*I don't remember one little thing about the time I was in there, only the dreams...*"

Pam: "*Yes*".

Harry: "*...they were so vivid, you know, and so vivid today*".

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This finding is in keeping with Storli et al's (2008) research which found acutely intact recall of dreams ten years post critical illness.

Andy (PR03) also had very limited recollections of his stay in critical care, remembering only "*bits and snatches*" which continued to limit his ability to make sense of his critical illness.

> **Andy**: "…*you know, I remember seeing the heart machine and thinking I remember seeing it flat line, and I don't know if it actually did or not, but I remember there was a bit of a panic, that's what I think anyway...and I can remember somebody discussing something about whether I lived or... not that I lived or died, but .. I don't know, but it was like very sort of all mixed and muddled.*" (PR03)

Andy had a diagnosis of pancreatitis and had very clear recollection of staff saying that he was an alcoholic. Pancreatitis is generally caused by either gall stones or alcohol abuse; in Andy's case it was the former. He stated:

> **Andy:** "*I can remember people talking to me, but they kept saying to me that I was an alcoholic. And I thought, I'm not an alcoholic, and I kept saying to them, I'm not an alcoholic. Oh yes, that's alright, and they kept on and on and on, and then all of a sudden they said, oh, that's OK then, you're not an alcoholic, and I remember that*". (PR03)

As a consequence he wouldn't drink any alcohol post critical illness. Neither he nor his wife (Lucy) recalled receiving any explanations for the hallucinations that he experienced, although they spoke of a friend who had been through a similar experience.

Sharon (PR10) shared the dreams that she experienced whilst in critical care. Drug taking or dealing is a common theme reported both in this study (Charles) and others. It does cause discomfort for some patients. It was clear that Sharon had shared the dreams with her daughter Gill.

> **Sharon**: *I dreamt I was on a boat and the nurses were saying, come on, I woke up and they were all packing my things. And I said, what are you doing packing all your cases and that? So they said, don't worry, they said, we've got to get off the boat in a minute. I said, well*

what's happened to me, I said, I've got to go to hospital, I'm in hospital! They said, oh don't worry, we're taking you with us. [laughs]. That's all I remember of that, but that was a bit weird. And then I kept seeing staff having parties at night.

Gill: *And taking drugs!*

Sharon: *Taking drugs!*

Gill: *[laughs] I used to come in and she used to say to me, coo, you should see this lot at night! [laughs] (PR10)*

Sharing dreams and hallucinations with family members appeared common but there was a reluctance to share with staff at the time as Barry disclosed; *"because I didn't know who to trust, I didn't know who I could tell, tell the family, certainly, but tell someone on the ward, I'm not so sure."* (PR15). Barry, like Linda, experienced more profound delirium following discharge from critical care and there is evidence from the literature and this study that staff on acute medical and surgical wards are unaware of the prevalence of delirium post critical illness.

Sleep deprivation is a known contributory factor to the development of delirium (NICE 2010), and both people and technology can, and do, limit sleep in both AGCCU and acute ward areas as seen below. Family members were also affected by the ever prevalent alarms. One family member claimed that he "*used to hear them machines in my sleep*" (Arthur PR10). The inability to distinguish reality also limited the quality of patients' sleep as Linda describes;-

Linda: "…*a young boy, while I was there, and it's funny how things sort of come to you out of the blue and I remember somebody saying that he'd been brought from X Hospital, he had something the matter with his heart, and he was only young, and I remember the nurse that was looking after him actually cried. And then you'd go back to sleep again and you're not sure whether you've dreamt it all or not, and it's quite strange that... you find it difficult to differentiate between reality*

and, you know, what you may have been imaging and what have you". (P04)

Pain was also a limiting factor for sleep in some patients. Post AGCCU Joy was on a surgical ward "*because I suppose when you're in a side room they sort of... they tend to forget a little bit, because when I was on the ward I got [pain relief] every four hours, and so that particular day I was in a lot of pain, I couldn't sleep properly, I couldn't get comfortable.*" (P11);

Family members struggled to sleep during their relatives' stay in critical care. Susan (R03) struggled to sleep since her son had been admitted to critical care:

> **Susan:** "*it was very much a shock, and you wake up in the middle of the night thinking all sorts of things. And I know they've said you can phone any time, but I don't like to, So no, my sleep pattern's gone out the window as well! I've been going to bed later and getting up fairly early and waking up in the night.*" (R03).

In the ward area Harry (PR16) complained of the noise from nurses talking at night:

> **Harry:** "*I think perhaps nurses don't understand is that when it's nice and quiet building up to turning all the lights off bar the night lights, they then get themselves into their ward stations and their conversation starts to go up. The level of voice goes up, and rightly, you know, it's not serious, it's jovial, but if you're a patient, you really start to think, what on earth is going on?*"

Sleep is crucial to physical and psychological well-being for both patient and family members (Alasad et al 2015) and there are obvious practice implications here which will be discussed in Chapter 7. The next section presents the findings in relation to the physical and cognitive sequalae of critical illness from a survivor and family member perspective.

5.3.3 Physical and Cognitive Sequelae

There are multiple factors that lead to physical and cognitive sequelae following critical illness, that is, a condition which is the consequence of a

previous disease or injury. As indicated in section 5.1 there are multiple cross overs between the initial codes and focus codes presented in this chapter. The purpose of rebuilding and presenting the data to elucidate the social processes of and between critical illness survivors and family members continues.
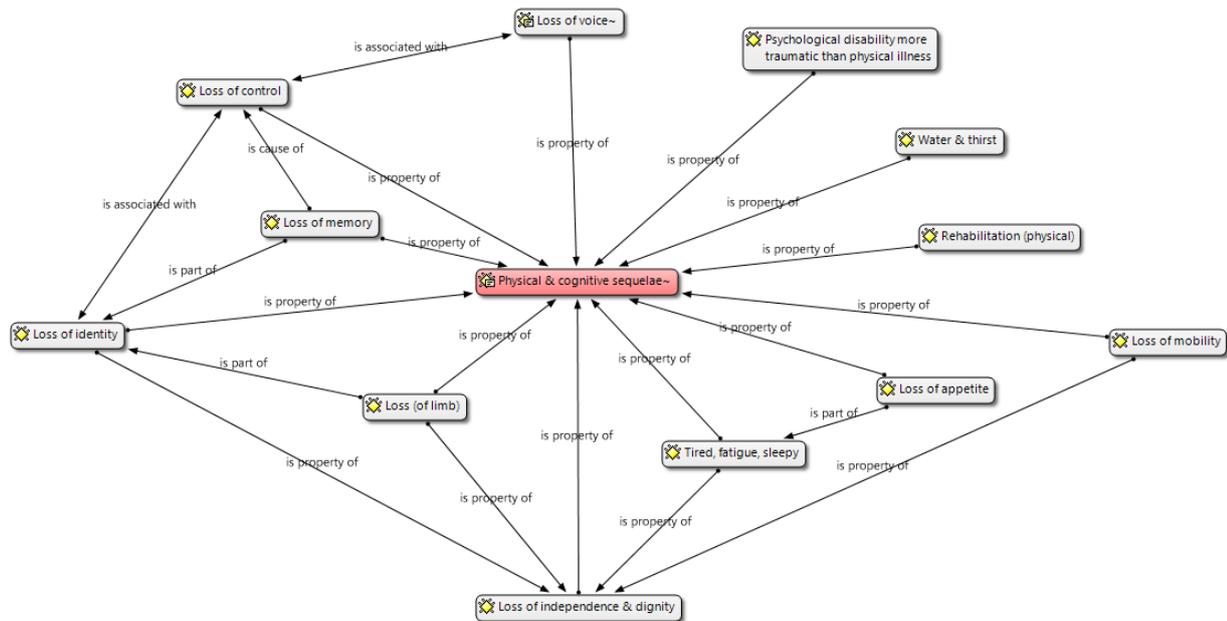
Figure 5.3 Network view Physical and Cognitive Sequelae (focus code)

All survivor participants expressed their surprise and dismay at the significant muscle loss and consequential debilitation with loss of independence whilst within AGCCU and on discharge. Jane spoke of her inability to do the "*smallest of things*";-

> **Jane:** "*I remember not being able to do the smallest of things and that was a little bit... I felt a little bit upset about that, you know, the nurses were brilliant on ICU, on HDU, they were absolutely brilliant, but I had no strength in being able to wash.*" (PR09).

The physical debilitation remained on discharge from hospital.

> **Jane:** "*the first few weeks were very hard, and things are still hard now, I mean I still have the thing in the shower cubicle, because I'm*

just frightened, because I haven't got my balance, it's just not as good
as it used to be, just isn't as good as it used to be..." (PR09).

As discussed under Critical Junctures (section 5.6.2) survivors and family members felt alone and isolated in learning to manage the physical sequelae of critical illness, as Jane describes;-

> **Jane:** *"We've felt very... on your own, we're on our own, everything*
> *we had to do we had to either Google this, do that, and we didn't*
> *know... It's all well and good coming out, but I needed a wheelchair."*
> *(PR09)*

Noting both the past and present tense, Jane indicated that she continued to feel isolated by her critical illness experience. My reflexive memo (chapter 3, box 3.1) suggested that Jane still had some way to travel to achieve what Morse and Johnson (1991 p321) refer to as "*regaining wellness*" post illness.

Kevin, a previously fit 42 year old, expressed his lack of comprehension at the muscle loss he experienced. This was undoubtedly exacerbated by the amputation of his left arm due to necrotizing fasciitis. He spoke of the first time physiotherapists attempted to mobilise him on the ward;-

> **Kevin:** *"...there was three physios and the first time they tried to get*
> *me out of bed I didn't feel safe so I said, I'm not having it today, and I*
> *wanted to get out of bed, I mean I was offering people money to get*
> *me out of bed and get me out, yeah".*

> **Pam:** *And did that come as a shock to you how weak you were?*

> **Kevin**: *Yeah, absolutely, yeah. I couldn't understand why I couldn't*
> *push myself up, laying on your side, I couldn't understand why I*
> *couldn't get out of bed."* (PR13)

Four months following discharge from hospital later Kevin was still experiencing marked physical and cognitive problems;-

> **Kevin:** *"even now I get really puffy [*short of breath*], I've got a bad*
> *back as well which is not particularly good at the moment, I've been*
> *falling as well, I don't like using it because, you know, but I've started*

using a stick. I've got this... stutter and a shake and a tremor in my arm, and the memory has been affected. So yeah, I can start talking and I won't just forget, completely gone, the next word in a sentence" (PR13).

This disclosure evoked emotion and poignancy and as a novice qualitative researcher I made the grounding comment "…*but you are here*" to which Kevin responded:

> **Kevin:** *"Yeah, I mean even more so, I just lost a friend of mine on Monday who was two years younger than me and he was as fit as a fiddle and just dropped down with a heart attack, so that's made me feel, you know, even more humble really just to sort of still be here."* (PR13)

This quotation is further evidence of the awareness and confrontation with mortality as discussed in 5.3.1 and the conflicting, yet coexisting, grief and gratitude.

Muscle loss and weight loss were commented upon by several survivors. They also made links to loss of appetite and hospital food. Alan was shocked by the weight loss:

> **Alan:** "*My weight went down incredibly, I mean my normal, well, I mean I've never been big, but my normal weight is sort of roughly between 10 and 10½ stone, and I went down to about... I think I lost over 2 stone...*" (P14).

David reported even more significant weight loss:

> "*I mean I lost a hell of a lot of weight, I mean I was overweight most probably, I mean when I went in I think I was about 14½ stone and I went down to just over about 10.*"(PR05).

This had obvious effects on muscle mass and the ability to mobilise; such effects are well documented in the literature (see 2.5.3). Family members discussed how they would try and tempt their relatives to eat, not always with success:

> **Hazel** *"...we must have spent hundreds of pounds in Marks [and Spencer] this year...*
>
> **Pam:** *"Tempting your appetite?"*
>
> **Hazel:** *"…tempting your appetite, because he was on the ward, we were trying to get tasty bites for him, and you would go in and just chuck them, you know, they sat on the locker and then the next day bring something in, and so it went on the whole summer."* (PR06)

Barry (PR15) disliked hospital food when on the ward commenting that his taste buds were "*shot*" post critical illness. Similarly, Harry struggled with hospital food, "*I never could eat hospital food, and I mean I lost nearly two stone in hospital in three /four weeks."* (PR16). James clearly also disliked hospital food, "*I hated the food, I hated it, I really did."* (PR12)

Hazel had watched with dismay and increasing frustration as her husband's (Mark) nutritional status deteriorated on the ward:

> **Hazel**: *"He was being sick and he couldn't have an appetite, he didn't fancy anything, he wouldn't eat, give him two grapes in a whole day and he was still being sick, and that went on for weeks and they still didn't feed him. So much so until his haemoglobin dropped to about 6 point something and they had to transfuse him, and he picked up from there, and then they restarted the feeds again, it was all like... dropping it then waiting until it got to crisis point and rebuilding, and it went on and on and on, and, you know, it was very difficult..."* PR06.

This evidence augments the published literature discussed in Chapter 2.6.3 and links directly with physical rehabilitation, since nutrition is explicitly connected with muscle activity. Access to physiotherapy was variable; some survivors had regained both weight and muscle mass and some were still on that journey. David reported positively, "*me weight's come back and me strength and within reason I'm doing virtually everything that I used to do*" (PR05) although he was still experiencing chronic pain from the site of his emergency surgery.

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Jane spoke positively of the physiotherapy she received on the ward although it was challenging, she saw the value retrospectively:

> **Jane:** "*I mean the physio people, even though I found them really, you know, you will get up, you will... but it's good. You need them to do... you need them to do that to you because... you don't want to do it...you really think, oh no, not the physio people, you know, but... yeah, they're good people to have, definitely, and they know their stuff, they definitely know their stuff." (PR09)*

Jane also indicated that the physiotherapists provided her with practical techniques to help with basic activities such as getting in and out of bed. However on discharge home several survivors and their family members struggled with basic daily activities; these critical junctures in the critical illness journey are discussed further in section 5.3.5.

Kevin was allowed week-end leave to his home as it was recognised that he was becoming depressed, but the muscle loss combined with the amputation of his left arm made the experience both challenging (physically) and worthwhile (psychologically). Reuniting the family was clearly a driving imperative.

> **Sarah:** *You needed [to come home]... he was getting quite depressed*.
>
> **Kevin**: *Yeah.*
>
> **Sarah**: *Although it was hard work when he came home...*
>
> **Pam**: *I'm sure...*
>
> **Sarah:** *...because he was extremely weak and I was very worried about that, he was still quite grey*
>
> **Kevin**: *Yeah, getting up and down the stairs, it wasn't good, was it? A walk up the garden was about all I could do, all I could manage, but...*
>
> **Sarah**: *You couldn't even do that.*
>
> **Kevin**: *I felt so much better at home though...*

> **Sarah**: *And that was the balancing point really, getting back, but he needed to be with the girls and they needed to be with him. (PR13)*

The above dialogue is a good example of how both survivor and family member coordinated their contributions of the critical illness trajectory, filling in gaps and prompting each other to share more information. This does not infer that they experienced the same events and interpreted them in the same way but they have access to each other's life world and they can perhaps understand it through the process of co-construction. From my subjective perspective, joint interviews invariable provided rich, detailed data that afforded an additional, augmentative dimension to individual patient interviews.

Ongoing fatigue, post discharge from hospital, was reported by several survivors and confirmed by their family members. Mark claimed that he "*could sleep all day really*" to which his wife Hazel added in the present tense "*He can sleep day and night*". Jane continued to struggle with the ongoing fatigue:

> **Jane**: "*I feel so tired, I'm so tired, you know, I don't want to do anything, and he goes (Gary), it's probably because you've been ill. And I think, oh, yeah, because I'm back at work, I'm OK, well, you know, I feel I should be...OK*" (PR09).

Jane (PR09) and Kevin (PR13) were both frustrated by the ongoing fatigue they were experiencing despite being discharged from hospital over three months ago:

> **Kevin:** "*I'm tired by about four o'clock'ish, and I can have a sleep for two hours and then by eight o'clock I want to go back to bed … it just seems really, really excessive.*"(PR13)

Alan felt he had made a good recovery but still struggled with fatigue and did not consider returning to work an option:

> **Alan**: "*I do get tired quite easily, but I still walk a lot, I do gardening quite a lot still, I mean that was my job, but I don't think I could actually work anymore,*"(P14)

Changes in physical appearance often came as a shock where explanations were either not forthcoming, or had been forgotten, as James explains:

> **James:** '...I found out that I'd had a tracheotomy when I first went back to our marital bed, if that's the expression, when they actually got me upstairs, I went for a shave, I thought, what the bloody hell's that? In fact only two, three days ago I found out from a conversation that I actually had a tube going in there (points to neck) as well, and so forth, but I didn't know.' (PR12)

This lack of knowledge mitigated against the survivor's ability to make sense of the critical illness experience and may perpetuate differences between the family member and survivors experience as they have witnessed events first hand.

The loss of a limb is a profound and very visual physical consequence of critical illness but Kevin and his wife Sarah discussed how Kevin denied the loss of his arm:

> **Sarah**: "But you couldn't understand why we were feeding you or doing things for you, could you?
>
> **Kevin:** "No. My brother in law, he was feeding me and I thought that was a bit strange, but I was eating it, and my sister said... they brought me a magazine and she sat on this side and I remember her saying, this was in X ward, so I was sort of coming back to... she said, when you want to turn the page just ask, and I... turn the page? I can turn the page myself!"
>
> **Sarah**: "But he couldn't, could he? One arm up and the other arm was not there, he wasn't comprehending that at all." (PR13).

Making sense of critical illness, from both a patient and family member perspective, developed as a focus code. Access to information, and learning to manage a roller coaster of emotions, were key initial codes and are discussed in 5.3.4.

5.3.4 Sense-making

This focus code relates to the process of making sense of a changing reality, namely, encountering and making sense of the critical illness trajectory from both survivor and family member perspectives. Sense-making is the interplay of action and interpretation that is instigated whenever the current state of the world is perceived to be different from the expected state (Weick et al 2005). It is an accomplishment that emerges from efforts to create order, and retrospectively, make sense of what has occurred. Sense-making is a sociological term that has symbolic interactionist roots (Sammon 2008). The origins of which lie in constructivism with an underpinning premise that people act on the basis of the meaning they attribute to situations. As the vignettes illustrate, meaning and actions emerged, developed and were modified through an interpretive process. The network view of the focus code "Sense-making" (figure 5.4) was influenced by and derived from many initial codes such is the complexity of critical illness trajectory.
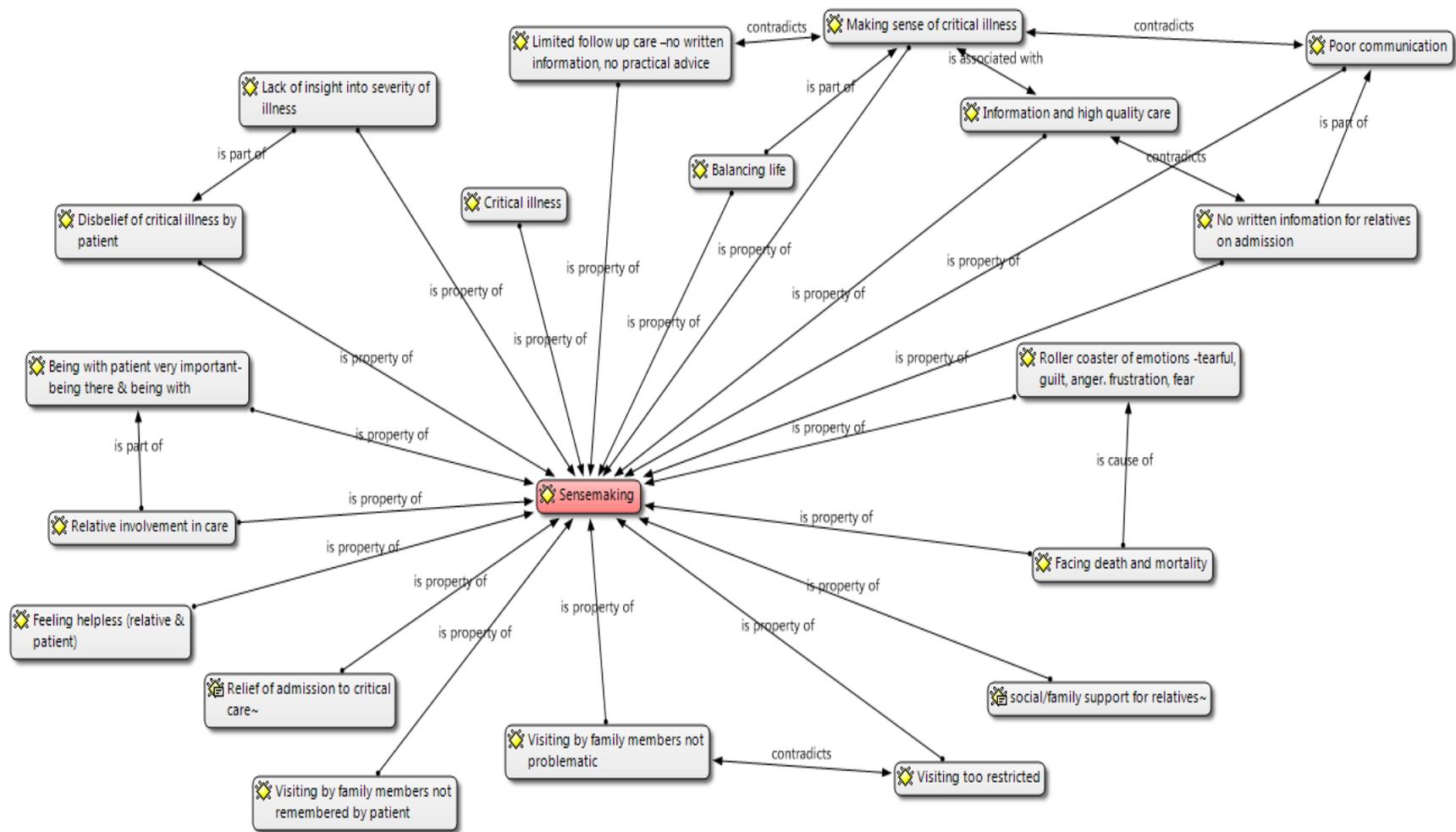
Figure 5.4 Network view Sense-Making (focus code)

Access to information is central to sense-making. Participants who received (or perceived they had received) high quality and accessible information felt greatly reassured. Access to senior medical information was valued by Sarah (PR13) after delayed diagnosis within the primary care setting.

> **Sarah**: "*But I mean once we got to ITU, to that stage, I really felt that he [Kevin] was in the best possible hands. I did feel reassured by him, Dr X was just amazing, and he always kept me informed, he even phoned me at home, so I didn't feel out of the loop at all, ever, and every time I went in to see him they would fill me in on what had happened since I last saw him and I could phone in the morning and speak to him.*"

Several family members spoke of "*brilliant*" critical care nurses who supported or helped facilitate sense-making in the unfamiliar world of AGCCU. Hazel spoke of *"a brilliant ICU nurse to begin with and I think she prepared us for... she really prepared us for the long haul, because pancreatitis was alien to me. So we were well prepared, I have to say, by a very good nurse initially.*" PR06

This preparation for the *long haul* made a significant difference when good days turned into bad days.

> **Hazel:** "*Then the next time you went back in he was intubated again, and that's how it was. So you think... in the end the kids started to accept no, we're not getting... not thinking positive or getting excited now because dad's extubated and he's talking to us and he's discussing the golf results or he wants to know what's happening with the football or whatever, because we know when we go in tomorrow that it will be different again, and that's how it was. But because of the way we were prepared by an exceptional nurse I would say initially and then any member of the team we came in touch with, they were brilliant, we kind of knew and accepted very quickly.*" (PR06)

High quality information and professionalism were also valued by Gary (partner to Jane). The perceived quality of care was clearly comforting for family members:

Gary: "*I thought everyone was so professional, everyone was really switched on, which is what impressed me most, the staff.., they all knew what they were doing, we're doing this, this does this, that does that, you know, they explained it all. Even if you weren't taking it in, you know, but it was comforting to hear all those explanations.*" PR09.

Being able to access information and keep in contact with AGCCU was very important for family members. This quality was highly valued by Sarah.

Sarah: "*The ITU nurses and the whole team were incredible, I have got to say that, they were amazing, and they were there every moment for all of us and, you know, they were very open with that, although they had to set times for us to go and see Kevin, they always said to us, phone us any time, and I did phone at silly times sometimes just because I had a feeling....and I needed to know he was OK*" (PR13).

This was emphasised further by John talking about the care his father was receiving in AGCCU at the point of interview. Here the emphasis was on the value of multidisciplinary team working in addition to communication to family members.

John: "*I believe that the high standard of care that they have in Intensive Care is so important with the multidisciplinary team, the process, everybody, you know, the physios, the radiographers that we've just had come in today to my father, and the doctors, the communication between the whole team to us, the relatives is so, you know, important, so that we keep informed as to we know how his progress is*" (RR01).

Penny described how she felt able to ask simple questions:

Penny: "*...all the nurses have been really good, and you don't feel an idiot......asking simple questions*". (R04)

She went on to describe the regular updates from medical and nursing staff;

I've seen the surgeon, I've seen the registrar and obviously the nurses, they've all explained everything that's going to happen tomorrow and today, yeah. (R04).

Some family members who had previous experience of critical illness (as a relative) recognised that the quality of communication was worse on the wards because of the staff: patient ratio:

Anthea: "*I mean obviously up here they're very good (AGCCU), they explain a lot of things, especially the nurses who are obviously at the end of the bed, they explain a lot to you, you know, and fill you in on the gaps and that, but on that ward actually seeing somebody, it's different, isn't it? And I'm sure that X Ward will be worse because of the amount of patients they have to deal with*". (R07)

Issues around transition from AGCCU to the ward and beyond are discussed further in 5.3.5.2.

Sense-making by survivors occurred later in the critical illness trajectory, as would be expected. Family members were central to providing information and often filling in gaps and correcting misconceptions. Linda spoke of the fear that her ventilator was being tampered with during her stay in critical care. It was only upon recent discussion with her son that it became clear to her that indeed this was not the case. It does seem to also indicate that for some patients returning to the intensive care unit may be beneficial in making sense of their critical care experiences;-

Linda "*...because although you've been in there [AGCCU], you don't know what it looks like. I always thought that... and this, again, this only came to light a couple of weeks ago when we were having dinner one night and a chat, I imagined on a couple of occasions that some of the nurses were going behind my bed and that was a big curtain behind me with all machinery behind that, and that they were going behind there and tampering with my oxygen and everything, and it*

wasn't until a couple of weeks ago that my son said to me, well no, the back of your bed was actually against a window". (P04)

Linda went on to explain why this sense-making was important for her; "*…so then there's no more lying in bed at night time trying to think of it…*" (P04).

The notion of bringing about closure of the critical illness trajectory is evident here and the importance of filling in the memory gaps and making sense of the whole experience was a recurring theme in the data.

Similarly, Judith described how her son had been central to explaining what had happened to her as she had no memory of her admission to AGCCU:

> **Judith**: "*my son was there as well and straightaway started to explain what had happened. At that time I had absolutely no memory of going, or even the day before going into hospital, you know…… him being there and telling me, you know, what had gone on really did help. I found it enormously helpful.*" (P07).

Some survivors were still seeking to make sense of their illness and for Barry, his diagnosis in particular.

> **Barry:** "*it's never been fully explained as to how I got the diverticulitis, I made assumptions, that's it, but no one's actually sat down, not even the GP….He just said, oh, you had diverticulitis, like, oh, you've got a dose of 'flu, you know, we all know how you get 'flu, you know, and to me, I didn't have a clue. And I still don't really, I'm putting it down to a number of factors and who knows, maybe I'm hitting the right spot, but I don't know*" (PR15)

Penny whose husband was still in AGCCU at the time of interview talked about how she was coming to terms with living with a partner who was critically ill. There was a slow realisation that she needed to carry on living; moving away from a state of limbo:

> **Penny**: "*…because I think I've been not wanting to do anything else, you know, they said, ooh, come to a pub, come for a meal in the pub,*

and I said, oh no, I can't, you know, but I am beginning to realise that as time goes on I can't stay like this." (R04)

She described the journey so far as an emotional rollercoaster; a commonly used metaphor by critical care nurses and family members alike. A metaphor undoubtedly aligned to Morse's model of suffering of alternating emotional suppression and release (see figure 2.4):

> **Penny**: *"it's just like a rollercoaster, one day, you know, you come in and you can cope, and another day you feel very down, but then when you get here, amongst everybody else, you feel, you know, more lifted again and... Yes, it is like a rollercoaster." (R04)*

Clearly access and proximity of family members to their relatives was important. This was most poignantly described by Sarah. The AGCCU does have published visiting hours but these are negotiable depending on individual circumstances. The debate around open visiting remains contentious, with wide variation in practice across the UK and Europe (see 2.5.5). Sarah articulates her own experience as a visitor to the AGCCU:

> **Sarah:** *"I mean I understood they were very busy and there's a lot going on and they were very good to me, I've got to say that, you know, I had access to the relatives room and I was here all the time. Some days I would wait 17 hours to see him for an hour, you know, because when I got in to visiting time then they had to do something with him, so I was asked to go back out, and then I had to go home for the children, so I'd glimpse him really. We've never been apart, have we, we've always been together, yeah, I just didn't want him on his own. So I would sit outside in the corridor really just... because I was that close, I wasn't with him but I was here, so..." (PR13).*

The importance of gaining access to and being with Kevin had a profound effect on Sarah's wellbeing:

> **Sarah**: *"Because even my dad used to say to me when I came in to see you, though I couldn't get near you half the time because his kidneys failed as well and he was on dialysis I used to cuddle his toes.*

*But he said to me, you're like a different person, he said I used to come back to life when I was with him, because I spent all the time being so worried and so stressed out that when I actually got with him and I could feel that he was still **here and warm**, I just relaxed and could talk to him then. So to have that access is so important. (PR13)*

The reference to her husband being "*here and warm*" undoubtedly reflecting confrontation with mortality and the possibility of him being absent and cold.

Annie from a patient perspective spoke of the value of family presence. Some survivors described how they could hear familiar family voices, but not always see faces, Annie described the value of both seeing and hearing her sister at the bedside in AGCCU:

Annie: "*You may see a few faces and remember them, but to have your own family there, the first thing, because you'll recognise them, and it does help, because you're sort of like in a strange place, you're waking up in a strange place, ...I think when I first came round my sister was there and she was stroking my hand and she went, that's it Annie, come on, you can do it, she said, I knew you could do it, she's saying, I knew you could do it.*" (P01)

Information following discharge to the ward and into the community was lacking, according to all the survivors and their family members who were interviewed. Advice and guidance had been sought by some participants through the internet or charities. None of the patient and family member participants were aware of organisations specifically supporting life after critical illness such as ICU Steps and the Intensive Care Society. For some survivors this lack of information created unnecessary isolation:

Jane; "*We've felt very... on your own, we're on our own, everything we had to do we had to either Google this, do that, and we didn't know... It's all well and good coming out, I needed a wheelchair. Now we didn't know... luckily my daughter, mother in law, she used to be a carer and a very good one and she says, get onto the Red Cross, they'll do it. So with a small donation we managed to get a wheelchair, they were brilliant, weren't they? And nobody told us, you know, and*

nobody said, well you may need... we didn't even think, you know...
(PR09).

James spoke of his inability to ask questions to help him make sense of both his critical illness and learning to transition to the new '*normal*':

> **James:** "*I'm probably my own worst enemy in this particular case, but I think if I'd have asked a few more questions or I spoke to somebody from my own point of view rather than their point of view, then maybe it would have been a lot easier for me. And one of the thoughts was… I'll never drive again. But I should have said to somebody, will I drive again? Today, for the first time, I spoke to like this young man and I said to him, will I drive? That's the first time I've asked anybody*" (PR12).

Access to such information from a survivor's perspective may have informed participants of many of the difficulties that they experienced post critical illness and explained why they had arisen. Hair loss and changes to nails are common post critical illness and evident in three of the survivors. As Charles said to me "*just talking to you, telling me about nails and hair has made me feel good...*" (P02). This conveyed a feeling of sense-making on behalf of the participant; meaning had been attributed, developed and modified through an interpretive process. Lack of information signposting, either written and/or verbal, appeared to be an unnecessary stressor.

5.3.5 Critical Junctures

The final focus code presented in relation to patient and family member data is entitled Critical Junctures. The critical junctures identified by participants are:

- Admission to AGCCU (5.3.5.1)
- Discharge from AGCU (5.3.5.2)
- Discharge home/primary care setting (5.3.5.3)

This section will be presented in a chronological manner reflecting both patient and family member's journey (i.e. from admission through to

discharge). As in previous sections there are overlapping initial codes as the experiences cut across the focus codes.
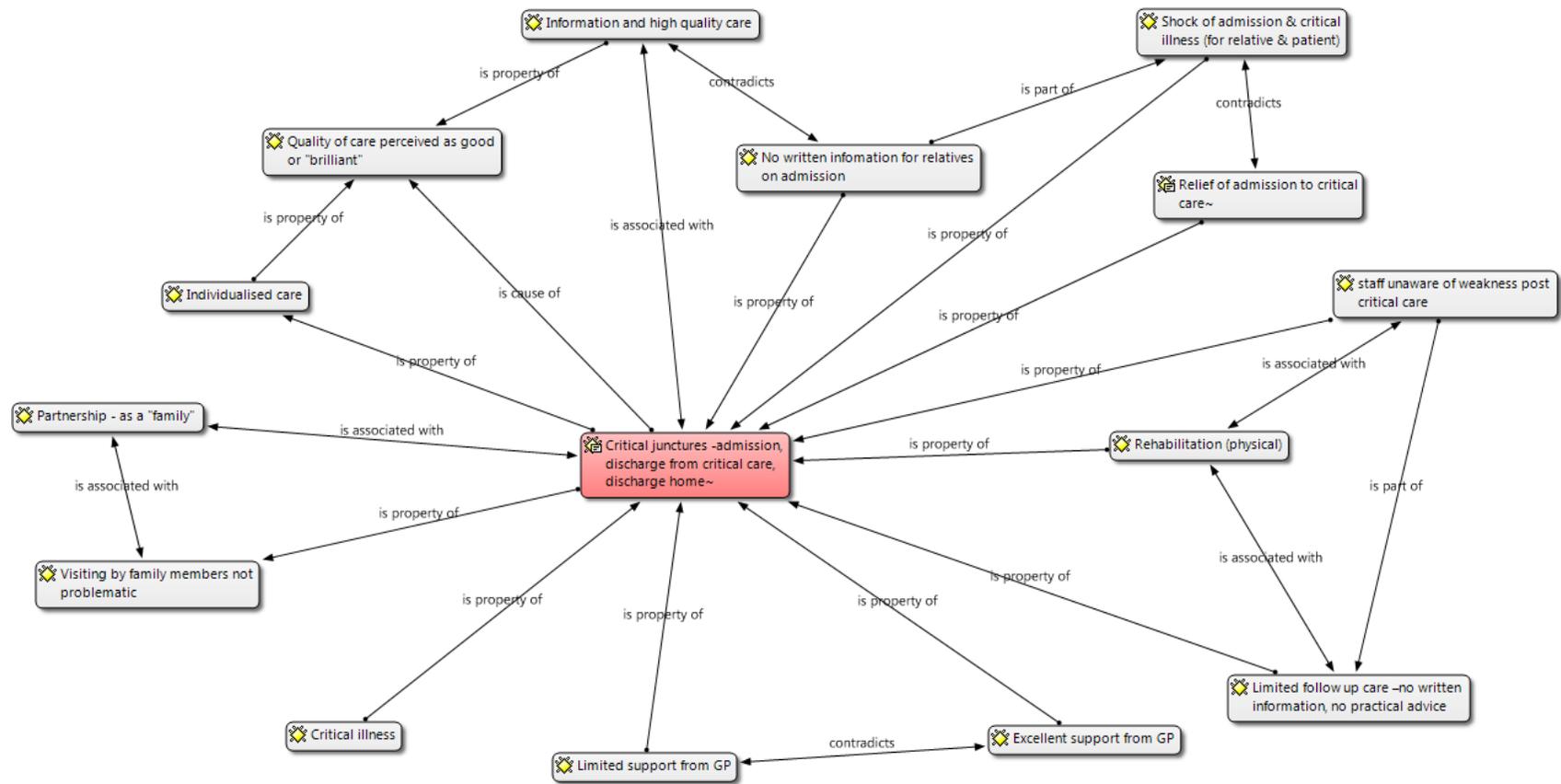
Figure 5.5 Network view Critical Junctures (focus code)

5.3.5.1 Critical Junctures -Admission to AGCCU

Penny whose husband was ventilated on AGCCU at the time of the interview spoke of her relief that he had finally been admitted to AGCCU and received support for his breathing.

> **Penny:** *I was there in the other ward with him and it was absolutely horrendous the way he couldn't breathe and he was collapsing and all round generally he didn't know what he was doing and he was reaching out to me like this. So when they came... I knew something had really, really got to help him, so when he came here I was relieved in a way because I knew he was going to get the help" R04.*

However for the majority of family members this was a time of overwhelming shock of learning that their relative was critically ill and may not survive. For Susan this emotion was exacerbated by poor communication when trying to locate her son within the hospital:

> **Susan**: "*to begin with we weren't even told that he was in Intensive Care,… it was really very difficult because when I phoned in the morning, because no one had phoned me to tell me that his surgery had been done or what was happening or where he was, which was supposed to happen, and when I phoned, I phoned the ward that he'd been in and they didn't know where he was and they said they would find out and phone me back and they didn't. And so that wasn't the best way to find out because when I spoke to someone from the Intensive Care Unit they assumed that I knew X's state, so they said, well, you know that he's on a respirator and da da da, and actually I didn't, so that was a little bit stressful...the shock, well, the whole thing that day was a real shock (R03).*"

All patient participants had no recollection of their admission to critical care and were reliant on staff and family members to fill the memory gaps as discussed by Judith (section 5.3.4). In contrast, admission to AGCCU is highly anxiety provoking for family members as demonstrated above.

5.3.5.2 Critical Junctures –discharge from critical care

For patients the next significant juncture was leaving critical care. For some patients this involved transfer to a high dependency care setting (level 2, ICS 2015) for others this was a direct transfer to an acute medical and surgical ward. Many patients spoke of their desire to move out of critical care only to regret the transfer later. Several patients spoke of the lack of staff on the wards, and facing the reality of the extent of their debilitation and associated dependence. Jane was desperate to regain some independence but this did not come to fruition:

> **Jane**: *"I couldn't wait to get off ICU because of one thing, you couldn't go to the bathroom... I'm going to be allowed to go to the bathroom, because I asked, is there bathrooms there, you know. I thought in my head that I would just get out of bed, be able to walk to the bathroom. It didn't happen, obviously, it didn't happen, and I was a bit dis...[appointed] nothing to do with the staff, you know, and I'm thinking, I'm still exactly the same as I was when I was in ICU, you know, still having to use bed pans, still having to do this, they're still having to wash me. I remember not being able to do the smallest of things".* (PR09)

The vignette above refers to Jane's transfer to a high dependency care area. She described her subsequent transfer and stay on an acute medical ward as "*frightening*".

> **Jane:** "*I was very frightened when I went onto X Ward because on HDU you do still, even though you haven't got, one to one, but there's loads of nurses, they will help you. On X ward, you know, you had to wait longer and obviously once my catheter came out I had to keep ringing for the bell to go... because again, feeling so... so dependent... so dependable on somebody, I can't get out of bed and I was thinking, help, I hope I don't wet the bed, please hurry up and come, you know, sort of thing. You know, just... like I think all my dignity went out the window...*" (PR09).

Jane articulated, very clearly, her profound vulnerability on the general ward. She went on to recall how the nurses on high dependency care had advocated on her behalf to prevent an earlier discharge to the ward. The consultant later apologised, explaining that he was under pressure for the bed.

> **Jane:** "*I felt like F Ward really, really could not cope very well with people that have got high dependency needs, so maybe... maybe you move too quickly, I don't know. It's... it's a little bit funny actually because I've got a kidney disease now and the one doctor that wanted for me to step down sooner is actually my renal doctor and I go, you were the one that wanted me off the HDU. He goes, oh, I'm so sorry about that, he said, but I was under pressure with the bed ... the nurses didn't let me, obviously, she's not well enough, and I think, thank God the nurses stuck to that because if I'd have gone into X Ward before…*" (PR09).

For Gill daughter of Sharon, the transition from critical care was a concern that did not manifest as a reality:

> **Gill:** "*I personally felt a little bit like, that 24 hour one to one wasn't there and I was worried that she wasn't going to get the same amount of care, which again I know is normal. But she did, you know, but that was a worry to me because she still had a trachy in and everything, so that was a personal thing for me. I don't know about how Arthur [husband] felt, I think he just wanted to get her home anyway, so for him it was like a step closer to coming home. But for me it was, is she ready?*" (PR10/11).

Transitioning from AGCCU to the ward was challenging for Judith but for different reasons:

> **Judith:** "*... there wasn't room in the ward they wanted to send me to, so I was sent to another ward and then I was sent to another ward after that, you know, it sort of... I didn't feel as though I belonged anywhere, if you know what I mean, you know, whereas I'd felt really supported in the Unit.*" (P14)

The winter bed pressures were a feature at the time of data collection (see 3.10.2) and may have contributed to Judith's experience. However it is a well-documented, distressing phenomenon that has been researched by Maben et al (2012) in their seminal research "*'Poppets and parcels': the links between staff experience of work and acutely ill older peoples' experience of hospital care*" that patients are moved from ward to ward losing their sense of identity along the way. In addition the transition from 1:1 care by registered nurses to general ward staff is well recognised as problematic (see 2.5.2). What was further evident from the data was patient and family member attachment to the staff within AGCCU and this had made the transition harder.

Alan experienced a difficult transition from AGCCU and premature discharge home having experienced high quality care in AGCCU:

> **Alan**: "… *before I was discharged from the Intensive Care Unit, after I'd come out of the coma, I couldn't have wished for a better care*. …*then once I came out and went onto a general ward things weren't so good. I basically think I was probably discharged too early because within two weeks I was back in again, virtually with the same problems, I couldn't breathe, my heart was going like the clappers, I actually had a heart attack at home which I didn't realise…*" P14.

The extreme pressure on critical care and acute beds is a consistent feature in the UK but premature discharge often exacerbates the problem further with re-admission required as Alan experienced.

Barry had a pragmatic approach to the change in staffing ratio and related care.

> **Barry**: "*when you get down on the general ward you should sort of make a few allowances for how busy they are and so on. I mean it is a different regime obviously, when you're in Intensive Care it's one to one care, when you get on the ward you've got one nurse for God knows how many patients and you don't obviously... I mean they are caring but they can't care for you in exactly the same way...*" (PR15).

Family members also recognised the change in staff to patient ratio. Jenny articulated her concern in a pragmatic manner:

> **Jenny:** "*I mean I take my hat off to the nurses because I would have liked to have doubled the amount of nurses on the ward, and the only thing I can say, where Intensive Care, boom, they're there, you'd be ringing the bell and I'm thinking, you will come won't you, because he had so many drips, he won't be left in pain, will he? Because it is a completely different thing. I take my hat off to them all...*" (PR05).

Poor communication around discharge to wards and discharge home was evident in several interviews. Anthea whose son was moved from AGCCU to a separate HDU area at night found this disconcerting. Undoubtedly pressure on beds contributes to discharge 'out-of hours' which clearly breaches NICE CG 50 (2007), but communication of the transfer to family members is imperative:

> **Anthea:** "*…this is what I find really confusing about hospitals, I mean I was here until 8 o'clock on the Monday night, I phoned at eleven, just before I went to bed, and the staff nurse said, oh, we're waiting for a bed, we're going to move him. I'm like, OK, sort of at eleven, so what had changed between 8 o'clock and 11 o'clock, because there's no doctors' rounds that sort of time. So I thought, OK, so I phoned again in the morning, he was still here, I visited him in the afternoon, he was still here, came back in the evening, we left here on the Tuesday at 8 o'clock and when I phoned up on Wednesday they'd moved him at half past eleven that night, nobody phoned me to tell me he'd moved,….*" (R07).

The unrelenting pressure on beds meant that her son (with learning disabilities) was subsequently moved from his HDU bed to an acute medical ward at 3.00am. She was not notified of his discharge. Whilst acknowledging she may not want a 'phone call at 3.00am her main concern was for her son, saying: "*how can they move somebody at 3 o'clock in the morning because, my first thing was, was he asleep? Did they wheel his bed,*

you know, him out of it and he wakes up in a strange ward the next morning?"

Anthea like Barry above recognised that communication and contact with health care professionals on the wards was very different from AGCCU:

> **Anthea**: *"I mean obviously up here they're very good, they explain a lot of things, especially the nurses who are obviously at the end of the bed, they explain a lot to you, you know, and fill you in on the gaps and that, but on that ward actually seeing somebody, it's different, isn't it? And I'm sure that the A ward will be worse because of the amount of patients they have to deal with" (R07).*

In contrast Barry spoke of the positive aspects of the transition from AGCCU to the ward; *"I was pleased, because it meant I was no longer under the microscope in terms of hour by hour [laughs]..."* referring to the hourly clinical observations taken within the AGCCU setting. Emily (Barry's partner) recognised the positive element of transitioning from a critical care setting; *"I think by going from ICU into an ordinary ward it makes you feel as though you're one step closer to... getting better, doesn't it?" (PR15).*

5.3.5.3 Critical Junctures –discharge from hospital

The final overt critical juncture is discharge home or to a rehabilitation setting. Both survivors and their relatives described the overwhelming desire to go home, but frequently the reality of coming home following critical illness was challenging; physically and psychological for both survivor and family member. Annie described the impact of profound weight and muscle loss in terms of attempting daily activities of living within her own home.

> **Annie**: *"And so I wanted to come home, I come home and I was about 7 stone 3 when I got home, so I obviously couldn't do anything. But that made it even worse because I couldn't even get to the toilet…" (P01).*

David was desperate to come home too but, in hindsight, recognised he had requested discharge home too early:

David: "*Well, I wasn't mobile enough really, the physiotherapist, she had started to come round and got me up and that, but I wasn't really mobile enough and as I say, and the sister of the ward, because it was a Friday, and she still wanted me to stay, but I said to A that I want to come home. I mean I didn't actually discharge myself, and in the end she said, OK, you can go. But I wasn't mobile enough, and I wasn't mobile enough when I got home, because unfortunately I developed...*"

Jenny: *DVT.*

David: "*…maybe in hindsight I should have perhaps had another week or so in but, you know, that was purely me, I suppose because I'd had... the length of time I'd had in, I felt as though I wanted to go home.*" (PR05)

Jane described the challenges of getting through her own front door following discharge from hospital. Despite living in a bungalow she describes access in and out as a "*nightmare*". Having successfully navigated the front door she felt trapped inside her own home.

Jane: "*…but you've got to get from the front door, from outside into the front door, that was a... nightmare, I think I couldn't... I can't even get into the front door, I can't even get through the door, you know… I couldn't get out the front... it wasn't... like I thought I'm in, now I've got to go out, you know? It's been an experience I don't want to repeat…I don't want to repeat.*" (PR09).

Family members spoke of their own anxiety when their relative returned home initially:

Lucy: "*Well I did worry when you came home...*

Andy: *Oh yeah...*

Lucy: *...I kept listening to see if you were breathing! [laughs]. I know it's ridiculous. I'd think, God, are you breathing?*" (PR03)

Others missed the reassurance of a health care professional being available to them. Alan describes how he didn't feel as safe at home despite being desperate to be at home:

> **Alan**: "…*because when you're in the hospital you feel, if there's any little niggle or anything you can sort of say, and you can press your buzzer or speak to somebody, but when you get home any little niggle you think, oh, is that something or do I ignore it, you don't feel quite so safe as it were.*" (P14).

Support from general practitioners was variable. Jane and Gary struggled to get support from their GP:

> **Jane:** *"I found it very hard having to go to the GP to get signed off from work, I found it very hard to go to the GP to get blood forms... I could hardly walk… to be quite honest once you leave hospital you're cocooned, you know, you've got this and you've got that, they you're out of hospital and you're on your own, you know."*(PR09).

At the interview James remained shocked by the profound muscle loss he had experienced as a consequence of surviving critical illness; this has led to a change in his lifestyle:

> **James**: "*It still is actually, it still is a shock to me, but my legs are still, even after 11 months nowhere near what they were before, in fact my biceps and shoulders are slowly getting somewhere where they were before, but that's personal because I'm pulling myself up the stairs literally, four or five, six, ten times a day…*" .(PR12)

He recalled how on return home he had to sleep in a bed in the dining room and the vulnerability and associated change in relationship with his wife:

> **James***: "We were having to sleep in the dining room, you know, and that was awful. Well no, it's nice really, but where she was asleep upstairs and I was asleep downstairs, and I couldn't get out of bed because I had no legs, I have all these pipes and bags and so forth, so if she decided to have a lie in, say 9 o'clock, if I woke up at 7.00... It was awful! [laughs]". (PR12)

Whilst discharge home is an obvious goal for survivor, family member and health care professional, it is evident from these transcripts that there is very limited support to help negotiate the new '*normal*' way of life and to come to terms with the different experiences that survivor and family member have suffered. The following vignette is from a member of ICU Steps supporting the developing theory of *dualistic worlds.*

> *"I think the hardest thing is accepting what will become the new normal which can be very difficult to come to terms with in the early days after ICU, in the beginning family and friends are there to support you but often slowly drift away never really understanding how traumatic a life threatening illness can change your life forever, with comments like "it's time to move on and put it all behind you" words that cut through you like a knife with their lack of empathy". ICU Steps support blog 2016.*

5.4 Conclusion

This chapter has provided the principal findings into the critical illness trajectory as experienced by sixteen survivors of critical illness and fifteen family members from within AGCCUs and beyond hospital discharge. These data have been constructed between myself and the participants providing a rich, in-depth insight into the critical illness trajectory.

Truth and reality are described by Ward et al (2015) as concepts reliant upon personal experiences and beliefs. Data have been broken down and reconstructed through coding and synthesis, new knowledge developed through an iterative and interactive process; not in an objective manner but through the process of construction. Whilst recognising the individual experiences that survivors and family members feel and encounter, one emerging abductive theory is of the survivor of critical illness experiencing '*dualistic worlds*' alongside their family member. In addition the survivor may experience an internal dualistic world where a self-contained separate reality co-existing with one's own.

Survivors of critical illness (in the context of emergency admission) have invariable entered an in-between or liminal state between life and death on

admission and during their stay in AGCCU. Family members are informed that their relative may be at the end of life and this creates a family illness narrative around confronting mortality. Survivors frequently (all in this study) experience vivid hallucinatory experiences which placed them in a different world or liminal space. They move or transcend in and out of these different realities. The core difficulty can be summarised in that survivors have little recall of the factual events of their critical illness within AGCCU but relatives have lived the whole event in a very real and ingraining manner. This can result in family members and survivors experiencing two totally different versions or narratives of the critical illness episode; reinforcing the construction of a middle range theory, namely *dualistic worlds*. The progressive coding construction is illustrated in figure 5.6.

The preceding vignettes have provided insight into this separate reality that frequently is out of reach to family members and health care professionals. The voice of one survivor summarises the key dimension of the two different experiences:

> **Jane:** *"It has been hard to reconcile the two separate lives that we lived during that time, and neither of us will ever be able to fully comprehend what the other went through". (PR09).*

Chapter 7 contextualises these findings in relation to the literature and applies the concept of liminality as a conceptual lens to develop our knowledge of the experience of surviving critical illness. Prior to this staff findings are presented in Chapter 6. The format of the second findings chapter will replicate Chapter 5; that is network views from Atlas Tii™ will be provided together with vignettes that illuminate the focus codes. The reader will recall from Chapter 4.7.2 that the questions for these interviews were structured around the patient and family member data; in true constant comparative style they evolved over the course of the interviews.
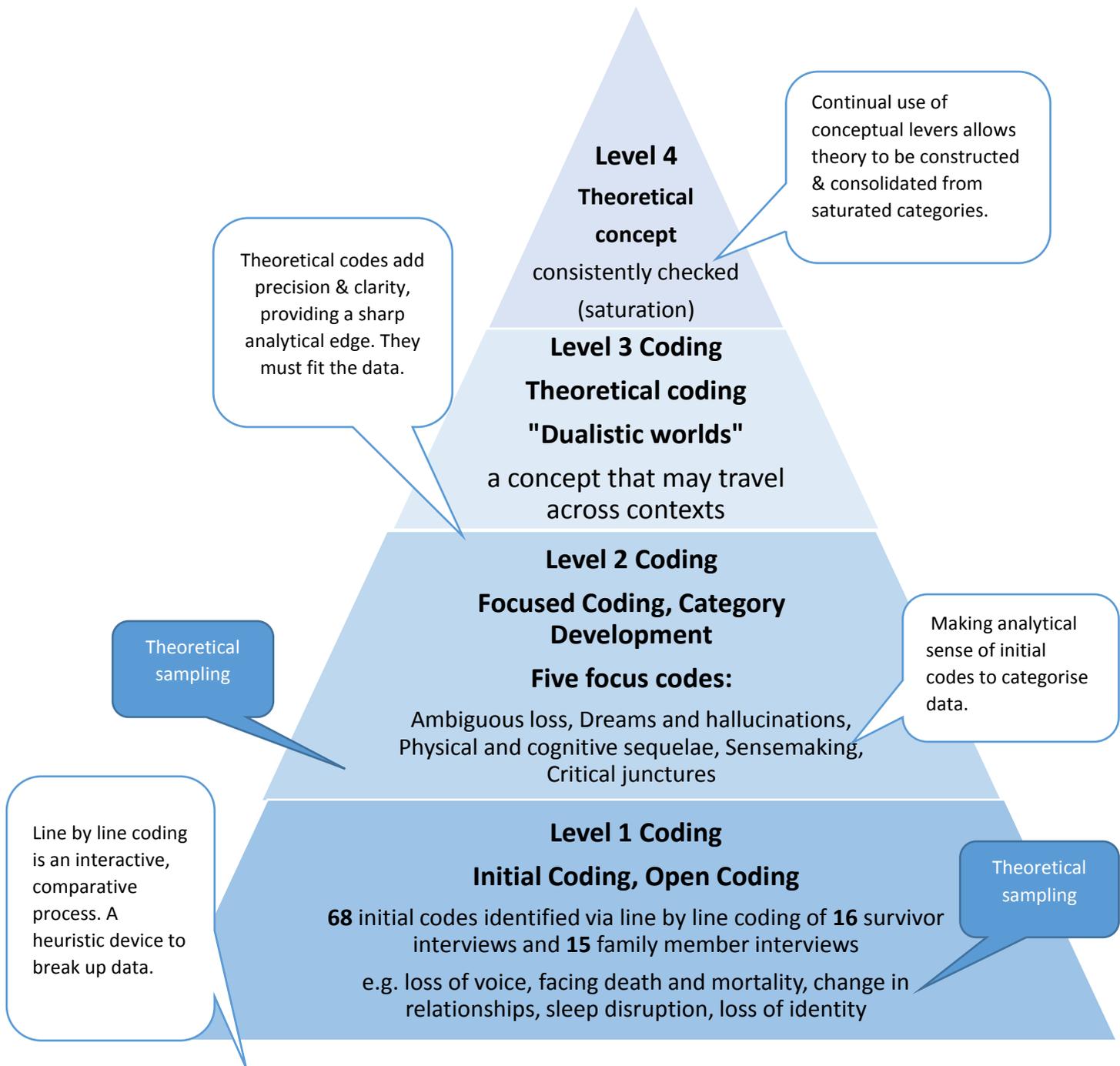
Figure 5.6 Progressive coding construction in relation to overarching theoretical code explaining survivor and family member experiences (adapted from Hamm 2015).

Chapter Six –Findings Registered Nurses (AGCCU)

6.1 Introduction

The chapter commences by introducing the participant characteristics to provide context to the findings of the second stage of this research study. Registered nurses who have worked within AGCCU for at least one year were invited to discuss their experiences of caring for patients and family members. The questions which informed the semi structured interviews were derived from the emergent themes from survivors and family members (chapter five). Five focus codes were constructed through the process of constant comparative analysis. These are explored in detail through the use of quotations from participants to illustrate the coding in a transparent and grounded manner. Network views taken from Atlas ti™ are provided to aid limpidity. Although the focus codes are introduced in discrete sections, they are interrelated within the chapter and with the findings from survivors and family members. Efforts are made to cross reference and rebuild the whole experience for the reader. The focus codes have no particular hierarchy as they contribute equally but differently in providing insights into critical care nurses' experience of the critical illness trajectory. There has been some attempt to order them in relation to the patient journey from admission to discharge (transition) from AGCCU.

Synthesis of the findings and subsequent discussion in relation to existing literature and theories are provided in chapter seven.

6.2 Participant's characteristics

The biographical details of RN participants, length of critical care experience and qualification are provided in table 6.1.

The number of years participants had worked with AGCCU ranged from 1.5 to 27 with a mean of 12.5 years. 73% of participants (n=8) held post-registration qualifications in intensive and critical care nursing. Characteristics of the AGCCU where the respondents were employed are detailed in section 1.3 (chapter one).

Research code	Gender	Pseudonym	Years of AGCCU experience	Post registration education in AGCC	Band
S01	F	Gail	11	Yes	6
SO2	F	Amanda	18	Yes	7
SO3	F	Aricha	1.5	No	5
SO4	M	Paco	4	Yes	5
S05	F	Kay	24	Yes	7
S06	F	Karen	27	Yes	6
S07	F	Clarin	3	No	5
S08	F	Mary	25	Yes	5
S09	F	Jane	11	Yes	6
S10	F	Cathy	11	Yes	6
S11	M	Velta	1.5	No	5

Table 6.1 Registered Nurse Characteristics

6.3 Findings AGCCU Registered Nurse interviews

The five focus codes presented in figure 6.5 are constructed from 51 initial codes identified via line by line coding of 11 interviews with registered nurses working with AGCCU for greater than one year.   The five focus codes are;-

- Personal and professional challenges (6.3.1)

- Delirium assessment and management (6.3.2)

- Family presence (6.3.3)

- Specialised knowledge and skill (6.3.4)

- Transition (6.3.5)

6.3.1 Personal and Professional Challenges

This focus code adds to the growing corpus of knowledge which reveals role ambiguity and role conflict when caring for patients and families within AGCCU (Stayt 2009). These data provide an insight into nurses' views of life for survivors and families both within AGCCU and beyond.

Dimensions of the code are visualised in the network view Figure 6.1.
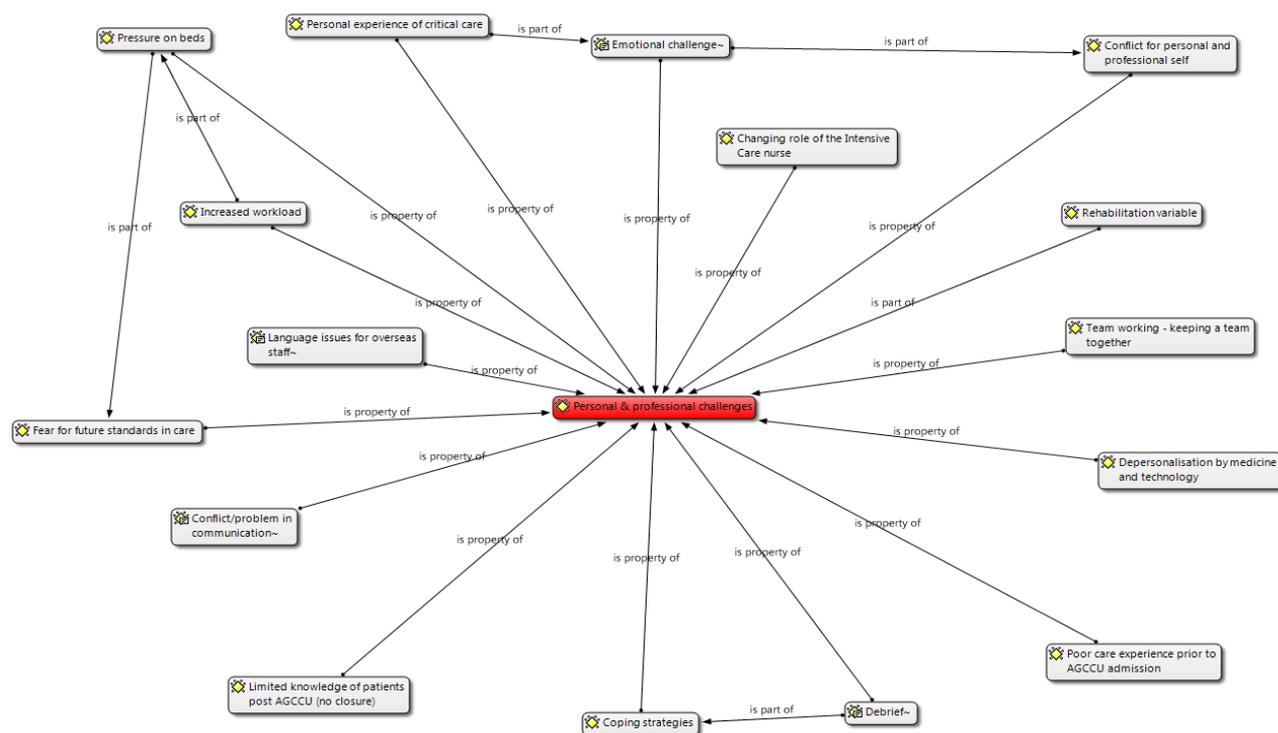
Figure 6.1 Network view Personal and Professional Challenges (focus code)

Critical Care nursing is a multidimensional role with criteria that differentiate it from general nursing (Jakimowicz and Perry 2015). Critical care nurses are frequently presented with unpredictable challenges both personally and professionally as the following vignettes illustrate.

Gail, an experienced critical care nurse of some 11 years, spoke of how she personally identified with patients and their families experiences and situations:

> **Gail:** '*what I find difficult is when I've looked after patients with bowel cancer, my dad had bowel cancer, so you can relate to things, and when relatives have got small children, I've got small children, and seeing what they're going through, that's quite challenging and hard emotionally sometimes, yeah*'. (S01)

Gail continued to confirm the humanity of nurses when caring in AGCCU:

> **Gail**:' …*you know, we are emotional people as well and I think sometimes showing a bit of emotion doesn't, you know, we are professionals but, we are emotional and, holding someone's hand ….one relative the other day, when her loved one died, she fell to the ground, and so I sat on the ground with her, …sometimes we cannot want to... it's hard to go to that place, but it's vital for the families that we do'* (S01).

This vignette illustrates how Gail invested her personal self in the relationship with the family, going beyond the perceived notion of it being '*just a job'* or being '*professional*'. Stayt (2007) highlighted the potential '*cost*' of emotional investment in terms of occupational stress and the following vignette reveals the emotional cost of long term exposure to critical illness and the challenge or conundrum of advancing technology.

Amanda after working in AGCCU for 18 years appeared to be struggling with the emotional challenges of working in an environment where proximity to death is ever present:

> **Amanda**: *I'm sick of death, I am sick of death, I went through a phase, about six months ago I thought, I am just so sick of death, not necessarily that we had a big patch of people dying, but I thought, oh, you know, we're either stopping somebody dying, they're dying, ...perpetual death, isn't it? Perpetual death, and I have had enough now, I have had enough. I've got another year and I'll be happy to go.* (S02).

Amanda seriously questioned the appropriate use of technology that may prolong life, which in her view, was of very poor quality: '*I think medical science is absolutely fantastic, but it needs to be used properly and I don't think necessarily these days it is, and that's why we've got the problems that we've got.*'(S02)

Working within an environment caring for people, literally fighting for their life, is evidently challenging at every level for the bedside nurse.

> **Aricha:** *it can be stressful because of workload, it can be stressful because of your emotions, you sometimes just have horrible, horrible days that you run all day and you don't get anywhere with a patient, you don't see the patient getting any better, actually sometimes just see the person going backwards and you just feel frustrated. And, yeah, if someone is deteriorating quite quickly and sometimes you just have very stressful situations. (S03).*

Aricha's narrative conveyed evident stress and frustration. The transition from active, aggressive intervention with complex technical and pharmacological approaches, into palliation or death, is extremely stressful for the bedside nurse as well as the family. Aricha had eighteen months experience in AGCCU at the time of interview and had yet to undertake any formal post-registration qualification in Critical Care. I would expect, and hope, that formalised CPD would ameliorate, although not completely remove, the stress that she was articulating.

Aricha went on to explain the personal cost of working in AGCCU in contrast to the ward environment: '*And I think the main thing like when I used to work on the wards and now, I see the difference, is that I can't actually, I can't actually go home and switch off.*' (S03)

Staff discussed coping strategies to help manage the occupational stress they experienced. These strategies were varied, Paco described how computer gaming or mentally '*closing the door*' on work helped him to '*switch off*', this was in contrast to Aricha above.

> **Paco**: *I've got plenty of brilliant things to do, kind of the shopping or of my games, and this is fantasy words which you can just close yourself in that funny world, and you don't have to thinking about what actually happened. But I think this one so far is working quite well and I am just closing the door, thank you, I've finished, I'll see you tomorrow, that's my way and I think that's working…(S04).*

Some respondents' spoke of the pressure of being '*observed*' at the bedside by relatives; something Kay refered to as the '*goldfish bowl*' phenomenon.

> **Clarin**: *"…but the people [family members], they're just constantly like observing you or they're telling you, oh, you haven't done nothing, …I don't know, it does intimidate me, or you're just going to do something and they just make a joke like, but it's not a nice joke, I don't like that, and I try to back off a little bit because that will make me fail as a nurse, because it will stress me out." (S07).*

In contrast, Mary who had 25 years of bedside critical care nursing experience spoke of her ability to '*switch off*' having done all that she can to care for both patient and family member in critical care, in the fullest sense of the word. There was one caveat:

> **Mary**: "*I think I'm able to switch off at the end of the day, I do my best while the patient is here, I do anything, I've taken a patient to a wedding, I've done all sorts, I take them out for walks and it's a lot, you know, and really tried to do my best while the patient's here. But once they've gone [died]…. then that's it…I don't go to patients' funerals..."* (SO8)

Jane, working as a more senior nurse (band 6) recognised the emotional impact of her working day.

> **Jane:** *From an emotional side of things I think we see an awful lot of death and a lot of family crises and you have do your job and you do your job effectively and you reflect afterwards, and it is a sad experience and I do feel myself saddened by the experiences that we have and I do question whether that constant bombardment of grief, because there is a lot, although there are obviously very positive outcomes, but a lot of it is [death]… And I feel I function absolutely fine when I'm here and I don't dwell on it as such, but it does make me wonder whether there's going to be long term effects of all of this. (S09).*

Jane was right to question this, as there is evidence that multiple exposures of caring for dying patients and their relatives may lead to cumulative grief (Marino 1998). The critical factor appears to be whether opportunity is given to grieve and come to terms with each individual event. If this is limited then

doubts about professional competency, identity and pre-occupation with grief and death may prevail (Marino 1998, Stayt 2009). There may have been evidence of this in the vignette from Amanda above.

Jane acknowledged the importance of debriefing for her own wellbeing although recognising that this may not be available to all staff within the AGCCU. Jane went on to raise an extreme example of role conflict.

> **Jane**: … *as a nurse in charge, I think our debriefing is fantastic, I don't feel that the bedside nurses probably have as much debriefing…if you're having a very challenging shift as a bedside nurse and a patient does sadly deteriorate, normally it's fine but you do get the exceptional circumstances, and whether there's actual time allowed to say, do you know what, let's just have a little chat, and I found, yeah, I've had a few challenging situations of nurses not being able to stop, noradrenaline[7] for example, in a deteriorating patient, they physically can't stop that button because it's the cause and effect, and that's been very challenging, from a nurse in charge, and to manage an ICU nurse that way.(S09)*

This vignette highlighted the complexity of the critical care nursing role and in particular the proximity to sustaining life or facilitating death. The continuous infusion of noradrenaline is likely to be life sustaining in this context and therefore discontinuation of such treatment will result in death. There is no question that emotional work forms an important part of critical care nursing. Nurses expend considerable emotional labour in caring within this context which is heightened by the close proximity of death in an acute, rather than palliative, context (Stayt 2009). Clearly Jane found it difficult to support and manage the affected critical care nurses.

Other staff sought support from family members, particularly if they had a clinical background:

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[7] Noradrenaline – vasoactive drug supporting blood pressure (life sustaining); delivered intravenously on a continuous and uninterrupted basis.

Cathy: "*I might tell my husband, he doesn't understand [laughs] or I might tell my sister who's a fellow nurse. Obviously issues of confidentiality maintained, and likewise I think my sister would seek support from me, but hers wouldn't be necessarily the patient group that she has, hers would more be her role as a deputy sister and the frustrations that she has, whereas my role may be a heart tugging thing because of something that's happened in a bed area.*" (S10)

The opportunity to reflect on critical events was highlighted as beneficial by Gail, specifically in the context of new staff to AGCCU. As this vignette illustrates:

Gail: "*…we do encourage reflection, I had a patient pass away the other week and I had a new staff nurse with me and I did some reflection with her afterwards because it was the first time she'd had a patient die up here and I think she was quite shocked by it because it happened very quickly, and one of the biggest things she said to me was, because her background was oncology and she said, I'm used to getting a relationship with the family, whereas we've had to suddenly call a family in, the first time we've met them, and their poor loved ones are so sick and they're probably going to die…*" (S01)

For Gail her faith, in addition to her family, was an important support for the sadness experienced within everyday working in AGCCU.

Gail: "*…my Christian faith is vital for me and I think I... it's very personal to me, but it is how I've got through things…if I've ever laid a patient out and had a death here and I always dedicate them to God when I get home, because it's a way of... it's a way of me passing over the person and it's... I have to give it over, because otherwise it is too... it's too heavy… sometimes...and my mum's a nurse as well, she works in a hospice, and so she's brilliant to talk to, especially when looking after patients dying and, you know, so we just... we'll share each other's burden sometimes...*" (S01)

These transcripts reveal the required compassionate nature and consequential emotional cost of working within an AGCCU environment and

individual strategies of coping with, and ameliorating the occupational stress, some with greater success than others.

Senior nurses (band 7) expressed different personal and professional conflicts from bed side critical care nurses. Senior nurses interviewed in this study were responsible for managing the clinical shift, agreeing discharges and admissions and ensuring optimal skill mix of staff. This, contrasted with the delivery of direct patient care by bedside nurses. It was very evident that there were increasing pressures on the service as Kay (band 7) explains:

> **Kay**: *"… the emotional challenges are the pressures like, we cancelled an elective yesterday, you've got the consultant having a go at you because you're cancelling someone who's [got cancer]... they've got three consultants coming in for a cancer surgery and that patient's obviously geared up... so you can only imagine, you gear yourself up for such a surgery and then it doesn't go ahead, like it's your fault. How is that my fault, we had 12 patients yesterday, and they don't want to hear it, and I totally get they're the ones that have got to go and face the patient at the end of the day, so I understand that, but that is awful, it makes you feel bad, …you don't just have them [beds], then you've got the anaesthetist ringing, and that's how it is most mornings, it's like ring, ring, ring when you're like this, there's no beds. And that is the emotion, because you feel you should be delivering, that is when you feel that you're not doing your job properly because you should be able to do it and you can't..." (S05).*

Kay demonstrated personal identification with such challenges; *"… and then you think, what if that was me, what if that was my op and it was cancelled? We've all got relatives, you know..."* This further illustrated conflict both between role expectations and patient care and between professional ideals and being a human.

She went on to share a difficult clinical shift which revealed further professional conflict in relation to quality of care and a genuine concern for the future in terms of the provision.

> **Kay**: "*we were sharing most of the patients both sides [level 3 and level 2] yesterday which obviously is totally unacceptable, so what you're doing is over sedating patients so that they're safe. But do you then not admit someone who needs that level of care because you can't because... I mean that's the balance, there's nowhere for these patients to go, every where's bursting at the seams, and then do we end up moving towards an American system where they restrain the patients physically or over sedating all the time? You know, we're proud that we don't do that, it's all about moving a patient through the journey in an appropriate timely fashion. Yesterday we didn't do that, so that was a failing,*" (S05).

This vignette reveals a health care system under extreme pressure; where potentially patient safety is at risk. Kay was considering documenting the events of the day as an adverse event. She, after 24 years' experience of working within AGCCU, expressed concern for future quality of care.

> **Kay:** "*…we're struggling to recruit now, the activity is greater, what will the future hold? I do fear for what the future will hold and we know what best care looks like and we will fight for best standards, but as the youngsters come through they possibly haven't seen that and so maybe the bar – and I was – what was it someone said to me the other day, one of the consultants? He implied that my bar was too high when I said something, so would a junior nurse fight for that?*" S05.

Jane also raised concerns over maintaining an appropriate skill mix and staff to patient ratio, and saw these as the greatest challenges ahead:
"Maintaining the staff patient ratio I think, and that probably does go back to beds etc. I just feel like it's got a lot busier of late, in the last maybe 5 years" (S09).

Karen had worked for 27 years within AGCCU and recognised how the role of the bedside nurse had changed over the years:

> **Karen:** "*…our roles are so different now, I mean I've been teaching a doctor all morning, so, the roles up here now are very different to what*

they were when I started, and what's expected of you as an Intensive Care nurse is very different."(S06)

The impact of technology; the challenges and the benefits are discussed in section 6.3.4. However depersonalisation by admission to critical care was clearly articulated by Amanda:

> **Amanda:** *"…when somebody is lying in a bed and they can't talk and you know nothing about them, you project your own theories of who they are, and it's like when they first talk and when you just hear their voice it's so amazing, and it adds a totally different dimension to them. But I think what we put them through can be virtually, some patients equate it to having been tortured, and I can totally appreciate that, but I don't feel that in the immediate time they're here that we truly see the psychological impact that it has on them, and I think that as a national critical care service it's sadly lacking because I think it really damages some of them so very much" (S02)*

The inference that she may be complicit in the "*torture*" is alluded to, both an awareness of the psychological effects of critical care illness, and its treatments. It also illustrated the conflict of providing humanistic care alongside physiological survival with the knowledge of deficient support for survivors and their families beyond the AGCCU. Amanda articulated her frustration at what she viewed as inappropriate admissions to AGCCU and a lack of knowledge around the effects and consequences of surviving critically illness:

> **Amanda***: "I find it challenging that we admit octogenarians who have so much chronic illness going on and we admit them and we ventilate them... my mantra is, just because you can, it doesn't mean you should, and that frustrates me.... the expectation of the public is to live forever, but it's not based on a reality. Well, you might live forever but you'll have a stroke, you'll be incontinent, you'll live in a home and no one will come and see you, and your quality of life will be significantly less than when you came into hospital.*
>
> **Pam:** *Why do you think this has come about?*

> **Amanda:** *I think it's lack of knowledge by the general public, isn't it, and I think because we've had our knowledge for so long, we think it's the norm, and it isn't, and they don't know what the potential future could be if they come in acutely unwell with all their comorbidities and they don't know what they're going to be put through and what they're going to end up like"* (S02).

The evident frustration confirmed conflict between Amanda's personal and professional roles that may, and in my view did, contribute to significant occupational stress.

Potential conflict with relatives, actual or as a subliminal thread was evident in several places. Karen spoke of one of the many difficult conversations doctors and nurses have with family members in AGCCU:

> **Karen:** *"I mean this chap we've just been talking to is a bit awkward because he doesn't want to have a DNR [Do Not Resuscitate order] on his dad, now his dad's had extensive cardiac surgery, he's on adrenaline, he's on 100% oxygen at the moment, he's been to theatre twice, he's in a terrible physiological state, and what we can't get him to understand is we wouldn't get him back if we did CPR, and that's an instance where you try and put yourself in their... he can't save his dad, and that's what you have to try and get in your head I think, and that's what he needs to understand, but he needs time to allow that. It's the one thing we're very bad with, time."* (S06).

Karen described the ability to see the situation from both a professional and personal perspective; two views that are frequently dissonant.

Kay highlighted the challenges presented by the experience of poor care prior to admission to AGCCU. Again, she revealed both a professional and personal perspective:

> **Kay:** *"But increasingly, the last few years, you've got families who have been disgruntled in other ward areas, they've had poor experience, they've had poor experience trying to rectify the poor experience, and then they come here and you're suddenly meant to*

try and make it good. That can be a bit of a double edged sword,
because if you then do achieve what they're looking for then they're
not going back there, we're not going back to that area,... and I get
that, because if that was my relative you'd feel the same way. And I
think that's where personally you kind of think, well, if that was my
loved one, and also when somebody has had suboptimum care... , if
that was your loved one what would you be doing? You can
understand why some of these people are feeling the way they do, let
down by the system, because they generally have been let down, and
then you can't say that. And you do feel sometimes you really want
to... So we do our best behind the scenes to try and shake things up a
bit if things have been suboptimal." (S05)

These data reveal the personal and professional challenges that adult critical care nurses experience and the variation between those experienced by bedside, and more senior, nurses. Insights into coping strategies are apparent, but I was left with the feeling that there was an emotional cost to caring in this technological environment where death, or the risk of death, is ever present. Jakimowicz and Perry (2015) claim that critical care nurses are at high risk of severe fatigue and anxiety, given that despite their best efforts at patient centred care the patient may not survive. The vignettes above certainly support this premise. Such prevalence of death and grief in the interviews was not expected. Death and mortality appear as intrinsic features within the reality of a critical care nurse life.

As all survivors interviewed described episodes of delirium (see section 5.3.2) it was appropriate to ask questions around the prevalence of delirium and to ask registered nurses in AGCCU to share their experience of caring for patients and their families during episodes of delirium. Section 6.3.2 details their responses.

6.3.2 Delirium Assessment and Management

This focus code adds to the corpus of knowledge around delirium in critical illness as perceived by registered nurses in AGCCU. Section 2.5.4 of the literature review provides insight from the literature and section 5.3.2 details

patient and family members' perspectives from this study. The data presented here further confirms the work of Elliott (2014) which showed deficits in health care professionals' knowledge of this important pathology. This is despite NICE guidance (clinical guideline 103) being in place since 2010 and providing further evidence of the theory-practice gap referred to in section 1.1. These data showed that nursing staff have an awareness of both theory and the need to change practice e.g. implementation of an assessment tool such as CAM-ICU (Confusion Assessment Method). However they struggled to implement the necessary change in practice.
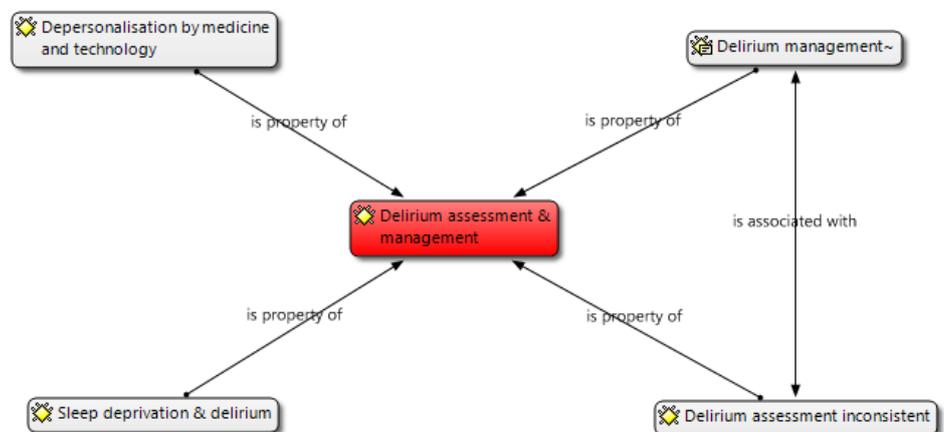
Figure 6.2 Network view Delirium assessment and management (focus code)

Jane, a band 6 and clinical facilitator in AGCCU with 11 years of critical care experience recognised that formal assessment of delirium was missing:

> **Jane:** *"I think that they're a very missed set of patients and actually thinking about it, even today I think maybe we had a patient that was probably a little bit hypo alert and you could almost say that, you could argue that we were misdiagnosing them as being maybe a little withdrawn or just uncomfortable about the situation, or depressed or something,…"* (SO9)

Jane went on to discuss her ambition to implement CAM-ICU:

> **Jane:** *"I'm really quite interested in looking at the CAM ICU tool, I think that's quite important, however we don't, and I'm actually at the minute trying to integrate it into the unit so we'll see how that goes, but very poorly and unstructured, I think, is how we assess it [delirium]".* (S09)

When I asked Amanda how delirium was assessed within the unit the simple answer was "*Well, we don't*". Kay however, clearly recognised the differing types of delirium and also a wider manifestation of mental health issues in the critically ill population:

> **Kay***: "…we assess for delirium in terms of we do the RASS [Richmond Agitation Sedation Score] scoring when we've got a patient ventilated, we assess for delirium when we look at the cognitive ability of somebody when we're just assessing them generally, how do we document that, we don't do CAMS [CAM-ICU]. We're aware that we don't, we have talked about CAMS and it is something we're looking at. I don't want to be... I wouldn't say that CAMS isn't any good because obviously it's a recognised tool, I think where we're lacking and where we need to look at is where people are hypo-alert."* (S05)

Kay described the risk and consequence of caring for patients who are experiencing hypo-alert delirium.

> **Kay**: *"…it's I think a failing probably from us and nursing, when people are withdrawn they're less demanding of our nursing time in terms of when you've got a very busy unit, and sometimes I think our focus can be shifted."* (S05).

Such a response demonstrates insight and honesty, but also concern, into the working world of critical care nursing.

One of the nurses interviewed had, only recently, become aware of the different types of delirium. This was through a CPD module undertaken at the local higher education institute (HEI). Aricha had 18 months experience working within AGCCU.

Aricha: *"I was just made aware that delirium you have two different ways of presenting, which I was more aware of the hyperactive one [laughs], and that... Now I wouldn't say that is the one we see most commonly because now I'm not sure, but it is the one that I was more aware of and, yeah, we do realise that loads of drugs can... and obviously changing of sleeping pattern and routines and everything can make them delirious…"* (S03)

Cathy, with 11 years' AGCCU experience, clearly recognised that delirium in all its forms was not always recognised:

Cathy: *"[delirium is] A lot more common than we give credit to, I think, because people suffer in silence, they're not always climbing out the bed, are they?"* (S10)

Interestingly, Karen who had worked with AGCCU for 27 years commented on learning from her mentees on the Critical Care course.

Karen: *"I'm mentoring at the moment A and B on the course, and I've learnt a lot [about delirium] because they're doing a different course to the one I did, and I think it is something we need to work on quite a lot. I didn't know all the sorts of delirium there are and I thought I did but I didn't know anything."* (S06)

For me, the honesty and desire to learn is heartening. A recognition of how, as health professionals, we (should) never stop learning.

Staff were able to readily recall patients experiencing delirium and for Clarin one particular gentleman was memorable:

Clarin: *"We just had a gentleman there, he's scared, and he actually said that he wouldn't close his eyes and he actually didn't, he wouldn't close his eyes because he was scared something was going to kill him. He trusted us all, but he wouldn't shut his eyes, and the fear on his face, that delirium on his face, it was actually quite scary..."* (S07).

Clarin explained how frustrating and draining it was to offer constant reassurance to no effect and to try and understand how he felt, witnessing

the terror etched on his face. The paranoid delirium described in the vignette above reflects the findings from patient interviews (see section 5.3.2) Dreams and Hallucinations (focus code) and specifically the vignettes from Linda and Alan.

Staff discussed strategies to both mitigate, and treat, delirium. These began with communication and reorientation, went through to mental capacity assessment and use of mittens or gloves as a form of physical restraint, to the use of chemical restraint. Gail makes specific reference to these approaches in delirium management:

> **Gail**: *"…it's a lot of reassurance, a lot of talking to them and a lot of explaining where they are, what's going on. I mean there are times where we do have to use haloperidol, we also use mittens, which I actually brought into the unit, is [sic] assessing their MCA [Mental Capacity Act] forms and doing the MCA"* (S01).

She went on to emphasise the importance of MCA assessment:

> **Gail***: "the doctors have to prescribe them so by prescribing them they have to fill in an MCA2 form because we were getting into problems with that. So yeah, so a lot of assessments, a lot of reassessments with our patients, because as well, even with the mittens on, they can still pull things, they're very clever at doing that…"* (S01)

Some staff recognised intuitively when patients were developing delirium. The vignette below uses colloquial language.

> **Amanda:** *"Like we've got a patient at the moment and you can tell that he's on the brew, he's just looking around, you know, I don't know what they're doing about it."* (S02)

Nursing staff described consistent strategies in delirium management, which in addition to those identified above included reviewing prescribed medication, assessing for pathology such as uraemia, promoting rest and sleep routines and involving family. Aricha particularly commented on the benefit of involving family members:

Aricha: *"Sometimes we'd use mittens as well and we do all the paperwork obviously that is involved with that and we tell the family, we always get the family involved as well and try to explain to them why is this happening, and sometimes they actually calm down, we had a few situations that actually they calmed down, and they are still seeing things but just to have someone that they know around...makes a difference for us to actually manage them."* (S03).

There appeared some intonation of surprise that family presence can have a significant effect on the wellbeing of a delirious patient and also to allow the nurse to "*manage*" the patient. However family presence may not always be possible, or practicable, at all hours of the day as Jane indicates:

Jane: "*We had a patient the other day that was hyper anxious and their English was very poor, and we actually had a nurse and the doctor that could speak the dialect, and they could definitely tell this patient was very delirious and we had to continue all the treatment, we had to, so this is like 2 o'clock in the morning, I know the wife, I know that she would possibly be good to come in and allay him and calm him down because he was delusional, he was, all over the place, bless him, he really didn't know where he was, he wasn't orientated at all. But the problem being, is, we, even by speaking to him, we couldn't convince him that this was the case, and I know that she'd been in during the day and I knew she had a small child and she didn't drive, so it's all these things that you're kind of balancing...*"(S09).

Further discussion around family presence in AGCCU can be found in section 6.3.3.

Kay provided further problem solving insights into the holistic care of patients with delirium within the AGCCU:

Kay: *"… if they're not uraemic and they haven't got underlying medical conditions, sleep deprivation primarily [causation], so we'll be looking at where they're positioned in the unit, that would be our first port of call. So if possible we'd be taking them away from the high activity areas like beds 3 and 4 where the phones are... and if it's*

feasible we'd move them down this end, but in the acute stage that
probably isn't, so we would tend to go down t'other end. Also from a
relative's point of view, sometimes relatives can make things better or
they can exacerbate anxiety in the patient as well, so we might look at
that avenue as well to see if there's anything we can do. Possibly
support the relative, and we have a counselling service now, so we
offer the relative more support and then that can sometimes allay any
extra anxiety of the patient. Medicines, obviously, alcohol withdrawal
is a massive issue for us now, which is still, it's relatively new and it's
in a younger generation". (S05).

The relatively *'new'* problem of alcohol dependency and withdrawal within
critical care was also identified by other staff. Kay went on to highlight the
importance of reassessment, acknowledging that problems remain beyond
discharge from critical care.

Gail also recognised the effects of sleep deprivation in causing delirium and,
also, the loss of time due to either sedation or delirium or a combination of
both:

> **Gail:** *"a lot of them [patients] are sleep deprived, that's a big thing,*
> *and I think obviously being sedated they've lost days or weeks and*
> *sometimes that can be due to delirium and they can get quite*
> *disturbed with that… [loss of time]".* (S01)

Loss of time and memory were initial codes from patient interviews (see
section 5.3.1) and contributed to the focus code of ambiguous loss. Gail
spoke of a patient's distress that she had lost precious time with her children
of which she had no recollection. This had surprised Gail: "*even though we'd*
saved her life and that was amazing, one of the biggest things was that 'I've
lost weeks with my children'". (S01)

Such data provided further insight into the initial proposal that physical
survival alone is not sufficient to allow wellbeing. The identity of who, and
what we are, is socially and culturally bounded. Insight and understanding of
the challenges facing survivors, and their families, beyond critical care
appears missing. However, sensitivity to supporting patients in the here and

now of delirium was evident in my interview with Mary who saw restraint in any form as a last resort to care:

> **Mary:** "*I try and stay there with them, talk to them, not restrain them at all because I think that irritates them even more, and just try to be sort of patient, go along with it, and just help them to talk through it and, yeah, but not go along with saying, oh yes, I can see that person over there or that thing running across the floor, but being there with them and for them*" (S09).

In relation to hyper-alert delirium where there may be a risk to the wellbeing of the patient, family or staff, chemical restraint is frequently administered, as Karen describes:

> **Karen**: "*Unfortunately it's usually a drug cosh isn't it? What drug depends on what doctor is on and what their choice is. I think we use Haloperidol a bit more now and we do use very small doses of Propofol, whether or not you're just increasing the problem, because these are the drugs that caused the problem initially, I don't know.*"(S06)

Staff generally showed concern for the use of restraint in whatever form or combination:

> **Cathy**: "*It's still restraint, isn't it, whichever way you go with mittens or drugs, we're restraining, aren't we?*" (S10).

Although she went on to suggest that for family members, physical restraint was harder to come to terms with:

> **Cathy**: "*I would say the mitts are the more challenging for the relatives to see, if we were to give some drugs to keep them calm, that's via the NG tube, that's very different to putting mittens on somebody, isn't it?*" (S10)

Some nurses spoke of striving to humanise an environment that appeared depersonalised by technology and medicalisation, an important strategy in trying to ensure the patient's identity:

> **Cathy**: *"…And also I see doctors who enter the bed spaces who start taking a limb and trying to cannulate it, …what I would normally do is just speak over the doctor and say to the person X 'The doctor's going to just…' and then usually they think, oh, yeah, I should have said that, and carries on! [laughs]* (S10)

Cathy discussed the loss of control that patients experience during critical illness (see also 5.3.1) and the vulnerability they experience. She emphasised the importance of continuing orientation and communication together with acknowledging the privilege of caring for dependent patients and their families.

> **Cathy**: *"… we're in a privileged position and we forget this because we enter the space of an individual and we can do quite intimate things with them, and I don't just mean catheter care, PRs and things, but actually mouth care, eye care, fiddling around with their hair, brushing it, moving limbs, you know, and I think we have to continue to explain to people what's happening around them"* (S10)

Overall, the data and illustrative vignettes revealed a varied knowledge base around delirium assessment and management in comparison with the literature and current NICE clinical guidance 103 (NICE 2010). They also revealed a sensitive and humanistic approach to patients and their families in the here and now of critical care. Whilst there were some references to the longer term effects of delirium this was less evident. One nurse, Aricha clearly recognised hyper-alert delirium post transfer from AGCCU:

> **Aricha:** *"Many, many times we go to the ward and we see the patients still completely delirious, like when we discharged them,…"* (S03)

The next section focuses on the presence of family members in AGCCU from a nurse's perspective.

6.3.3 Family Member Presence

Providing family centred care in AGCCU is a central tenet of holistic care (Stayt 2009, Wilkinson 1995). The perspectives of registered nurses

augments the patient and family perspectives, detailed in section 5.3.4, and are identified as important elements in make sense of critical illness as well as providing comfort and reassurance (see Judith and Annie in Chapter 5). Family members also described the importance of having access to their relative in AGCCU as central to their own wellbeing (see Sarah) and the ability to make sense of having a relative who is critically ill. This section provides registered nurses' experiences of having family members present at the bedside. Section 2.6.5 articulates the contention that exists in both the literature and in practice. These data add to this growing body of knowledge and remind us that we are social beings. Context and contact develop a reality that has meaning, albeit often different, for patient, family member and nurses.
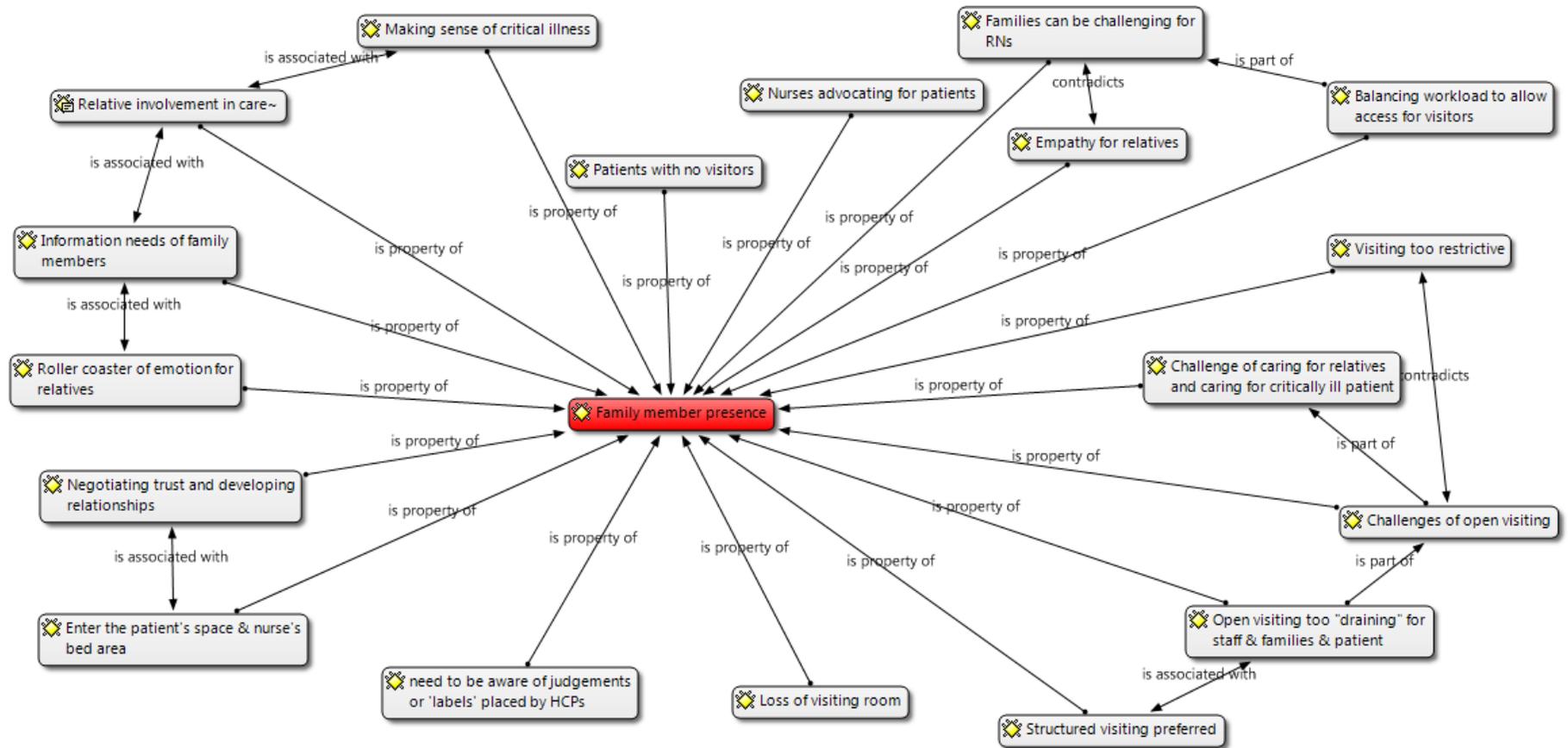
Figure 6.3 Network view Family member presence (focus code)

Participants spoke of the challenges of caring for the patient and meeting the needs of their relatives concurrently at the bedside. Gail also had personal experience of being a relative in an AGCCU which had influenced her as a bedside critical care nurse

> **Gail:** *"I had a relative in Critical Care, it's the biggest shock that you can face, and just the unfamiliarity of monitors, tubes, I mean I think a lot of our families we have to go through, step by step, what is actually going on…they need a lot of support because, especially when I was the other side, it is like a rollercoaster of a ride, and I do say that to relatives, we're going to have good days and bad days, and emotionally you're all over the place. So it is for us to keep talking with the families, it is sometimes hard when you've got a very sick patient [laughs] and you do have to manage looking after your patient and looking after relatives as well, which I think is a bit of a skill sometimes…"* (SO1)

Some participants reported that they were torn between caring for the patient, which they perceived to be their priority, and recognising their responsibility towards the family. Gail describes how family presence can be challenging because of this.

> **Gail:** *"Sometimes challenging, I must admit, especially when the patient's very sick and you're torn between... obviously you've got your job to do as looking after the patient and then you've got relatives asking you questions all the time…. I have said in the past, I'll just finish what I'm doing and then as soon as I'm done I will come and talk to you, just when it's really constant and very... But... yeah, it can be challenging at times! [laughs] But we do our best! [laughs]"* (S01)

Similarly, Mary recounted the challenges of dealing with the technological requirements to keep the patient physiologically alive and acknowledging and talking with family members:

> **Mary**: *"…because, well, you're trying to do your pumps and concentrate on changing the infusions and the relatives are chatting away to you as well, not particularly about the patient but about everything, and you're trying to make sure that you're doing it right...with them chattering there. And I usually try to say to them, sort of very politely, I can talk to you in a minute if I can just do this, you know, and sometimes they realise and sometimes they still chatter [laughs]."* (S08)

Amanda recalled rare occasions where family members were perceived as delaying care and expressed her concern at the interview:

> **Amanda:** *"…sometimes there is so much happening. And I did have a few experiences of patients deteriorating and needing to go to theatre, and I do understand that family gets anxious, and they are deteriorating there and they see us rushing around and they know that something is wrong. But at the same time I found a couple of times that it wasn't really in the best interest of the patient for them to be there because we were being delayed, and I know that happened with a few colleagues, but it's something I would say that is rare, it's not really something that I would say that happens all the time"* (S02).

This account again reveals the reality of working in situations where there is a real tension in balancing physical survival with psychological needs of patients and their families, which in turn can cause personal and professional conflict for the bedside nurse.

Amanda recognised that for junior staff in particular family presence at the bedside in AGCCU can be stressful:

> **Amanda**: *"I think the more experience you have, the more comfortable you are with them [relatives]. I think when you're a junior having relatives come into the bed area when you're really, really trying to get on top of what you're doing and getting it right can be very stressful. I remember being quite stressed by a family being in the bed area when I was a junior. "*(S02)

The above vignettes clearly illustrate the emotional labour of caring within adult critical care which links with the personal and professional challenges detailed in section 6.3.1.

Similarly, Kay acknowledged the challenges faced by nurses at all levels in what she describes as, "… *the goldfish bowl scenario, you're very much embroiled in it and there's no escape, and so relatives will ask probing questions, they will challenge, they will test, and so it's very challenging for even experienced nurses often*". (S05).

Aricha, a relatively junior nurse recognised the challenges that arise when patients deteriorated.

> **Aricha:** *"It can be challenging sometimes because obviously you do the best you can and you're not achieving what you want and you're not achieving what the family wants either, and it can be frustrating..."*(S03).

Kay talked about some of the challenges she had experienced with family members, who in her view, resented not having access to their relative.

> **Kay**: *"I don't think family members can appreciate the need to carry on with activities and get the job done and how, it isn't very private, is it, and washes and care have to be done, and people resent being kept waiting outside,... that's your visiting hours so the patient should be ready, and unfortunately if they've had their bowels open five minutes before visiting that has to be sorted, …And I find that hard to rationalise, I don't understand why people don't get it,... So I'm not against open visiting if I thought that people would be understanding of the need to do what has to be done, but experience of late, it doesn't seem to be that way, and people are obstructive, because I think more and more people have had suboptimum experience and I'm not sure that we're going to get round that totally. And some people are blatantly rude and abusive…"* (S05)

The language used in this vignette reveals a frustration in families not understanding that care needs to be delivered in a way that attempts to give

the patient some dignity and privacy. It also conveys a note of authority and may be illustrative of the "*work*" family members have to undertake to gain access to their relative (Vandall-Walker and Clark 2011(see 2.5.5)). The AGCCU does have fixed visiting hours that have in recent years been further curtailed, this was also an area of contention amongst staff (see Karen's and Cathy's responses below).

In contrast, Cathy suggested that the stress of having a relative critically ill is very likely to cause people to behave differently and that health care professionals should not be quick to judge:

> **Cathy:** *"I think we're quite quick to make a judgement but not necessarily coming up with the right analysis of an individual really, because they're in a crisis, aren't they, and the person that knocks on the door, the person that rings at the other end of the phone isn't always the person who they really are…"* (S10).

Mary welcomed family members at the bed side but she did express some concern around the ongoing dilemma of truly knowing the wishes of a person who by virtue of their critical illness, lacked autonomy and ability to give consent.

> **Mary:** "…*it's the ones that are sometimes [laughs] constantly touching and feeling their relatives when you're just wondering whether that relative actually wants to be touched and felt, but they obviously feel there's a need for it. It can be a little bit challenging at times*" (S08).

Section 2.6.6 (Chapter 2) articulates the very variable practices around providing family members with access to their relatives in AGCCU both in the UK and further afield. Some form of restrictive visiting is the dominant model in Europe (Hunter 2010 (UK), Cappellini et al 2013, Spreen and Schuumans 2011 (Netherlands), Plakas 2014, (Greece)). Registered nurse participants in this study generally favoured restricted visiting but with flexibility. Gail had experience of open and unrestricted visiting in a previous hospital and could also recall open visiting within the current AGCCU previously.

Gail: "*I think that can be really draining emotionally for the staff to have open visiting…what I would try and do is get all the dressings done and all the changes done so that when the family comes in I might be able to get to spend a bit more time with them…because otherwise, sometimes when they are here, I mean I did work here when we did have open visiting, but sometimes you're asking them to keep going out and sometimes they get annoyed with that, so they're like, I'm going out again and it's like, well, I just want to... I'm doing some dressings and some people they don't want to sit there while you're doing a [blood] gas– because they can't cope with it, so I do think it's better having the times allocated actually, obviously when they're really sick and we've got patients dying we let relatives stay, on night duty the other night I had relatives staying all night. But yeah, I think it's good for the staff as well to have a bit of space*" (S01).

This was a common response from staff suggesting that restricted visiting gave relatives a structure to their day too. One of the family members interviewed – Gary made this point too (PR09).

Gary: *On the first day they said to us, you know, there's no visiting hours, you come and go as you please and whenever you want you come in, and on the second day, you know, still critically ill, still in danger, but they imposed visiting hours. But I don't think any of us worried about that, we actually kind of thought, well that's OK, that's normal, that's alright, we don't need to be there 24/7 and what can we do anyway, so I can't criticise on that, I didn't really want to come up here 24/7, ...in some ways perhaps it was a way of saying that actually things are normal. These are the visiting hours and you will stick to them and I didn't feel bad about that, does it sound funny to say that?*

Pam: *No, not at all.*

Gary: *You know, it feels like normal, normal. Monday, the first day, wasn't normal. Tuesday became a bit more normal because they said we've got to come at 12 o'clock,*

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One participant felt strongly that, without some form of restriction to visiting hours, it would be impossible to deliver the care required:

> **Paco:** "*Right, from my point of view unfortunately it's good as we've got the restriction visiting simply because you won't be able to do all stuff that we have to do, personal care, physiotherapy, ward rounds, medication, investigation, kind of tests, etc, etc, it's impossible*" (S04).

Some of the participants who had undertaken their pre-registration nurse education outside of the UK (S03, S04, S07 and S11) found even flexible visiting an unusual concept. They were more familiar with a prescriptive, authoritative approach by health care professionals. Although S07 commented, conversely, on the lack of visibility and involvement of family members in supporting bedside care. Evidence of cultural variation in nursing practice is well documented in the literature (Capellinie et al 2013).

Karen, however, objected quite strongly to the visiting regime in place at the time of interviews:

> **Karen**: "*I don't like it... if this was my family member in here, I would feel very restricted to come in. The average person we have is elderly, you've got elderly people coming in with horrible weather like we have currently, and they're coming in when it's dark, we're having to drag them in when it's dark and it's horrible. I understand not being able to visit in the mornings, we have physio, we have ward rounds, we've lots of procedures going on, but surely we could have visiting from 12 'til 9 or 10 o'clock at night so you've got people that are working. It's a 24 hour, 7 day a week place now, everywhere most people work shift work, very few people work Monday to Friday and I just think the accessibility should be there, I'd want it for my family so I don't like it….*" (S06).

Mary and Cathy also expressed concern over the restricted visiting hours:

> **Cathy:** "*Currently our visiting hours are limited to two hours in the early afternoon and then four hours later on in the day. I think they*

should be a bit more flexible to the patients' needs actually…
especially if they have delirium, because often it's their loved ones
that bring them back to where they need to be" (S10).

Amanda recognised the very alien world that family members find
themselves in and how nurses can orientate them and facilitate
communication between doctors and families:

Amanda: *"…it's a totally alien environment so you have to draw them*
into the environment and help them to... adapt to coming into it on a
frequent basis. It's our role to be an adjunct between the medical staff
and the relatives, and also just to make what can be an absolutely
appalling episode more tolerable to deal with. (S02)

Velta also recognised the alien world or '*different reality'* that confronts family
members when entering critical care:

Velta: "*Yes, it's easy to see when they're entering the door and they*
see a kind of different reality from the wards, they see patients with
lines, tubes, and it quite confuses them, machines alarming,
everything's so different from the common hospital ward. And, yeah,
kind of a shock to them to this reality". (S11)

Kay articulated the cruciality of that first meeting with the family. Many staff
discussed the importance of building trust between themselves and the
family and how fragile this can be at times.

Kay: *"… I hope to convey that their relative is in safe hands,*
…because their trust is totally in you and they need to feel confident
and that's your first meeting point, and if that barrier was to break
down right from the early outset that it could actually scupper the
entire path of the journey for that patient," (S05).

In a similar vein, Karen referred to the alien environment that confronted
family members (again with personal insights) and their information needs.
Reference is made, once more, to accessing medical staff:

> **Karen:** "*we forget that we understand the terminology that we use, we understand the machines and everything around, this is an alien environment from the word go, you know, I can remember my first day as a nurse, fainting, …so these people have an awful time... I think accessibility to the medical staff should sometimes be greater than what it is, but there's pressures on them obviously, and everybody always wants to talk to the top dog, we all would in their position*" (S06).

The status of medical staff is prized by Karen (from both a professional and personal perspective) as an important and valued source of information.

Jane described her approach in establishing a relationship with family members and meeting their informational needs:

> **Jane:** "*... I always like to sit down, I often get a chair, or definitely come down to their level and just discuss everything that's been going on and how they feel and what they expected and how much they know, how much information they know, what I can add, whether that's the same, whether their expectations are the same, and how they're feeling about everything, and how their home life is*". (S09)

Meeting the information needs of relative's links directly to the sense making focus code (section 5.3.4) identified in Chapter 5. Participants recognised that informational needs were individual and some questions cannot be answered, at least not in the short term.

> **Karen:** "*People are usually very hungry for information, questions to be answered. Unfortunately we can't always answer them, but we do the best that we can or use the resources available to us to answer them.*" She later added in more philosophical manner "*as Intensive Care nurses I think you end up nursing the family as much as the patient and the people around them. Time, giving them time, people don't always have time for people anymore, so I think we need to give people time*" (S06).

Some nurses had experience of relative involvement in patient care, generally this was a positive experience that helped build up trust:

> **Gail:** *"I did have a young boy and the mum was here and she asked to stay to help wash him and I let her stay, because I know if that was my child I wouldn't be leaving his side, so from a mother's perspective as well I wanted to include her. And that helped us bond as well, so... some people it can be a bit uncomfortable, but I found that quite good for us, for our relationship actually, she then could trust me, because I'd trusted her and she knew, like he was sedated at the time but she could see I was still talking to him, could see the respect and dignity that I was giving him, and that helped our relationship as well,"* (S01).

Gail, again, referred to herself both in a professional role and as a mother although, here, the personal and professional roles are harmonised and not in conflict.

Aricha also found relative involvement in care to be helpful; probably to all parties.

> **Aricha:** "*sometimes they [family members] ask us if they can do that and we say of course, basic things that we think is not going to harm the patient, that's fine. And actually I think it's comforting for them to be helping, and they help us as well because sometimes we are rushing with time to do things and prepare medications if they need some mouth care and they can provide it, is good, it is. I think most of the time we do that unless, which I found as well, that some family rather not do anything [laughs]..."* (S03)

Clarin who trained outside of the UK was startled by the lack of involvement of relatives in supporting personal care; clearly a cultural variation in nursing practices.

> **Clarin:** *"…when I first started here in England it was a bit shocking, I mean that the families weren't that involved. And I was like, what? Why? They don't come here that often, why? Why do they call you to feed them if they are there, for example? It did shock me…"* (S07).

These data illustrate critical care nurses' experiences of the benefits and challenges of family presence in AGCCU. They complement the data presented in Chapter 5, specifically section 5.3.4 where family member presence is seen to assist making sense of critical illness for both the patient and the family member. However, the views of both family members and registered nurses varied with no evident consensus.

Some of the specialised knowledge and skills of critical care nurses have been alluded to in the preceding sections. Section 6.3.4 explicitly discusses the specialised knowledge and skill developed by registered nurses in AGCCU which are constructed and developed over time. This knowledge and skill was also reflected in the data from patient and family member's interviews; see section 5.3.4 (Sarah and John).

6.3.4. Specialised Knowledge and Skill

The care that patients and family members receive in the AGCCU requires specialised nursing knowledge and skill (Jakimowicz and Perry 2015, McGrath 2008). This in turn requires interface with technology, complex pharmacology and significant efforts to humanise an alien environment (Tunlind et al 2015). This section of data constructs a background of knowledge concerning the reasons that nurses work in critical care and their experience of the effects of critical illness on both patients and families. Experienced nurses appear more able to transcend the intrusive nature of technology. There appears to be evidence of a journey that junior nurses travel to gain specialised knowledge and skill in developing the craft of critical care nursing.

The initial codes that make up the focus code of specialised knowledge and skill are dimensionalised in figure 6.4.
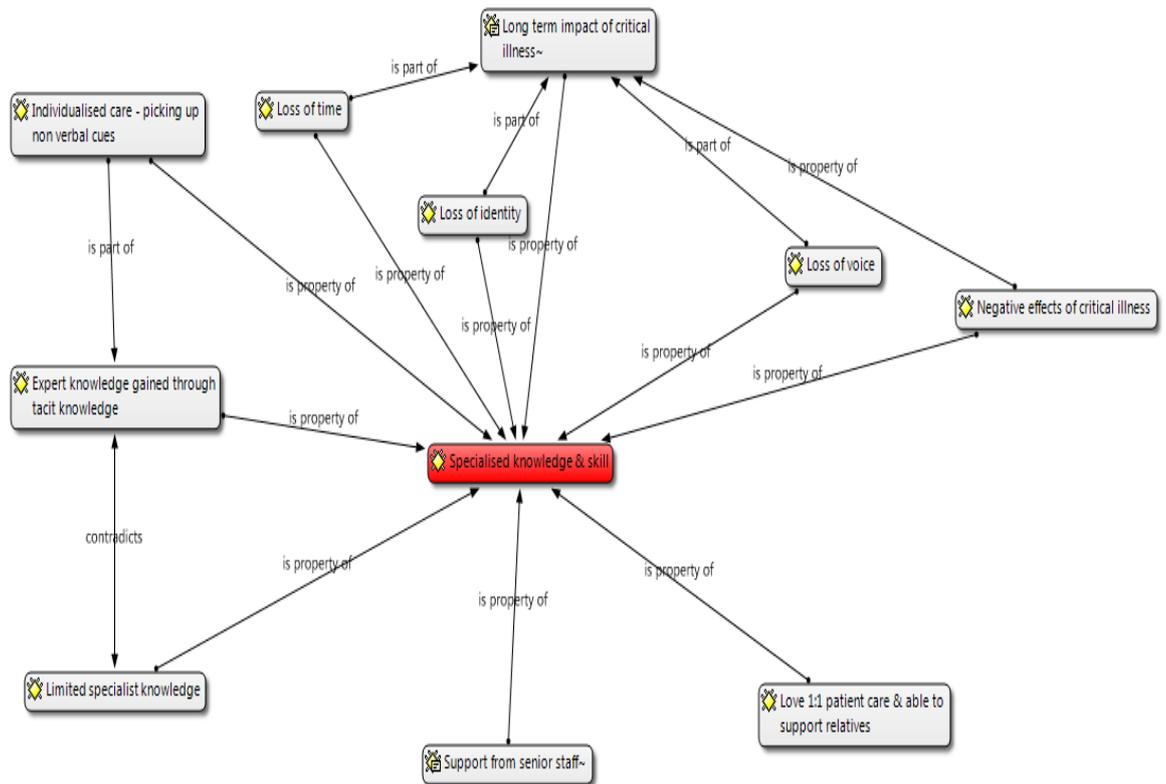
Figure 6.4 Network view Specialised knowledge and skill (focus code)

Many nurses spoke of their passion for nursing on a 1:1 basis and being able to support families in addition to providing high quality nursing care. Senior nurses also spoke of the opportunity to continue to deliver '*hands on*' care. This was clearly important to Karen who had spent 27 years in AGCCU:

> **Karen:** *"I like bedside nursing, I like the hands on nursing that you do, and I feel that you can achieve that here …in my position now I'd be more of a paper based nurse and I like the hands on". (S06)*

Similarly, Kay expounded her '*love*' of delivering high quality nursing care.

> **Kay**: "*I love it! [laughs] I still love it, I just like being able to do everything, and even though it's obviously a lot more acute and a lot busier than it was, we're still afforded the luxury of, for the most part, being able to do everything that you desire to do for the patient in your shift and you don't go home thinking, if only I'd... you're not leaving*

people in wet beds, your mouth's attended to, and you have the time to talk to families, to spend with the patient, it's still a luxury".(S05).

Several staff contrasted this with their experience of delivering care in a ward environment. Providing holistic care was clearly important to Jane; getting to know the patient and the family provided her with a sense of satisfaction which was important to her own wellbeing:

> **Jane**: "*I think it was just being able to provide holistic care for a patient, knowing them very well, and being able to deliver very individualised care, and just kind of, yeah, just being able to do everything for them, you're part of their family and just be able to care for them and know what their face looks like at handover. That was probably very important, you know, from working on a ward that sounds very callous in a way, but it's not, just being able to know exactly what's going on with them, I think, is really, really important to me".(S09)*

The more junior staff also expressed great satisfaction in being able to deliver care in a timely and individualised manner. Clarin makes reference to the support that she received and this was also a recurring theme from the interviews with more junior members of staff.

> **Clarin**: "*Since I started in Critical Care I actually go home saying, I've done it, another day, tick, like really, really big and proud, because we've got the time to actually go and do it. Whereas on the wards it was like, it's just really, really stressful, really, really stressful. But in here I've got the time to do it, I mean even though on a busy day, you do have so much support, but that is like, if you kind of somebody's going to just hold you and lift you and it's like, OK, let's do it together, because that is what happens.*"(S07)

Some senior staff also referred to the intellectual stimulation of working in an environment that provided and supported learning opportunities:

> **Cathy**: "*I liked the support around me, the opportunity for learning, very rare to ask one of the nurses around me when I was very junior*

and they not be able to give me an answer or an explanation. I loved the time to do my job properly, dot the i's and cross the t's". (S10).

Paco, as a newer member of the team, also saw a direct association between knowledge and confidence and, by inference, competence.

Paco: "*I think this is the biggest benefit which you can get on ITU really, the knowledge. And after, when you've got the knowledge, you can build in confidence, you can deal with the patient. We are very close with the patients, not the same like on the wards, you're more close because you spend 12 hours with the same person, so yeah, I think I would say on the first, top is knowledge.*" (S04).

This clearly provided staff with a sense of satisfaction in their work, Cathy again:

Cathy: "*some days I go away and I know I've done a good job in the care or in the fact that a family may have softened or they get it or they've been happier and you go away feeling a bit like, yeah, did that alright today,*" (S10).

Staff, in particular senior staff, discussed the challenges they perceived patients to experience within AGCCU. Kay with 24 years' experience in AGCCU provided insights that matched the survivors' narratives in chapter 5:

Kay: "*...fear has got to be predominant, scared for their own health, scared of a changing environment, scared because they've absolutely got no idea what's going to happen to them, they've got no control, total loss of control, and for many people, regardless of what you are in society, that is overwhelming, and again, you're putting your trust and previous experiences of the healthcare system, what's led you to become unwell, your family relationship, worries you might have at home, in business, and everything would be what's going through your mind at that time, how am I going to do X, Y and Z, how's that going to function and, you know, am I going to get out of this, and your ultimate survival I suppose. So it's enormous, absolutely enormous.*" (S05)

In a similar vein Cathy recognised the loss of autonomy by patients:

> **Cathy:** *"… loss of autonomy, and if they're trache'd or they're ventilated and they're awake they can't express their needs, can they …"* (S10).

> **Jane:** *"... the hardest thing psychologically for a patient is probably not being able to communicate effectively, I think that would probably be the first thing, and they get very frustrated by that, don't they?"* (S09)

This again matches closely with the powerful impact of losing voice, both literally and metaphorically (see 5.3.1, Andy (PR03) and Charles (P02)).

Mary identified changes in body image as being a consequence of critical illness and treatments which was not sufficiently recognised.

> **Mary:** *"I mean we do things like tracheostomies, the emergency patients, they can have drains, colostomies, and especially for ladies, certain ladies, especially if they've taken care of themselves, to actually have that, I don't think we take enough notice of altered body image."* (S08)

This statement reflects James experience (section 5.3.3) of confronting his reflection in the mirror at home and recognising a tracheostomy scar that he knew nothing about.

Making sense of critical illness is clearly an important element in gaining wellness. Patients are transitioning to a *'new normal'* (see section 5.3.4). The notion of gaining narrative coherence between survivor, relative and staff of the critical illness experience is important in achieving closure (Jones 2014a). Narrative closure is where familiarity with the illness is achieved, the after effects are understood, and so all parties are able to support the survivor. Data from survivors' and relatives' interviews (Chapter 5) revealed differences in the illness narrative which may contribute to conflict between patients and families (section 5.3.1 Annie (P01), Jane (PR09)). The consequences of Mary's insightful comments around changes in body image, and consequentially identity, may affect narrative closure.

Knowledge gained through experience allowed Cathy to make judgements in preparing family members for changes in their relative's condition:

> **Cathy**: "*I think often you know what's wrong with the patient and through experience you can make a judgement as to whether you'll need to be preparing people that things change very quickly.*" (S10)

Kay also referred to instinctive, or tacit knowledge in advocating for patients to stay longer within AGCCU, acknowledging the vulnerability of patients particularly at the very early stages of the survivorship journey.

> **Kay**: "*I mean obviously a lot of our patients are vulnerable and you know what they're going out to [wards], so I mean we've got the use of HDU now so it's transitioning into very much a step down, like today we're discharging down to there, so we're confident in the fact that you know you've got that step down. However, if they're not there, they don't know how frequent their suction is, they might cough on the ward round and then that might be it for the day, they're totally shattered, and there's just some people, from a nursing point of view, an instinct, call it whatever, but you just know that it's all going to go wrong if they... and sometimes it's just 24 hours, I don't know what it is, but it's just that little bit longer they need here....*"
> (S05).

Having developed specialised knowledge and skills, maintaining them can be a challenge because technology is constantly changing and evolving in the AGCCU.

> **Cathy:** "*…my patient's my priority and I need to get that right and I need to be happy that I understand everything that's going on at my bed area. I find hemofiltration a challenge because I don't do it as often as I used to, with the old machines, I worked full time and I was alright, I was good, and Dr X was very precise in the prescription that he wanted, and the settings that we were to be using. Whereas now with the Prismaflex we use hemodiafiltration, we also use Citrate or Heparin, and, you know, the set up and the prime of the circuit is different, also the programming of the system is different and some of the troubleshooting is different because we can manipulation pre-*

dilution fluid, can't we? So I find that more of a challenge because I don't do that as frequently as I used to because, wrong place, wrong time, right place, right time, that's what it is in this environment, isn't it, to the exposure?" (S10)

Patient safety is clearly at the forefront of Cathy's mind. The detail provided in this vignette served to illustrate the complexities that bedside critical nurses must manage alongside the competing roles of supporting family members and junior staff.

The final section discusses nurses' experience of patients and families transitioning to the next stage of their journey to wellness. This is identified as a critical juncture in Chapter 5 (section 5.3.5) and discussed within the literature (section 2.5.2). The data presented provides some stark illustrations as to why it is indeed, a challenging juncture in the survivorship journey.

6.3.5 Transitional Care

We know from the literature and this study that transitioning from AGCCU to the ward is a stressful experience for patients and their families, (see literature review 2.5.2 and survivor and family member experiences 5.3.5.2). Pattison et al (2015) refers to the relocation anxiety experienced by both patients and family members despite the presence of follow up from critical care outreach teams. This section contributes to the growing body of knowledge around transition and, additionally, provides the perspective of the AGCCU nurse which is under represented in the current literature.
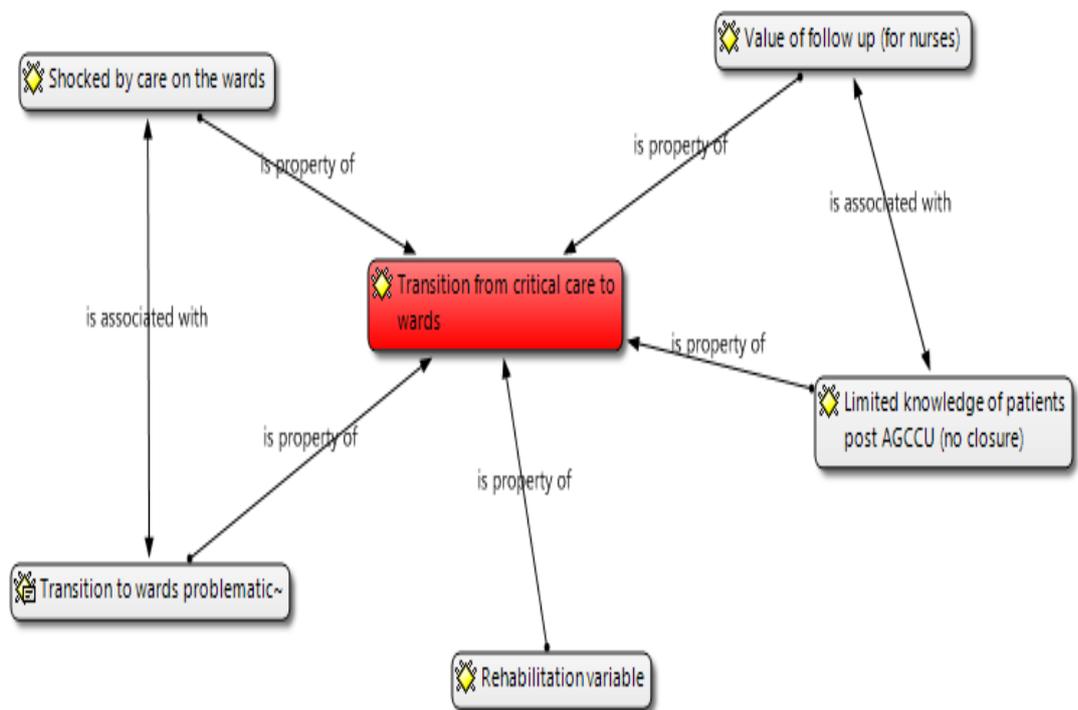
Figure 6.5 Network view Transition from critical care to wards (focus code)

Nursing staff from AGCCU articulated their concerns around the significant differences in staff ratios and continuity of care when discharged from AGCCU to general ward areas.

> **Gail:** *"…it's a big jump when you've had that one to one and then going to the wards where you might not see anyone for ages, or you see a lot of agency staff, you don't get that continuity".* (S01)

She went on to refer to the pressure on critical care beds that could lead to a "*busy discharge*" but how she would endeavour to prepare patients for the transfer to a different level of care:

> **Gail:** "…*sometimes it is quite a busy discharge I must admit, if we've got pressure on us to get patients out, but if I know I've got a patient going [to the ward], I talk to the patient about how things are on the ward and obviously you're not going to have this one to one care,…*(S01)

Amanda implied that there had been a retrograde step in relation to transitional care to the wards. This was attributed to the loss of the follow-up team of nurses and the increased workload of both the AGCCU and the hospital: "*I don't think we probably do as much as we used to, and I think that's because of the amount of work we're doing…*" (S02).

Paco also made reference to the busy reality of daily life in critical care implying that insufficient time for preparing patients and families for transition to the ward.

> **Paco**: "*The reality is we've got admission and discharge so quickly …I mean it's lovely to sit with the patient but we don't have the time really. So I couldn't find here that we've got the time to do it.*" (S04)

Aricha recognised that discharge could be a double edged sword, as evidenced in the literature (see 2.5.2 and the relative and patient data in 5.3.5.2 Barry and Jane especially). She recognised that patients saw the AGCCU as a *'safe'* environment.

> **Aricha**: "*But some of them are quite anxious about actually leaving us because they know... I think they know they are safe and they know they are going to where it is a little bit more challenging for the nurses when it comes to having like 10, 12 patients for just one nurse. So in one way I think they get quite scared about it, anxious about it, but in another way I think they are actually quite happy. I see both emotions in different patients.*" (S03)

Kay also made reference to patients valuing the feeling of 'safety' within AGCCU. She questioned whether, in fact, there was any preparation at all for discharge to the wards:

> **Kay:** "*…do we prepare patients for discharge? We talk to them just generally, so say they've had a protracted stay then obviously you're encouraging them and letting them know that things are improving, invariably these longer stay patients may well have a tracheostomy so they can see the transition between periods off the ventilator on and they can see that steady state, but then on balance, even though they*

know that it's coming, they're more fearful because they're terrified that they're going to be leaving a place of safety, in their belief, to something different." (S05)

As a critical care nurse of some 24 years she recognised the challenge but said; *"I don't know how you'd bridge that because I can't see it changing, but I can totally understand why it would be scary."* (S05). She was referring to the increased workload and activity through the AGCCU and the hospital as a whole.

Gail referred to the way in which her own personal experience has influenced her professional behaviour in relation to recognising the significance of transitioning from AGGCU to the wards, with discharge being described as:

> **Gail**: "…*a big change, a massive change. I mean my loved one that was here, him getting to the ward was so difficult and unfortunately he did pass away on the ward, but yeah, it was a huge change for the family and I was trying to tell my family, you know, he won't be getting one to one care, he'll be getting... there'll be a nurse there but she'll have a bay of patients to care for…*"

Mary recognised that previous experiences of care may enhance the fear of transitioning to lower levels of care.

> **Mary**: *"… I think they're frightened, especially if they've had a bad experience of being on the ward before. Being sat out and left in a chair for too long. They're obviously weak and it's going to take a long time for them to build up their muscle strength and to be... instead of having perhaps two short episodes in a chair, they're going to be left there and they want to get back into bed, so it's going to make them not want to get out again. And I think sort of generally sort of... they need more help, they need more help for washing, again, sort of personal care..."* (S08)

Jane showed real insight into the patient experience post discharge from AGCCU but seemed frustrated at the inability to improve the transitions.

> **Jane:** "*I think, if I'm honest, we're very, very poor at this. Just looking at the vulnerability of these poor patients and how heavily reliant they are on us from being a one to one basis …I can't even start to imagine how debilitated some of these patients are going to be,*" (S09).

When I sought to clarify her thoughts on transition I asked how confident she was with the preparation for transfer to the wards.

> **Jane**: "*No, I'm really not [confident], really not. But Pam, may I add, I don't think, I don't know whether that is because our transition between them being a level 3 patient, level 2 and then off, I don't know whether we've just sped up that process so much that we actually haven't allowed ourselves the time to think about these things.*" (S09)

Again, this related to the growing evidence of pressure on beds and throughput which was a common thread emerging through the staff interviews.

Cathy described, in technical detail, how a discharge can be enacted.

> **Cathy**: "*suddenly they've been half asleep using their PCA, pain control's better, inotropes are off, they've still got a chest drain in, they're coming round, they're waking up, we've said everything's alright, we're going to try and get you a bed, they don't really know what that means, and then a bed comes up, this is in an ideal situation obviously, a bed comes up, quick as a flash, arterial line out, off we go. You know, we're sending more patients out with central lines now,*" (S10).

This is a familiar scene that I have witnessed many times in my clinical career, despite the evidence that this is a critical juncture for patients and their families.

Many nurses referred to concerns around staffing and consequential levels of care on the wards. Gail discussed her own personal experiences.

> **Gail**: "*I did six months on the Bank on all the different wards and to be honest I was shocked at what I found. My friend was up here and she kept saying, come up, come up, and I was at the point of, do I leave nursing, because I felt scared of my PIN number on the wards, to be honest.*(S01)

Clarin also cited her experiences of working on the general wards and concern around staffing.

> **Clarin**: "*the fact that I used to manage a 28 bed ward and you cannot deliver the care that you want, it's just impossible, absolutely impossible, you're just like running around here and there, then somebody goes off…there is somebody that is really, really, really sick and potentially would be going off, and you cannot spend the time there..*" (S07)

This experience will undoubtedly influence critical care nurses' views of patients transitioning to wards.

It was noted that none of the family members or survivors interviewed in the study received any written information to either provide or signpost support. When I asked nurses if they were aware of any written materials and/or if they were given out, the answer was "*no*". Cathy gave this additional commentary in response to my questions.

> **Pam:** "*…thinking about discharge from critical care, because that has come up in the [patient and family] interviews quite a lot, do you ever give any written information or sign post any online information to patients and relatives?*

> **Cathy**: *We've got a booklet for recovery after critical illness.*

> **Pam:** *Is it given out?*

> **Cathy**: *No! [laughs] I would give the welcome one and a business card with our telephone number to families with their relative's admission, but no, guilty of forgetting, you've prompted me to remember, so no, I don't. I should do."*

My subjective interpretation of this narrative is that the nurses within this AGGCU are grounded within the 'here and now' of caring for critically ill patients and their families, often with evident compassion, and struggle to foresee what lies ahead for both survivor and their family. Given the pressures on beds, and the high demand of the service this is not surprising but it does have obvious consequences for the survivor and their family. Staff had limited knowledge of patients' progression beyond AGCU and some regretted not being able to close the loop in terms of patient outcome. There appeared to be little in the way of formal mechanisms to gain feedback, with the exception of cards, and letters that were visible and accessible to all staff.

Gail expressed pleasure on gaining information about the positive outcome of survivor of critical illness, however this was via a personal, rather than professional, route.

> **Gail**: *"…it would be nice to hear how people are doing, I had another person from my church, her daughter was here, and she's updated me because she got discharged from here to the ward, but because I know her, she's updated me how things are and it's been really nice actually to know how well she's doing..."* S01.

Amanda's perspective was slightly different with the pressure of work preventing time to reflect on what will happen beyond the '*doors*' of critical care.

> **Amanda**: "*I think we've got a mentality up here that once you're out of the doors you're onto the next anyway. But I do feel to make us more rounded practitioners, if we knew then we could improve how we treat people, especially with the juniors, I think they don't... they need to know more about the psychological point of view of what we do, and I don't think we have time to teach it*". (S02)

There was a consistent theme in chapter six, of staff recognising what needed to be undertaken to enhance the wellbeing of all three sets of participants (nurses, patients and family members) but enactment was

prevented by barriers. These barriers included; lack of education, poor skill mix, and pressure of critical care bed provision.

Kay referred specifically to the word '*closure*' and this has always struck me as valuable to practitioners in making sense of the care they have delivered.

> **Kay:** "*…there'll be a ring on the door bell or whatever and they'll come up, and you might not even know who they are, that's the awful thing, people have been here ages because they look so different. But sometimes even when patients have passed for us it's quite important to know what they died of, and you don't get any feedback of what the mortuary report was or what the... so... because it's kind of piecing together, especially if you were involved in that direct admission, it is about closure, isn't it?*" (S05)

As a senior nurse on the AGCCU Kay recognised this was a deficit or was "*lacking, and we've brought that up many a time, but nothing has changed there. So no, we get very little feedback and the most I do is I check through Extramed [intranet] to see where patients have gone….*" (SO5).

Karen felt that there was less feedback than in previous years under a different consultant. When asked the question "Do you get to hear how patients are doing post discharge?" her response was:

> **Karen:** "*Not very often, in fact I think it was better years ago than what it is now. We used to get the visits, because they used to come up and visit from Dr X's clinic, so we don't really get that so much now, I have to admit.*" (S06)

Karen particularly commented that seeing people in a normalised psychological state was beneficial for her (for closure), "*especially if they've had the psychosis while they're up here and everything, it's nice to see people when they're not in that state*" (S06). Cathy, in addition to Karen commented that it is "*very rare that people come up to visit us either now*" (S10).

Jane also referred to the nurse-led follow up team that, for a short while allowed, critical care nurses to follow up their patients on the wards. This

has been abandoned in the last three years. The service was never funded and pressure on critical care resources and specifically nurses required the initiative to be abandoned, yet from Jane's perspective there were benefits.

> **Pam**: "*Do you get to hear about how patients are doing post-discharge?*"

> **Jane:** "*No, not at all, and that's a real shame and I think, I was part of the follow up team that we did a good number of years ago and I feel that's a real... that was a real asset and I feel that we're lacking, and it was very nice, it was positive and negative going and seeing these poor patients, no, not all poor patients, but it does seem a little bit sad that there may be... there was more that we could have done, and it definitely opened my eyes to a world outside of ICU. It isn't enough just to survive ICU, is it?*"

Jane's eleven years of critical care experience both in the UK and Australia had clearly given her valuable insights into life post critical illness. She evidently missed the follow up previously afforded.

The benefit of gaining closure of the critical care experience is likely to be mutual across the three participant groups as Clarin describes:

> **Clarin**: "*…a patient who was with us for two months, and we discharged him to the ward and he came over a couple of weeks ago and the man opened the door and I'm like, oh! I said, oh, it's you! And he just... he was in a wheelchair and he stood up and that was really, wow, because obviously I mean we saw him intubated, we saw him with the trachy, getting delirious, I mean the whole thing, and he wasn't very good, we actually thought [he was going to die], and he was between 30 and 40, so he came in, he knew us all, every single one of us. Thank you very much for what you guys have done for me, I wouldn't have made it without you, and that was like, wow.*" (S07).

Memo extract staff interviews 10 and 11 (January 2015)

Theory sampling in relation to the variance in junior and senior critical care nurses. These 2 interviews were undertaken to check the co-construction of an emerging experiential craft of critical care nursing developing with clinical experience. Again the two interviews provided a contrast in that the junior member struggled to deliver care to both patient and relative and welcomed the shortened visiting hours. Whilst all staff recognised the evident informational needs of family members, junior staff would ask family members to leave when giving medication etc. This may be because of personal discomfort and the "*goldfish bowl*" effect.

Reflexive memo in relation to staff interview.
Returned from undertaking 2 staff interviews. 1 very experienced staff member and 1
 junior. The two interviews have confirmed for me central differences in knowledge and insights into caring for critically ill patients and their families. Experienced staff members have developed specialist and tacit knowledge that underpins their practice. This provides a sense of confidence and competence particularly in dealing with the complex **minute by minute** changing situations common within critical illness. Senior staff describe the challenges of caring for both patient and family members. Frequently they are aware of the critical junctures and challenges that patients and family members experience e.g. Transition to the ward, delirium yet they do not appear **empowered** to make changes to mitigate delirium or enhance transitions. Indeed, the removal of the follow up team (due to lack of resource) appears a retrograde step. This confirms for me the concepts of **being bounded** both by the walls of the critical care unit and **bearing witness** in the **here and now** of surviving critical illness. Both concepts limit the ability of RNs to prepare and support survivors and family members in their ongoing survivorship.

Senior staff are more critical of the restrictive visiting hours whereas junior staff feel they give structure and allow them time to complete the care, they lack confidence to undertake care in the presence of family members yet show empathy and understanding of the challenges they are facing. Senior staff frequently have positive experience of relative involvement in care some junior staff lack confidence to offer this option. There appears to be a trajectory of developing expertise that allows integration of physical, psychological and family care with technology and humanity. Experienced critical care nurses demonstrate an ability to transcend the obtrusive nature of the technological environment that is critical care. The journey to such proficiency is demanding and the data presented here reveals the challenges that nurses experience along the way.
 Whilst the journey is challenging it is clear that there is support along the way. The notion of the developing "*craft*" of critical care nursing may be extrapolated from Carmel (2013) and Melia (1987), very much construed as coalescing of art and science and in particular taming of technology. This has lead me to read around a cyborg ontology in critical care; with practitioners moving into the liminal space between technology and person centred care. Surely it is time to move away from thinking of technology and humanistic care as parallel dualisms rather that they are part of our social reality (Lapum et al 2012, Oakley 2007 seem to agree).   Carmel refers to "*craft*" as the application of knowledge that "*encompasses both insightful judgements and interpretations*". Senior nurses value and include relatives in their care because they are able to juggle the many elements of complex care at the bedside. Although one senior nurse (SO9) can still recall how she did not like having relatives at the bedside because she did not feel she could care for them as well as the patient nor did she like being "*observed*" as in a "*goldfish bowl*".
Virtually all staff members spoke of the ability to give high quality care together with the intellectual stimulation of working within critical care as being central drivers to staying in AGCCU. Many made direct comparisons with the ward and the better staffing ratios although they also spoke of the challenges of increased pressure on beds in AGCCU and the lack of staff resulting in the "sharing" or "cohorting" of HDU L2 patients and sometimes L3 patients as negative experiences.

Box 6.1 Reflexive memo – staff interviews

6.4 Conclusion

This chapter provided the principal findings of nurses experiences of caring for patients and family members within an AGCCU. The conversations were constructed using triggers and insights from the patient and family data cited in chapter 5. These data were constructed between myself and critical care nurses and provided a rich, in-depth insight into critical care nursing experiences. The data confirmed that working within a critical care environment is an emotionally charged encounter. Nurses experienced personal and professional challenges on a daily basis as they *bear witness* to the death or physiological survival of the patients in their care. Further, nurses working within AGCCU found themselves *bounded* by the walls of the critical care unit. The critical care environment was clearly identified as a demanding place of work which appeared to limit nurses to immediacy of care in the *here and now* or *in the moment* (Naef 2006). The specialist knowledge and skills that nurses provided were central to physiological survival. They also provided psychological support to patients and families in the moment but they were unable to support the onward survivorship trajectory.

The contribution of the focus codes to the selective code or core category is illustrated in figure 6.6. The selective code of *bearing witness and being bounded* has been abstracted and elevated from the focus code personal and professional challenges.

Level 4

Theoretical concept

consistently checked (saturation)

Continual use of conceptual levers allows theory to be constructed & consolidated from saturated categories.

Theoretical codes add precision & clarity, providing a sharp analytical edge. They must fit the data.

Level 3 Coding

Theoretical coding

"Bearing Witness and Being Bounded"

a concept that may travel across contexts

Level 2 Coding

Focused Coding, Category Development

Five focus codes:

Personal and professional challenges, Delirium assessment and management, Family member presence, Specialised knowledge and skill, Transitional care

Theoretical sampling

Making analytical sense of initial codes to categorise data.

Line by line coding is an interactive, comparative process. A heuristic device to break up data.

Level 1 Coding

Initial Coding, Open Coding

51 initial codes identified via line by line coding of **11** interviews with Registered Nurses in AGCCU

e.g. coping strategies, pressure on beds, delirium management, empathy for relatives, transition to wards

Theoretical sampling

Figure 6.6 Progressive coding construction in relation to overarching theoretical code explaining RNs experiences of survivorship in AGCCU (adapted from Hamm 2015).

Chapter Seven Discussion and Conclusion

7.1 Introduction

This chapter discusses the novel insights derived from this empirical study. Sections 7.2 to 7.4 synthesise the major findings with reference to relevant literature. Findings are viewed via the conceptual lens of liminality in relation to identity and self. This approach is original in illuminating the critical illness trajectory. Such an approach, has however, been previously applied within the field of cancer survivorship (Blows et al 2012, Kelly 2008, Little et al 1998), infertility, (Allan 2007) and transitioning between child and adult services (Tierney et al 2013). The emergent middle range theory of *dualistic worlds,* (introduced in the preceding chapters) experienced both within the individual survivor, and between survivors and their family members, is explored utilising this lens.

In relation to the data presented in chapter six the critical care environment is evidently a demanding place of work which appears to limit nurses' role to the immediacy of care at the expense of supporting longer term survivorship of patients and family members. Critical care nurses are present with patients and families within the walls of critical care and witness profound changes in health and quality of life. Nurses live and experience intense and overpowering moments of questioning, struggling, and finding meaning (Naef 2006). In essence, nurses are with persons (survivors and their families) in the moment, as lives unfold, and they experience joy, sadness, fear, and suffering. They *witness* (Naef 2006) the early stages of the survivorship trajectory and provide complex care in support of survival however they are bounded by the walls of AGCCU such is the proximity to death and the pressure of work. They are unable to support the onward survivorship journey.

Subsequently the authenticity of the research is considered and a final reflection on the research journey is provided (section 7.5 and section 7.6). Implications for policy, education and clinical practice are proposed in section 7.7 and recommendations for future research in section 7.8. The original

contribution that this study makes to the field is discussed in section 7.9. Section 7.10 concludes this chapter and the thesis as a whole.

7.2 Theoretical Insights

This study has captured the critical illness experience from the holistic, perspectives of survivor, family member, and registered nurse for the first time in the United Kingdom. Maintaining the centrality of the enquiry on the survivors of critical illness and family members has provided novel understanding of the longer term wellbeing of survivors and the legacy of critical care. The transcripts of survivors and family members reveal a complex interrelationship of identities that have changed as a consequence of critical illness. Contemplation and confrontation with mortality of themselves and others has been part of the pathway of survival. This provoked anxiety, and worry for some, and a new zest for life for others. Constructing the perspectives of critical care nurses provided new insights into conflicts between professional and personal selves and how nurses are bounded within the AGCCU in the here and now, managing increasing acuity of illness.

Survivors experience changing and dynamic identities as they transition and transform along the critical illness trajectory. A health trajectory being defined as an understanding of the course and causes of changes in health over time, which may allow enhancements by health professionals and through self-care (Henly et al (2011). This study reveals an evident, and evolving, interplay between emotional, psychological and social identities accompanying a quest for normality albeit a '*new normal'* in many cases. There are a number of critical junctures that survivors and their families have to negotiate; making the trajectory a non-linear process. Despite the individual, and context bound stories, commonalities have been revealed through constant comparison of data. Original insights into the complexity of the survivor experience and their family's lives have been elucidated across contexts.

7.3 Findings in relation to the literature

Congruent with the approach and orientation utilised in this research, (as explored in chapter three), the findings elucidate an interplay between self and social worlds. On reviewing the findings in conjunction with existing research and theory it is evident that they do not sit within a distinct discipline but across subject fields. This is a natural alignment with nursing as a discipline which draws upon arts and sciences to realise the holistic and multifaceted nature of care and enquiry (Munhall 2012).

7.3.1 Registered Nurses in AGCCU

This study reveals the personal and professional challenges that critical care nurses experience on a daily basis within AGCCU. The level of empathy evident in the study illustrates an emotional price for caring and how caring may become a burden on the personal lives of professionals. This does raise questions around the emotional wellbeing of staff working in critical care where death is ever present and is echoed in van Mol et al (2015) systematic review of the prevalence of compassion fatigue and burnout within intensive care professionals. Some participants exhibited signs of a preoccupation with death and doubts around professional competency, both aspects highlighted in Stayt's phenomenological study of death, empathy and self-preservation in adult critical care (Stayt 2008). Emotional work or labour (Stayt 2008, Siffleet et al 2015, Kelly and Smith 2016) clearly form a central role for the critical care nurse; the daily confrontation with death is evident from this study and others (Stayt 2008). The emotional toll appears to have been exacerbated further by the increased bed pressures aggravated by current austerity measures (Roberts et al 2012).

The personal and professional challenges experienced by nurses in this study are as a consequence of acting in the human mode of coexistence. They are present at the bedside, listening and being with both survivors of critical illness and their family members. Nurses bear witness to early survivorship within AGCCU, in particular, physiological survival. Witnessing can be understood as a personal experience, "*the direct, personal*

apprehending of something in the moment" (Cody 2001 p.289). This is extended further by Cody (2001), Naef (2006) and Webb (2016) to the concept of bearing witness or "*attesting to the veracity or authenticity of something through one's personal experience*" (Cody 2001, p. 289). Naef (2006) argues further that such presence is a central concept in nursing. The data from this study shows that nurses choose to bear witness rather than to not bear witness but with the consequential effect of emotional disquiet for some. Further, they appear bounded by the walls of the critical care unit due to the acuity of illness and the pressure on bed availability. This limits nurses' ability to support the onward survivorship journey of both patients and family members. Nurses show insight into the challenges that survivors and their family members may encounter but were unable to, (and indeed had been disempowered through termination of the follow up team) support survivorship needs beyond the walls of critical care. This is not a criticism but an observation of nurses in AGCCU being forced to live and remain in the moment by the pressure of clinical work. There is no question of the significant intersubjective support that nurses provided at the outset of the survivorship journey to patient and family member alike. There is also evidence of emotional sequelea for AGCCU nurses as well as for survivors of critical illness and their relatives. Compassion fatigue (CF) is a recognised source of suffering among critical care nurses and the field of study remains lacking in terms of both conceptual clarity and theoretical grounding as to how to best identify and respond to this (Webb 2016).

7.3.2 Survivors and Family Members

Biographical disturbances due to chronic illness have been conceptualised from patient perspectives by Bury (1982) (see also 5.3.1) who suggests that chronic illness experiences expose individuals to disruption in relation to their social and practical selves (Bury 1982). Whilst Bury's work focused on chronic illness there are comparable biographical disruptions identified in the findings within the critical illness context. For the critical illness survivor, this can be due, in part, to amnesia of the critical illness episode and subsequent biopsychosocial sequalea; such disruptions include the struggle to transition to a '*new normal'*. It is clear from this study, and the wider literature, that

there are critical junctures to be negotiated. The challenges of regaining muscle mass to achieve mobility and adapting to the profound fatigue commonly experienced are just two examples from this study. There are also parallels with cancer survivors. Trusson et al's (2016) study explored the way in which women engaged with and managed the myriad of challenges, in what it is to live in the afterlife of breast cancer. The study revealed a continual process of renegotiation of identities, daily lives and futures as time passes and lives evolve. The emphasis is on moving to a '*new normal*' rather than returning to a '*normal*' pre cancer self. Whilst physical sequelae were clearly evident, the psychological and cognitive sequelae were more dominant in the empirical data. There were also consistent accounts of amnesia as a critical illness survivor indicates:

> *"I have no recollection of being found or my stay in XX but when I was in YY I had such incredibly crystal clear dreams that I could even write down every one of them a year on. I now feel as if I was put through a tunnel scanner and came out the other end a different person. I feel my personality has changed. I am still weepy at times and always feeling down most of the time. I know I think differently" (Critical illness survivor, ICU Steps blog 2016).*

Such amnesia limits the ability of patients to navigate their own biography and post critical illness life course (as cited above). This can exacerbate the sense of loss which includes what Charmaz (1995 p.660) refers to as loss of "*body-self unity*". For the relative, confrontation with the mortality of their family member can also create indirect biographical disruption through relationship transition and change. This may manifest itself as a changed relationship. Mark and Hazel's narratives clearly revealed identity and relationship change (see p. 154). Navigation out of the disrupted state is, of course, highly individual and the findings suggest that family members may move through this phase ahead of the survivor. This can potentiate disruptions in the relationship, as changed perspectives and uneven experiences introduce a change of step or rhythm between partners and family members. Despite the contextual homogeneity of environment, disparities exist between survivors' stories and their family members stories.

This corresponds with a study of stroke survivors reported by Faircloth et al (2004 p.244) who considers that "*not all physiological illness or disease will have the same impact on lives*" and urges consideration of different lenses to perceive, experience and story the same phenomenon.

It is therefore, important to stress that these findings do not suggest a single trajectory of survival that illuminates the course of biopsychosocial well-being. This is, partially, because survivors of critical illness and family members form a very heterogeneous group that vary in chronological age, gender, ethnicity, cause of admission, social class, health status and recovery time. More significantly, dynamic and evolving constructions of well-being emanate from an inter-relational and fluid state that transcends individual, social and societal domains (Sarup 1993).

The importance of sense-making as a strategy of biographical repair is identified in this study (see 5.3.4). Bury (1982) and Charmaz (1995) identified the same phenomenon in the context of chronic illness. Whilst the literature focuses on individuals navigating from a state of disruption, it is clear from the findings that both survivors and families strive to regain homeostasis, achieve a normalised state, albeit a '*new normal*' (Atkins et al 2012). Some survivors were forced to conform to different identities. Kevin for example, had developed an explicit disabled identity through limb loss. Having a visibly altered body image provided immediate images of change. The term appearance can also be considered symbolically, as well as in the literal sense, since knowledge of loss can construct new self-images upon individuals (Charmaz 1995).

Family members frequently become carers as a consequence of their partner's critical illness; see Gary and Hazel's vignettes. These provided further evidence of biographical disruption and change in role and identity as they too transition to a '*new normal*'. Charmaz, (2014) in her work with people living with progressive chronic ill health, recognised the dichotomy of physically appearing well but identifying that how you feel (not how you appear) defined one's self. Annie (P01) commented to this effect, explaining how outwardly she appeared "*fine*" but "*inwardly*" was still recovering or

transitioning to a '*new normal*', and how this created tension within her family. There is a need to support and further understand the discontinuity between the 'self', prior to critical illness and 'self', post critical illness

There is evidence within this study and others (Stayt 2012) that during critical illness the bodies of survivors become alien terrain to themselves. Survivors are transported into unfamiliar worlds where body and self, become estranged (see 5.3.2). Stayt (2012) refers to "*My Useless Body*" where the body is disassociated and invaded by technology. Both studies reveal patients experiencing emotions, and exhibiting behaviours, that are uncharacteristic and unfamiliar to them. This suggested a division between body and self which subsequently underwent a journey of transition and transformation. The following quotation from a survivor of critical illness suggests that a new identity has transitioned to a '*new normal*', where self and body have been reconciled:

> "*You must decide what that life will be like. It will be different from before the ICU, because you are different. The people who care about you may not understand, but that's OK. The only way to really understand it is to have lived through it*". (David PR05)

In parallel, Frank (1993) refers to May's work (1991) who considers the self-change of a burns survivor (albeit from a practitioner perspective):

> "*If the patient revives after such [life threatening] events, he must reconstruct afresh, tap new power, and appropriate patterns that help define a new existence …a new Phoenix must emerge from the ashes…*" (Frank 1993 p. 40).

The journey to such reconciliation of self and body can, however, be tortuous and there may be little support along the way to reconcile grief and gratitude, as the following vignette clearly illustrates.

> "*…unfortunately many people never get the psychological support they need and are left not knowing why they feel so bad, when they've just survived a near death experience and everyone tells them how*

happy they should be, if only it could be like that." (Critical Care
survivor ICU Steps blog 2016)

The findings from this study clearly illustrate that survivors within AGCCUs can, within themselves, experience dualistic worlds that imposes flux and disassociation from the real world; this can vary from a near death experience[8] (Alan) and oscillation between delirium and normality (all survivors). I suggest this to be an internal '*dualistic world'*. Charmaz (1995) claims that illness (not specifically critical illness) can be such an assault upon the self that the person views his, or her, bodily changes as unreal. Kevin's reaction to limb loss is a good example of evidence of this unreality where there was no self-acknowledgment of the loss of his arm. The notion of '*being there, but not'* so evident within the transcripts of survivors in this study confirms further biographical disruption that is experienced by survivors in isolation; i.e. not shared with family or practitioners. Gary Black, a survivor of critical illness from the USA, provides an insight into this alien world through published artwork and poetry that reflects the dramatic impact that delirium can have on identity and self (Black 2012) and in particular the isolation and fear experienced. An example of a constructed image of self in AGCCU is shown in Figure 7.1.

Figure 7.1 Constructed image of self by critical illness survivor

Many of the survivors in this study were unaware that the profound delirium they had experienced was considered '*normal*' by practitioners given the

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[8] See Cant et al (2012)

severity of their illness. The need to make sense of this unreality is important in gaining closure and to coalesce body and self (Jones 2014a).

Divergence in the critical illness experience was also evident between the survivor and the family member as alluded to above. This was particularly evident in Annie, Jane, Sharon and Kevin's stories. The aforementioned theoretical insights, such as those evidenced in Box 4.5 (reflexive memo around the developing theoretical code of a *dualistic worlds* and use of liminality), led me to initially consider and then apply the concept of liminality as a conceptual lens to further explore the apparent dualisms within the findings. It would appear that critical care medicine has created a new ontology of health and illness which can place survivors of critical illness in a liminal space (in an in-between world) and create social and relational change. Therefore to understand patients who survive critical illness it is important to explore the liminal space between life and death and to develop fluid models of thinking.

7.4 Liminality as a conceptual lens

The concept of liminality originates from the work of the anthropologist van Gannep (1960), and subsequently developed by Turner (1967). It relates to rituals and rites of passage. Turner had a particular interest in the sociocultural properties of the liminal or transitional period. He contended that liminal people were invisible and that they were '*no longer classified and not yet classified'* (Turner 1967 p96) hence the term '*betwixt and between*' the normal network of classifications that locate us in cultural spaces (Turner 1969 p95).

> *"The attributes of liminality or a limited personae ('threshold people') are necessarily ambiguous, since this condition and these persons elude or slip through the network of classifications that normally locate states and positions in cultural space. Liminal entities are neither here nor there; they are betwixt and between positions assigned and*

> *arrayed by law, custom, convention and ceremonial place' (Turner 1969 p.95).*

I am not suggesting that survivors of critical illness within this study are invisible, (although those who remain in a coma may become so) more that they are transitioning and transforming to a '*new normal*'. Consider Hazel talking about her husband Mark:

> **Hazel:** *"He just sounds a bit different, from our point of view, you know, coming home, he looks different, he sounds different and he behaves a bit different, so it's almost like there's a bit of him that's not the same anywhere." (PR06).*

Living in a liminal cultural space can, according to Turner (1967 p97), lead to negative feelings of '*ambiguity and paradox*'. This is evident in the transcripts of survivors of critical illness and links directly to the focus code '*ambiguous loss*' (5.3.1) and is further supported by Tierney et al (2013). In Tierney et al's (2012) qualitative study of young people with cystic fibrosis, liminality was a useful lens to view transfer to adult services. However, Turner suggests that liminal space can also provide a '*stage of reflection*' (1967 p105). According to Van Gannep (1960) transitioning from a liminal space can return the person back to their social space or, I suggest, forward to a new social space, through a process of transformation (see figure 7.2). Such reflection can take people to a new normal, in a positive sense, see David and Jenny:

> **Jenny**: *We've always been active and done things, but we do even more, and we appreciate things a lot more, and it's only because of what happened to him. Drastic measures! (PR05).'*

It is propounded that, at the point of admission to AGCCU, the patient experiences an acute liminality characterised by total loss of control, entering a world of disorientation and disorder, invariably existing within a liminal space between life and death. Family members are informed that their relative may be at the end of life which creates a family illness narrative around confronting mortality; facing the prospect of death and then pulling back from this reality or oscillating between the two (see Jenny and family

p.158). Further, survivors frequently (all in this study) experience vivid hallucinatory experiences which placed them in a different world or liminal space. They may move in and out of these different realities. The core difficulty is that survivors have little recall of the factual events of their critical illness within AGCCU but relatives have lived the whole event in a very real and ingraining manner. This can result in family members and survivors experiencing two totally different versions, or narratives, of the critical illness episode.

Survivors of critical illness can and do find themselves on the margins of normal life. They are often in a borderline physiological, psychological or cognitive condition of being well and unwell, surviving but being threatened (Andy, Jane and Kevin for example). Existing on this threshold between death and recovery, frequently with no means to predict how the process will evolve is extremely stressful according to Johnston (2011) and is clearly evident within this study. This can be considered an acute period of liminality and may continue for an indeterminate period, often beyond discharge from hospital to home or longer term care. This may be attributed to '*communicative alienation';* a theme constructed by Little et al (1998) from a narrative enquiry into cancer survivors; defined as a "*state of variable alienation from social familiars brought about by an inability to communicate and share the nature of the experience of illness*" (p 1486).

The data from this study illustrates '*loss of voice' as* a focus code (see 5.3.1) in both actual and metaphorical meaning, often due to the presence of an artificial airway, but also subsequently where survivors are alienated from their family members because they have not been through the same experience themselves. Equally, the survivor has not experienced what the family member has witnessed and endured and this creates a *dualistic world* of different experiences of the same episode.

The survivor's social world may contract physically, psychologically and socially as a consequence of critical illness, a feature also identified in cancer survivors (Little et al 1998, Thompson 2007) and referred to as '*boundedness*'. This can, and often does, have consequential effects on

their family members and family dynamics. This is particularly evident in Annie's (P01) interview where she described the changed and disrupted relationship with her daughter. Kevin (PR13) and Jane (PR09) also experienced a contracted world and appeared to be existing within a transitional liminal space, yet to establish a '*new normal*'.

Undoubtedly both parties experience a greater awareness of their, or their relative's, mortality which may be either limiting or occasionally emboldening (in the case of David and Jenny). Emergence from transitional liminality to the '*new normal*' is an individual journey, indeed, some survivors may remain in a transitional liminal state. In contrast to Van Gannep (1960), I am not suggesting a demarcated tripartite process (acute, transitional and permanent), rather a variable and enduring state. A reflection of the symbolic interactionist view that humans act towards things on the basis of the meanings they have for them. Such meaning will differ from one person to another. The notion of liminality used in this study is to capture and illuminate the nature of the subjective experience of critical illness rather than to categorise or medicalise the changes in social relationships inherent in being critically ill. I do suggest, in common with Little et al (1998) that survivors enter an acute liminal state and "*emerge much modified*" (p 1492) after an unpredictable time, the length of which is dependent on the biography of the individual and the support available. This oscillating trajectory is acknowledged also by Frank (1995) in his own experience with cancer and is evident within this study too. Little et al (1998) suggests that, for cancer survivors transitional liminality is life long and represents a prolonged dialectic between body and self. Similarly, within the context of chronic kidney disease (Molzahn et al 2008 p15) suggests that '*liminality refers to the ambiguous experience of one's life story being disrupted through illnesses*'. This is also evident in the more homogenous population of transplant patients who may remain in a 'betwixt and between' state of health and illness referred to by Crowley-Makota (2005) as a state of '*persistent liminality*'. This study does not provide support for such a model as a substantive, prospective longitudinal study would be required to do so (see section 7.7.1). There is, however, some evidence to support the

emergence of a '*new normal'* for some survivors and their relatives. Examples would include the experiences of Richard (P08), Jenny and David (PR05) where there has been a recovery of body and self. Some participants had yet to achieve the harmony and reconciliation of body and self in a new identity. Further, some survivors may not accept the role consigned to them and this may create difficulties between themselves and family members.

Let us now consider the view of the critical care nurse who cares for patients whose bodies have technology embedded within them, rendering them both more safe and more at risk, with the possibility of physiological deterioration ever present. The patient may be perceived to be in a liminal space, with the identity of the individual hidden by profound pathophysiological challenges and medication, often inducing coma. The physical body's functions are rendered visible and physiologically alive through monitors, ventilators and medication but the identity of the person is not. This is eloquently conveyed by Amanda (S02).

> **Amanda:** *"…when somebody is lying in a bed and they can't talk and you know nothing about them, you project your own theories of who they are, and it's like when they first talk and when you just hear their voice it's so amazing, and it adds a totally different dimension to them". (S02)*

The family member may share insights into their relatives' identity but essentially the normal interactional conventions of social life are lost on admission to AGCCU. Loss of voice robs people of their coherence and certainty in the world, leaving them '*in limbo'* (Tembo et al 2015). Consequentially, uncertainty and ambiguity in relation to self-identity is evident as survivors find themselves in unfamiliar, perplexing in-between and ambiguous spaces. This can result in social indefinition and isolation (Molzahn et al 2008). Whilst critical care medicine can, and does, save lives, it fails to understand the consequential effects on individuals and in particular how people '*live'* (Oakey 2007 p 149) in their bodies.

Nurses are further challenged since the boundary between life and death has been changed by modern scientific developments. Physiological limits can be stretched with techniques such as extra corporeal membrane oxygenation (ECMO) allowing the nature and trajectory of lives to be reshaped. The form and trajectory of human life no longer has clear biological limits; beginnings and endings of life are no longer fixed but fluid (Blows et al 2012). It is proposed that within such technological advances the person who is subjected to these life saving techniques may enter a liminal space. The decision to place patients in such acute liminal spaces can be problematic for nurses to fathom:

> **Amanda:** *"…just because you can, it doesn't mean you should, and that frustrates me.... the expectation of the public is to live forever, but it's not based on a reality."(S02)*

Such moral dilemmas are just one example of personal and professional challenges experienced by nurses interviewed in this study. The data constructs a picture of oscillation between personal and professional identities when delivering and managing care. Daily confrontation with death, or the potential for death, creates a significant amount of emotional work. Moral distress and compassion fatigue are reported by Siffleet at al (2015) and are evident in this study. This was clearly articulated by Amanda:

> **Amanda***: I'm sick of death, I am sick of death, I went through a phase, about six months ago I thought, I am just so sick of death, not necessarily that we had a big patch of people dying, but I thought, oh, you know, we're either stopping somebody dying, they're dying, ...perpetual death, isn't it? Perpetual death, and I have had enough now, I have had enough. I've got another year and I'll be happy to go. (S02).*

There is no question that patient acuity is higher, and that technology continues to push the boundaries of life and death into ever greyer areas (Siffleet et al 2015, van Mol et al 2015). In addition, caring for patients with profound delirium was also seen as emotional work exacerbated by an awareness of both knowledge and practice deficits in this area. Yet nurses

demonstrated a passion for learning and appreciated the ability to deliver holistic nursing care afforded by the (largely) 1:1 ratio of staff to patients.

In this section, liminality has emerged as a relevant concept to illuminate analysis of the critical illness experience of survivors and their families. It has helped to elucidate the legacy of critical care in the 21st century. It has not been applied previously within the arena of critical illness and provides a unique perspective on the phenomenon.

Collectively the study findings, concurrent analysis, and synthesis have allowed the construction of a conceptual model which illustrates the fluid and dynamic transitions that the dyad (survivor and family member) may experience (see Fig 7.2). This has been collectively derived and constructed from the data presented in Chapters 5 and 6.
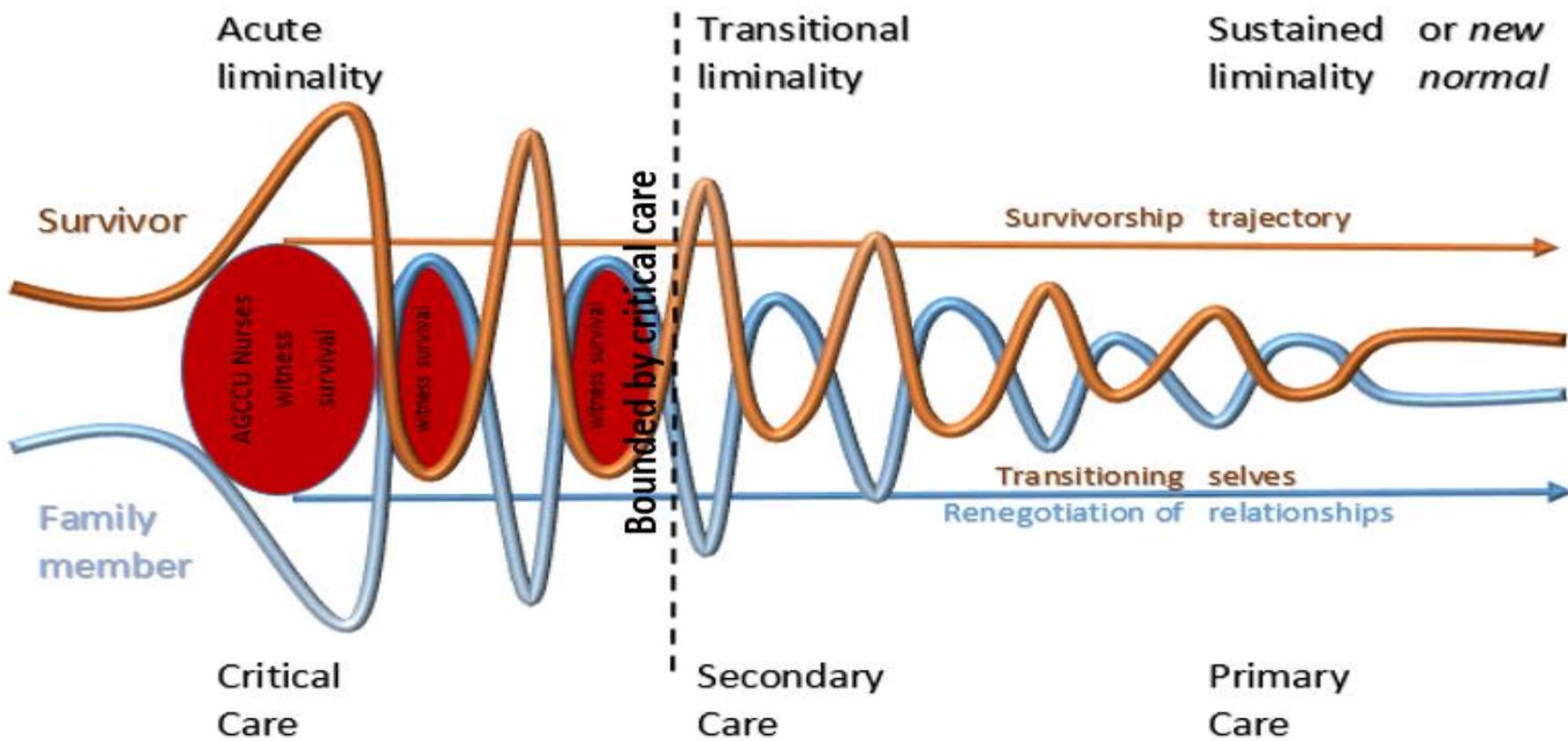
Figure 7.2 Conceptual model of the dualistic worlds of survivors and family members

The fluctuating and overlapping spirals of family and survivor represent both the shared and separate experiences of critical illness and illustrate the selective code *dualistic worlds*. The liminal phases that survivors may traverse through are highlighted; culminating in either a *new normal* with relationships renegotiated or remaining within a sustained or permanent liminal space. The red circles represent the interface nurses in AGCCU have with both patient and family members. They are key to the very survival of patients and gate keep access to family members thereby influencing relationships. Critical care nurses witness the early stages of the survivorship trajectory and provide complex care in support of survival however they are bounded by the walls of AGCCU such is the proximity to death and the pressure of work. They are unable to support the onward survivorship journey. This is represented by the dotted line and associated text.

Having extrapolated the key theoretical insights from the study and applied the concept of liminality as a conceptual lens, assurances around the authenticity of both the study and the findings are discussed.

7.5 Authenticity

The concept of trustworthiness has been discussed in section 3.10 and provides assurances of the methodological adequacy of this study. This section augments the concept by considering the authenticity of both the study and the findings. Authenticity involves shifting away from concerns about reliability and validity dominant in quantitative research, to concerns that the research is worthwhile and thinking about its impact on members of the community being researched (Given 2008). Authenticity is considered an important component of establishing trustworthiness in qualitative research so that it may be of some benefit to society. It consists of five criteria; ontological, educative, catalytic, fairness and tactical authenticity (Lincoln et al 2011) which involve consideration of the wider impact of the research findings (Bryman 2008). In relation to this study, these five criteria are applied as follows.

Fairness relates to the balance of reflection of participants views, perspectives and concerns; essentially that "*all voices should be heard*"

(Lincoln et al 2011, p 122). To ensure fairness all interviews were transcribed verbatim and an expansive selection of quotes have been included so that the viewpoints, positions, and perspectives of each individual contribute to the theory construction. Whilst the analysis presented is my representation, through my own lens, the inclusion of participant data helps provide transparency to participants' stories and the subsequent conclusions drawn.

Educative authenticity and ontological authenticity are considered by Morse et al (2002) as criteria of 'knowledge sharing'. Distinctively, ontological authenticity results in an "*improvement in the individual's (or groups) conscious experiencing of the world*" (Lincoln and Guba 1985, p. 81). Educative authenticity refers to an augmented understanding and appreciation of other's constructions (Lincoln and Guba 1985). Both criteria denote a raised awareness of participants' experiences and assistance in understanding their social worlds and the perspectives of other people.

Within the study itself, there were several points where study participants, particularly survivors, commented on the benefit of taking part in the study; this implies that the research had some ontological authenticity.

> **Charles**: "*I'm pleased you brought that up because I hadn't thought about it until now, but I did feel so weak, depressed as well…*" (P02).

And

> **Annie**: *"But it's nice to speak to someone that understands, because I try to speak to the family and I say to them, you don't know how... oh yes, we do know how you feel, but you know they don't"* (P01).

And

> **Charles**: "*…I'm telling you this because it makes me feel better…*" (P02)

When presenting the findings from this study at conferences, colloquia (see p. 15) and local clinical seminars, I received consistently positive feedback from clinicians, researchers and lay people. One lay person stated that I had

captured the experience that she and her husband went through following his liver transplant. Following a clinical seminar, one nurse wrote on his evaluation form of his own critical illness experience and how a critical care nurse visited him on the ward on her break; "*she chatted to me, it helped me more that I can say and I will never forget her*". He added "*Thank-you for a fantastic talk on your work, I could see cogs whirring in people's heads – you can change things*". An administrator within critical care wrote, "*I feel this is very important research and should be shared as much as possible*". This illustrates that the findings resonate and illuminate aspects of the critical illness trajectory that may not have otherwise been considered. Furthermore, it suggests that the study has both educative and ontological authenticity.

The remaining two criteria are catalytic and tactical authenticity which relate to social action (Morse et al 2002). Catalytic authenticity refers to the extent to which the research has stimulated some form of action on the part of the research participants, whereas tactical authenticity refers to the degree to which participants are empowered to act (Given 2008).

Evidence of such action occurred following presentation of my initial findings to staff working within the AGCCU where data collection had originally taken place. The presentations occurred in May 2015. A range of staff attended; student and registered nurses, senior management, physiotherapists, ward clerks, and administrators. Evaluative feedback revealed that the presentation had been both illuminating and educative. Subsequently, I was asked to make the same presentation to medical consultants and trainees in AGCCU. Direct actions that arose as a result of both research participation and presentation of the findings, included the setting up of a local support group for people who have been admitted to AGCCU (February 2016) and a business case being developed for the appointment of a Critical Care liaison nurse to address critical junctures in care. Additional examples of catalytic authenticity came from survivor and family member participants and included intentions to contact support groups such as ICU Steps and request a referral for physiotherapy as a direct consequence of participating in this research.

Moreover, to further augment the authenticity and credibility of this study my reflexive thoughts and processes have been shared throughout this thesis. In summary, this discussion has focussed on the authenticity of the findings generated by this study. It has illustrated that participants viewed the research as authentic and credible. The implication being that the proposed middle range theory of *dualistic worlds* may represent part of the critical illness trajectory and a longer term legacy of critical illness for survivors and family members.

The next section provides a final reflection on the research journey, acknowledging the influence that I had on the research process and findings.

7.6 Final Reflection on research journey

Qualitative research recognises that the researcher shapes and influences all stages of the research process; it is, therefore, imperative to consciously reflect how I may have impacted on the research and constructed findings. This has additional importance in the context of constructivist grounded theory where the researcher is a participant in construction of the developed theory.

Chapter 1 reveals my research experiences and acknowledges my *a priori* knowledge, reflections and personal values. It also explains my personal motivation and how professional experiences led me to conceive the research area and develop research aims and questions. The process of reflexivity has been threaded throughout the thesis with inclusion of memos to enhance transparency and grounding of thought processes (see Box 3.1 and Box 4.3). My philosophical viewpoints influenced the methodological choices made during the research and this is discussed further in Chapter 3. Critical reflection on my relationship with study participants during interviews and the potential influence this may have had is explored in Chapter 4 (4.7.4). In this section, I reflect on the research journey in terms of the effect it has had on me and I on it.

At several junctures in my work as a critical care nurse, and as an educator, I have been concerned by the impact of surviving critical illness both for the individual concerned and for the associated family members. The obsession

with physical survival was, and is, at odds with my own values and beliefs; undoubtedly influenced by my exposure to profound morbidities as a consequence of both critical illness and the associated treatments. My initial research involving family members (Wilkinson 1995) was a profoundly insightful and moving experience which heightened the value of qualitative research to me. This indubitably influenced the epistemological direction of this study, and the decision on which research paradigm to locate the study. In the light of the research questions and aims of this study (section 1.5) which emphasised 'how', 'understanding' and 'experience' together with theory generation, grounded theory was chosen. I acknowledged a relativist view, where multiple meanings are constructed by people interacting with a world, which they themselves are interpreting, thus leading me to *constructivist* grounded theory (Charmaz 2000, 2006, 2014). Further, I recognised that I am an integral part of interpreting participants' meanings and actions, as they indeed have to interpret mine.

I have been constantly committed to conducting ethical, moral and relational inquiry; the products of this have been multiple presentations, undergraduate and post-graduation education, support groups and the production of this thesis.

The process of resolving the research paradigm and selecting in which variant of grounded theory to position myself, involved reflecting on my own views of knowledge. In essence, to situate my own epistemological and ontological position. This was important to provide theoretical security and to be able to live out my beliefs and values during the study (Birks and Mills 2011). Reflecting on my previous academic studies I have received a '*mixed methods*' exposure of positivism in physiological sciences and interpretivism, constructivism and pragmatism in nursing and educational studies. Undoubtedly, my previous qualitative research with family members influenced me, but it took a number of months for me to explore my assumptions and familiarise myself with the varied ontological and epistemological positions and the differing variants of grounded theory. This required an iterative process between literature on grounded theory and qualitative research, the process of academic supervision and pivotally my

first annual review in this research journey which both challenged and crystallised my methodological thinking.

Another challenge was re-focusing the research questions and aims in response to the data and developing theory. As I started to interview survivors of critical illness and interact with the data I re-evaluated the fit between the data, the title and initial research questions. The surprising finding that family presence was not as important to survivors as the literature, and indeed my previous research had indicated, caused me to stop and reflect. In retrospect this was a very early insight into the dualistic worlds that survivors and family members' experience, the narrative of survivors helped crystallise this; phrases such as "*two different nightmares*" from a survivor (Sharon) and "*I don't know if David to this day, will ever know what the family went through, but there he is sitting there*" from a family member (Jenny) were key insights for me.

On reviewing my early research proposal and following initial data collection, the fluid nature of reality was exposed. My preliminary title was "*A descriptive, qualitative appraisal of visiting experiences within adult general critical care units (AGCCUs) utilising a grounded theory methodology*". This was undoubtedly influenced by my previous research and academic study. However remaining open and following leads in the data, a central tenet of grounded theory, allowed me to explore topics that I had not intended, and this led to refocusing of research questions and aims together with a consequential change in working title. Such an approach reflects an interpretive framework acknowledging a relativist rather than realist ontology. The findings from the early period of data collection clearly illustrated to me the organic, fluid and exploratory nature of qualitative research. I had not previously experienced the uncertainty associated with grounded theory although this is well documented in the literature (Charmaz 2014, Birks and Mills 2011).

The actual practices and procedures associated with grounded theory research posed some uncertainties for me. Coding data and working through the stages of coding was initially challenging, my concern being

whether I was doing it '*correctly*'. Studying and working with fellow Ph.D. students under the guidance of experienced qualitative researchers allowed my confidence to grow. The opportunity to code data in a practical manner and outside of my own study was very helpful and an experience I would recommend to all qualitative researchers. Initially, I was frustrated at my inability to think abductively and arrive at abstract interpretations of the data. I was concerned that I would not be able to develop an explanatory theory that would account for variations and have explanatory power. This was surmounted by constant iteration between data analysis, reflection and engagement with the literature for analytical insights. This helped me construct a theory to illustrate a higher level of abstraction (see Chapter 4, box 4.4, Chapter 5 fig 5.7, Chapter 7 fig 7.2).

In an effort to limit criticism of '*forcing theory*' (Glaser 1998); (a long standing criticism of grounded theory) I have consistently stayed close to the data, trying to keep an open mind and to write reflexive memos to note the way in which my lens influenced how I saw and interrelated with the data (Charmaz 2014). I was also mindful of the ultimate goal of grounded theory being the generation of a new substantive theory and not the verification of an existing theory.

The researcher journey itself has had a profound effect on myself, as I am undoubtedly a different person as a consequence of the experience. It has influenced both the way I teach and what I teach. It has influenced both my clinical and academic colleagues in relationship to critical and acute care nursing. The study has provided me with the opportunity to share new insights and new knowledge through presentation and publication at national and international level. It has also allowed me to share data and insights for practice development at a local level. At times, I have struggled with transitioning between professional registrant and researcher, as noted at my upgrade examination and I have explored the ethical dilemmas that this can present.

Some of the interviews with survivors have been emotionally challenging and have made me call in to question my own practice and indeed my raison

d'etre as a critical care nurse. Being personally challenged is an uncomfortable reality of qualitative research and one which needs support and supervision. This I gained from my academic supervisors and my academic colleagues who have had similar experiences. My experience of listening to participants and exploring the experiences of critical illness and critical care has expounded my knowledge base of what it is to be critically ill and recover, what it is to share a critical illness trajectory with a relative and what it is to be a nurse in AGCCU. It has been a privilege to gain these rich insights.

The consequential implications that the findings in Chapters 5 and 6 have for clinical practice and policy, education and research are considered in the following section.

7.7 Implications for clinical practice and policy

From the outset of this study, a primary aspiration was to have beneficial impact on clinical practice and policy. The importance of achieving this was emphasised to me, (by me) during the process of data collection. The data from interviews in this study are powerful and illustrative and provide what Benner et al (2011) describe as "*the emotional colourings in clinical situations*" (p.20).

There is a clear need to provide support for survivors of critical illness, and their relatives, beyond critical care both within secondary and primary care settings. This need for support is established from this study and case studies from the Netherlands (van Mol 2016 et al). Support to come to terms with critical illness was largely absent from within the population studied, with the exception of a single follow up appointment, with a consultant intensivist available to only a very small percentage of survivors. In 2014 there were 490 emergency admissions to the AGCCU in this study; 8 follow up clinics were available in 2015 with 3 hours slots and 20 minute appointments. An average of 6 patients attended each clinic; a total of 48 over the year which reflects less than 10% of the population being followed up. This is contrary to the current ICS and FICM guidance (ICS 2015 p66) which state "*Patients*

must have access to an ICU follow-up clinic". This indicates a mismatch between holistic models of care promoted by Department of Health (2010) policy and how care is both delivered and received. Whilst exhortations of health care professionals to '*make every contact count'* (Local Government Association 2014) are published in policy, the data from this study reveals the daily reality of clinical work mitigates against achieving this goal. Connolly et al (2014) UK survey of implementing NICE CG 83 reveals the absence of any form of critical care follow up provision in 73% of hospitals (n=182, 240 organisations surveyed). Further evidence of the theory/policy practice gap is discussed in section 1.1. The recommendation is therefore, that survivors of critical illness have access to follow-up clinics, recognising that interventions and effectiveness of treatments within these clinics remains underexplored (Lasiter et al 2016).

The findings from this study highlight the need for a rehabilitation infrastructure to support the existing national guidance, ensuring the holistic needs of survivors and their families are met (ICS 2015, Connolly et al 2014, Cotton 2013, NICE 2009). In comparison with cancer survivors there is very limited, and in several cases, no follow up care or support pathway for critical illness survivors and their families within the UK health systems nor globally (Iwashyna 2010, Wright al 2015). The recommendation is for NICE 2009 guidance to be financially resourced to allow effective implementation.

The word '*abandoned'* was used by survivors in this study and resonates with the literature. Charitable organisations such as ICU Steps in the UK provide excellent resources and, in some areas of the country, support groups for both survivors and family members (http://icusteps.org/support). The support blog is also accessed by survivors and family members from around the world (https://healthunlocked.com/icusteps).   However none of the survivors or family members interviewed in this study were aware of these organisations; they had no capacity to search for something they knew nothing about ('*you don't know what you don't know').* Further, whilst the staff interviewed recognised that they did not provide any signposting to support groups, they were grounded in the here and now of achieving physiological survival and struggled to see beyond discharge from AGCCU.

This is further evidence of being metaphorically bounded by the walls of the critical care unit. The recommendation is that the informational needs of survivors and their families are met to support them in transitioning from physical survival to their '*new normal'.*

There is clearly a need to support critical care nurses, through effective policy and leadership, as their role is undoubtedly challenging and there is a clear requirement to maintain and grow a sustainable workforce (Francis 2013, Willis 2012, ICS 2015). The data from this study and the literature reveals significant personal and professional pressures that may be relieved through clinical supervision, debriefing and working within a culture of care (Siffleet et al 2015, Baggett et al 2016). This may help limit compassion fatigue and moral distress, thereby sustaining person and family centred care (Jakimowicz and Perry 2015, McGrath 2008, van Mol et al 2016). Nurses thrive in a practice environment and culture that allows them to be seen, heard and understood. Transformational leaders who demonstrate empathy and engage with staff have been shown to evoke the human emotion of feeling cared for in the workplace (Baggett et al 2016). This may help build resilience against compassion fatigue (van Mol 2015) and ultimately prevent the development of PTSD (Mealer 2012). The recommendation is for transformational leadership within critical care settings, to facilitate connection with staff and foster a healthier practice environment.

Further specific recommendations for clinical practice include the need to have early conversations with survivors and their families around critical illness survivorship. This study and Govindan et al (2014) have confirmed that issues arising from surviving critical illness are rarely addressed during hospital stays and beyond. There is a paucity of support structures and no dominant model available to be tested or compared against. Unlike in Cancer Care there is no emerging framework of '*aftercare*' services being developed. The recommendation from this study is to avoid a '*one size fits all'* approach, given the heterogenous nature of the population. Instead a personalised (person centred), tailored and risk stratified approach is proposed. Providing information around life after critical illness, both in paper and web based formats, together with access to self-help groups, in both

physical and virtual form are sensible and achievable starting points. As a consequence of this study, a support group has been set up in conjunction with critical illness survivors and is meeting bimonthly. Access to a key worker, such as a clinical nurse specialist in critical illness, as a point of contact, is a model taken from cancer care survivorship and worthy of evaluation within the context of critical illness survivorship. There is evidence of single centre appointments of a Critical Care Liaison Nurse role in Australia (Chaboyer et al 2007), Argentina (Alberto et al 2014) and in the USA (Mitchell 2005), however, these roles relate only to the secondary care setting.

It is clear that further support is needed to improve co-ordination and communication at critical junctures of care, namely; on admission to AGCCU, at discharge from AGCCU to wards and discharge home. Transitional points of care have been identified in this study and by Lasiter et al (2016) as being ignored gaps in care delivery in the UK.

Finally, knowledge of the post critical illness sequelae within primary care is acknowledged to be poor (Wong and Wickham 2013) and further confirmation is provided in this study. An initial study to identify general practitioners' knowledge and understanding is being undertaken in the UK by Bench et al (2015 IRAS ID 169192). This should help identify knowledge deficits after which strategies will be required to address these gaps. There is an urgent need to provide support and co-ordinate rehabilitation for both survivor and family members within the primary care setting.

7.7.1 Implications for Education and Knowledge Transfer

As an academic, I am already in the privileged position of supporting learning in undergraduate, post-graduate and CPD (Continuing Professional Development) education within the classroom, practice setting and through curricula development. The findings of this study have been shared with practitioners through such avenues with beneficial impact reported (p. 271). Dissemination of the findings of this study across the wider academic

community via presentation and publication has been undertaken, (see p.15) and will continue. This enables health care practitioners in both primary, secondary and tertiary care settings to gain greater insights into the critical illness trajectory and in particular the novel theoretical insight of survivors and family members experiencing *dualistic worlds*. Learning should also be focused on developing emotional intelligence, enhancing interpersonal skills and the therapeutic use of self. The relevance and promotion of person and family centred care is pertinent to all practitioners together with facilitating what '*recovery*' looks like in the '*new normal'* world, post critical illness and moving away from a pathologised recovery.

Health Care Professionals should be supported and educated to elicit and listen to views and experiences of survivors and family members and enter the liminal space with survivors. This approach will strengthen holistic care and raise awareness of the breadth of possibilities that may present to survivors and their families. This approach will not fit into a checklist culture (Bruce et al 2014). Further, such a statement requires qualifying in terms of staff needing time, space and supervisory expertise to allow for emotionally intelligent reflection and constructive responses to meet the messy and swampy realities of lived experiences.

7.8 Recommendations for further research

The James Lind Alliance have undertaken a research priority setting exercise in partnership with survivors of critical illness, staff working within critical care and family members who had visited critical care (Reay 2014). The second highest priority for future research was identified as the question "*How can patients and their families be best supported as they start living at home again?*" (Reay et al 2014). The data from this study adds further support for this as a research priority. Further unranked priorities from the James Lind Alliance included "*What psychological support should be provided for patients in intensive care?*" and "*How can we use the experiences of patients and families to improve intensive care?*" Again, data from this study supports these as important research priorities.

An analogy has been drawn between cancer survivors and critical illness survivors in chapter one. This is considered further in box 4.5 (theoretical memo). A significant difference between critical care and cancer survivors, is the lack of support on discharge from hospital within critical care survivors. Both types of survivor have emerged from confrontation with their own mortality. They have endured highly technical and invasive interventions, psychological confusion and upheaval and been discharged alive but often with a new and alienated relationship with their bodies. They are also disconnected from their general practitioners, as evidenced in this study and the literature (Wong and Wickham 2013). This has been recognised in cancer care for the last twenty years or so (Blows et al 2012), and support has been made available extending beyond five years of diagnosis. There is a need to work with survivors and patient centred organisations such as ICU Steps to develop a comprehensive framework of support for survivors of critical illness and their families. Learning from our colleagues in cancer care may be a good place to start. Survivorship Care Plans have been adopted in cancer care (Blows et al 2012) and are worthy of evaluation, with appropriate Patient and Public Involvement (PPI), within the context of critical illness.

A prospective, longtitudinal study exploring relational changes and experience overtime would add to the evidence base. There is a dearth of evidence exploring the meaning and experience of critical illness survivorship overtime. This study retrospectively explored individuals' experiences of life during and after critical illness, in additional to exploring nurses contribution and understanding of critical illness survival. A prospective, longitudinal study would enable exploration of the meaning of events as they happen, and then later, exploration of how those meanings may have changed and why. This would allow focused exploration of the salience of the survivorship trajectory; exploring continuity of past-present-future experiences in more depth.

7.9 Study limitations

It is important to place this study in to context and consider its limitations. This was a single centred study conducted in the UK. The sample consisted of white Europeans, which whilst reflective of the local population, may not reflect other regions in the UK and further afield. A multi-site study may have

increased the diversity of the population. Further, it is acknowledged by the James Lind Alliance Research Priority Setting partnership that survivors of critical illness are a hard to reach group (Reay et al 2014). The study sample of survivors was further restricted, as only those who agreed to attend a follow up clinic were recruited. Survivors who chose not to attend, or did not have the opportunity to attend, may have contributed rich and varied data. Nevertheless, discussion of the study population's experience does resonate with published research and with local, national and international audiences suggesting the concepts and theories may '*travel*' (Charmaz 2014).

A further limitation relates to the method of data collection used in the study. The choice of interviews as the data collection tool was congruent with my subjectivist epistemology and undoubtedly allowed participants to reflect deeply on their experiences. However, participants may have modified their answers because of who, and what, I am. Further, some of the registered nurses already knew me as an academic and they may have modified their answers to please me or appear in a positive light (Holloway and Wheeler 2002). Being aware of the 'interview effect' empowered me to probe participants responses. This undoubtedly assisted in the co-constructed, deep and contextual understanding of the critical illness experience. It was never an ambition to measure and quantify this experience.

Undertaking the interviews retrospectively and as a single interview is a further limitation to the study. The data collected may be subject to recall bias, although from a symbolic interactionist perspective and from a relativist ontology the fluid nature of reality is acknowledged. The data collected was undoubtedly the reality that was perceived by the participants at that point in time. As stated in 7.9 a prospective, longitudinal study would enable exploration of the meaning of events as they happen, and then later, exploration of how those meanings may have changed and why.

The data collected was rich in both detail and emotion, providing poignant insights into the experience of both surviving and witnessing critical illness. Data from registered nurses was equally significant, revealing the impact of confronting mortality and the challenges to crafting person centred care.

Undoubtedly this warrants further analysis and is likely to be the focus of subsequent papers.

As a relative novice in qualitative research I would consider myself a limiting feature of the study. However the doctoral journey has developed and honed my expertise in qualitative methods. Immersion in the grounded theory literature, attending workshops and developing a robust understanding of the method was less challenging than the enactment of the method. The most challenging aspect was the data analysis and the coalescing of data from three different participant groups, but in true constructivist grounded theory style, I interacted with the data and consulted with the literature to trigger analytical insights.

7.10 Contribution to knowledge

This study has provided a unique holistic perspective of critical illness in the UK, at a time when the long term impact of critical illness is finally being realised. The significant new knowledge connections that have been constructed are based on major themes grounded in the experiences and perspectives of adult survivors of critical care and family members during and beyond critical illness. Survivors of critical illness have invariable, on admission to AGCCU, entered a liminal state between life and death. They frequently experience vivid hallucinatory experiences which place them in a different world or liminal space. Survivors may move in and out of these different internal '*dualistic worlds'*. In addition, there is evidence of an external '*dualistic world'* between survivor and family members which provides an explanatory insight in to life during and after critical illness. The process of transitioning and transforming post critical illness can lead the survivor to a '*new normal'* and establishing a new relational normal with family members. Regaining family homeostasis can be a challenging journey for both parties.

The critical care environment is known to be a demanding place of work and this study has identified that nurses in AGCCU experience personal and professional challenges in the delivery of increasingly complex care. Further, nurses can be limited to the immediacy of care in the *here and now* or *in the*

moment; they bear witness to both survivors and family members experiencing profound changes in health and confrontation with mortality. Consequentially, nurses in AGCCU are unable to support the onward survivorship trajectory, they are, metaphorically, bounded by the walls of critical care. The study confirms that nurses provide significant intersubjective support at the outset of the survivorship journey to patient and family member alike.

Application of liminality as a conceptual lens is novel in relation to the critical illness trajectory and the critical care setting; this lens has augmented the theoretical insight of *dualistic worlds.* Viewing phenomenon from two different participant groups, whilst not unique, has contributed to a holistic and relational construction of reality which adds a depth of understanding not previously apparent within the UK.

Further, this thesis contributes to a wider and growing corpus of knowledge around patient and family member experiences of critical illness with associated practice, policy and research implications.

7.11 Conclusion

To conclude, this study has explored the adult critical illness trajectory from a dyadic perspective and focused on the longer term biopsychosocial impact of survivorship following critical illness. Understanding the survivorship perspective from differing viewpoints has provided a holistic view of the complex and fluid nature of this journey. The study identified dualistic worlds between survivor and family member, and within the survivor. These temporal events occur during and after critical illness and expose a non-linear, fluid journey towards a '*new normal'*. Theoretical insights in to the legacy of critical care have been revealed (Fig 7.2).

Nurses in AGCCU bear witness to the early stages of the survivorship trajectory and provide complex care in support of survival however they are bounded by the walls of AGCCU such is the proximity to death and the pressure of work. They are unable to support the onward survivorship journey.

My final concluding commentary comes directly from an ICU survivor whose words represent both the '*dualistic worlds'* experienced between survivor and family member and the relational changes in the '*new normal'* world post critical illness evident in this study:

> "*You must decide what that life will be like. It will be different from before the ICU, because you are different. The people who care about you may not understand, but that's OK. The only way to really understand it is to have lived through it".* (David PR05)

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Appendix 1 Literature use within thesis

Starting point	Body of literature selected for review	Aims	Location within thesis
May 2012 –May 2013	Preliminary literature review; • Family, patient and nurse experiences in AGCCUs	• Registration on to MPhil/PhD • Ethical approval and access to the field	Pre-thesis and Chapter 1
January 2014	Literature review; • Patient trajectory of critical illness • Gaining access and being with critically ill family members • Challenges experienced by registered nurses in AGCCU • Triadic experiences of patients, family members and registered nurses	• Developing and refining research questions • Refining of prompts and probes (in conjunction with data collection) • Developing theoretical sensitivity	Chapter 2
Sept 13 –	Methodological Literature review • Qualitative research methods • Grounded theory; historical and contemporary approaches • Symbolic interactionism • Social constructionism	• Reflecting on ontological, epistemological and theoretical assumptions • Situating the study within research paradigm • Selecting the methodological approach • Designing the study (protocol) • Preparing for data collection and analysis • Interviews and the researcher	Chapter 3 and 4

		as the instrument of research	
May 2015 (search will be guided by concurrent data analysis)	Revisiting literature with greater focus (this will be more focused on the emerging categories and sub categories)	• Gain conceptual leverage • Update preliminary literature review • Situating the study within the context of category specific literature	Chapters 2 and 7
May 2016	Integration of conceptual framework with formal theory	• Scaling up the emergent theory • Identifying original contributions • Engaging and integration with formal theories	Chapter 7

Appendix 2 Literature Matrix

2.1 Family members in AGCU

Name	Journal	Date	Country of origin	Research design	Sample size and population	Focus and findings of study	Relevance to my research questions
Agard A and Harder I	ICCN	2006	Denmark	Grounded Theory	7 FMs	Enduring uncertainty, guilt, making sense of ICU were emerging themes. Dissonance between nurse and family members' perspectives. No reference to theory emerging.	Reinforces the vulnerability that family members experience in ICU
Blom H et al	ICCN	2012	Sweden	Phenomenology	7 FMs	Participation in care and being close to loved one. Support needed for patient involvement, need to be confident in the care provided by nurses . Acute vulnerability.	Participation in care can be helpful for FMs, FM perception of care very important, vulnerability of FM reinforced.
Capellinie E et al	Dimensions of Critical Care Nursing	2013	Global literature review. Italian authors	Literature review	29 primary research articles reviewed	Open visiting;- Sweden =70%, Italy=1%. Significant global varaiation. Visitors do not contribute an infection risk.	Links with Hunter's study – UK dominantly restrictive in visiting. Restrictive visiting in situ although flexiblility permitted.
Chiang V	ICCN	2011	Hong Kong	Grounded Theory	11 FMs	Survival achieved by "Mutually being there for each other" as core category. Categories include "being there with", "coping" and "self relying".	Interviews with both patient and FMs confirm these categories.

Davidson J	Critical Care Nurse	2010	USA	Case study based on Grounded Theory	Paper applied to case study –original sample size not stated	Application of middle range theory "facilitated sense making" in relation to Roy's adaptation model as applied to family members in ICU	Nurses role in facilitating family members making sense of having a loved one who is critically ill.
Dithole K and Thupayagale-Tshweneagae	Issues in Mental Health Nursing	2013	Botswana	Mixed method Quantitative – questionnaire for PTSD reporting Qualitative interviews	28 FMs	PTSD symptoms evident in 15 spouses of critically ill survivors. FMs experienced sleep disturbances, emotional instability and fear.	Not directly assessed, although some FMs have described intermittent fear 3-5 months post discharge.
Engstrom A and Soderberg S	ICCN	2004	Sweden	Narrative	7 FMs	Being present, showing respect to loved one. Receiving social support and obtaining information	Further confirmation of the importance of access to patient, by loved one and be supported.
Engstrom B et al	ICCN	2011	Sweden	Qualitative, 1:1 interviews, content analysis	8 Registered nurses	FM involvement in care appreciated but registered nurses experience challenges with lack of time. Protection of patient integrity also cited.	Relative involvement in care more challenging for junior registered nurses. Trust can be developed between RN and FM through patient care involvement.

Eriksson T and Bergbom I	NiCC	2007	Sweden	Prospective, observational design.	198 met inclusion criteria. 148 had visitors, 50 (25%) did not.	Limitations – included elective admissions and ≤48hrs. Spouse most common visitor – length of visit 15mins to 153hrs with a frequency of 84 visits.	Emphasises the individual nature of FMs visiting patterns. Surprising that 25% had no visitors but note population included elective admissions and short LOS.
Eriksson T et al	ICCN	2010	Sweden	Hermeneutic	Observations of patients (10) and FMs (24)	Physical environment hindered interplay between patient and FM. Nurses important in promoting the interplay e.g. touch to strengthen connectedness.	Physical environment challenges further the psychosocial well-being of patients and FMs
Hunter J.D.et al	Anaesthesia	2010	UK	Quantitative Postal questionnaire	ICUs in UK n=271	19% have "open visiting". 93% restrict visiting to maximum of 2. Facilities available to FMs were surveyed.	Confirms restriction of visiting within the majority of UK AGCCUs
Johansson I et al	NiCC	2005	Sweden	Grounded Theory	29FMs	FM needs identified, included social and family support. Need to develop trust and need to develop some control of the situation. Vulnerability. No theory identified or link to grand theory	Development of trust and gaining some control. Need to move away from just discussing FMs needs and are they met but how they can be empowered to make sense of the situation.

Johansson I et al	Journal of Advanced Nursing	2006	Sweden	Simultaneous concept analysis from 2 empirical studies		Theoretical model of coping devised.	Illustrates how effective and ineffective coping strategies correlate with strong and weak social support.
Karlsson C et al	NiCC	2010	Sweden	Mixed methods Descriptive, retrospective questionnaires (20 questions in total) with 2 open ended.	35FMs	High level of satisfaction noted. Flexible visiting highly valued. Lack of access to medical information, discomfort whilst waiting and poor preparation for transition to ward noted	Flexible visiting improved FM experience. Transition to ward problematic.
Kutash M and Northrop L	Journal of Advanced Nursing	2007	USA	Qualitative interviews	6 FMs	Close proximity of waiting room important, need for comfortable environment and perceive quality care, roller coaster of emotions shared by relatives in waiting room	Common themes from FM interviews.
Mitchell M	NiCC	2005	USA	Invited Editorials (Grey literature)		Highlights Institute of Family Centred Care in USA. Position of a Critical Care Family Liaison Nurse and Learning from out PICU colleagues. Contention that FMs are not visitors it is the HCPs that are visitors in patient's lives.	Single centre of outstanding excellence in USA- St Vincent's medical centre Massachusetts. Aspirational but not transferable care settings.
McKiernan M and McCarthy G.	ICCN	2010	Ireland	Phenomenology	6 FMs	The need to know, make sense of it all, being there and caring and support were emerging themes.	Family presence (access and being with) and honest

							information recurring themes
Mitchell M and Chaboyer W and Burmeister E	American Journal of Critical Care	2009	Australia	Quantitative – prospective interventional study (pre-test – post-test design)	174 FMs 75 control 99 interventional	Partnering patient FMs to provide care e.g. wash, hair wash, shave etc. significantly improved FMs respect, collaboration and support.	Registered nurses have some positive experience of relative involvement – more evident in staff with several years ICU experience.
Plakas S	NiCC	2013	Greece	Constructionist Grounded Theory	25 FMs. 15 1:1 interviews, 4 by 'phone, remainder group family interviews.	Vigilant attendance OUTSIDE the ICU was evident due to highly restricted visiting. Tried to access information by alternative means as access limited. Change needed.	Emphasises the importance of having access both to patient and information. Denial leads to alternative strategies of coping.
Spreen A and Schuurmans M	ICCN	2011	The Netherlands	Nationwide, 'phone based questionnaire survey	Head nurses n=105	No units have open visiting despite national and international guidelines	Evidence of dissonance between theory/policy and practice in relation to visiting by FMs.
Vandall-Walker and Clark A	Journal of Family Nursing	2011	Canada	Grounded Theory	Two staged study 20 FMs + 14FMs	Middle range theory that FMs engage in "work"; work of gaining access; patient related work; clinician related work and self related work.	For registered nurses to remove barriers to allow FMs to do their "work"
Wong P et al	ICCN	2015	Australia	Grounded Theory	12 FMs	Family's information needs may become secondary to patients primary physiological well-being.	Registered nurses have reported conflict in time to spend with

					Facilitating communication with FMs in response to non-verbal cues can help the family to provide valuable psycho-social support to the patient	FMs when patient is deteriorating. This can cause dissonance between FM and RN.

2.2 Registered nurses in AGCCU

Name	Journal	Date	Country of origin	Research design	Sample size and population	Focus and findings of study	Relevance to my research questions
Agard A et al	NiCC	2009	Denmark	Quantitative questionnaire	68 Registered nurses (61% response rate)	Registered nurses did not support the presence of FMs in critical situations. Variation in agreement as to when to involve relatives in care.	Possible dissonance between Registered nurses can lead to confusion for FMs. This in itself can cause dissonance.
Agard A and Lomborg K	Journal of Clinical Nursing	2011	Denmark	Qualitative GT - interviews	11 Registered nurses	Registered nurses balance the needs of their patients with the needs of FM. Shifting context of ICU leads to defining the situation and guiding FMs on a minute by minute basis.	Some junior Registered nurses struggle with balancing the demands of patients and FMs, however support available from experienced and senior Registered nurses.
Buckley P and Andrews T	ICCN	2011	Ireland	Quantitative, descriptive correlational study use questionnaires	55 Registered nurses	Registered nurses demonstrated a good knowledge of relatives need but this knowledge was not necessarily transferred into practice.	Evidence of theory practice gap. Need to go beyond meeting "needs" of FMs.
Engstrom and Soderberg	Journal of Clinical Nursing	2010	Sweden	Qualitative interviews with	8Registered nurses were interviewed	Registered nurses gained a new picture of how critical illness had influenced the patient's every day	Registered nurses have very little insight or knowledge of

				thematic content analysis	about their experiences of follow up visits by patients	being. Registered nurses were disappointed that patients had limited recall of ICU stay. Registered nurses were unable to recognise most ex patients (positive).	patients on going journey post discharge. Some staff would like to know more about patient outcome.
Everingham K et al	Journal of Clinical Nursing	2014	UK	Phenomenological study	16 Registered nurses	The use of targeted sedation and sedation "holds" militate against patient centred care.	Sedation links strongly with delirium.
Gibson et al BACCN	NiCC	2012	UK	Position Statement from BACCN on visiting in AGCCUs		Individualised open visiting is recommended	In the AGCCU visiting is restricted although discretion is allowed. Staff unaware of position statement.
Haggstrom M et al	ICCN	2012	Sweden	Grounded Theory Focus groups, 1:1 interviews and observation	34 Registered nurses	Focus was on transition from AGCCU to wards. Core category of "being perceptive and adjustable" but not linked to grand theory. Nurses forced to compromise their care.	Transition from AGCCU to ward remains highly problematic for patients, Registered nurses and FMs.
Kean S and Mitchell M	Journal of Clinical Nurses	2014	UK and Australia	CGT (UK) and quasi-experimental (AU)	20 Registered nurses (UK) (AU) Control AGCCU n=75 Intervention AGCCU n=99	Nurses should promote, facilitate and integrate active involvement to help start the journey of recovery from critical care illness.	Links strongly with the need for integrative care in relation to critical care survivorship. Registered nurses may need further insight into the critical illness trajectory to help assimilate this role.

Lin F and Chaboyer W and Wallis M	Journal of Clinical Nursing	2013	Australia	Ethnography (interviews, observations and documents)	56 1:1 interviews with 46 Registered nurses	Registered nurses need to develop greater situational awareness to improve patient discharge from ICU. Team work and communication influence quality of transition.	Increase pressure on ICU beds may impact on the quality of the discharge to wards. This then increases "relocation stress" for patient and FM and ward nurses.
McGrath M	Journal of Clinical Nursing	2008	Ireland	Phenomenology	10	Experienced critical care nurses are able to transcend the obtrusive nature of technology to deliver expert caring to their patients. However, the journey to proficiency in technology is very demanding and novice nurses have difficulty in caring with technology.	Junior Registered nurses struggle to juggle the competing needs of patients and family members. Experienced staff develop advanced nursing skills to do so. There may be an emotional cost in doing so.
Marco L et al	NiCC	2006	Spain	Quantitative-descriptive correlational design- self-administered questionnaires	46Registered nurses (AGCCU)	Correlation between nurses' beliefs and attitudes regarding the positive effects of open visiting on patients, FMs and nurses	Within this specified population (Spain, one AGCCU) coherence in the belief of the benefits of open visiting by Registered nurses
Stayt L	Journal of Advanced Nursing	2007	UK	Qualitative study, interviews informed by	12 Registered nurses	Registered nurses reported role expectation and role conflict. Some participants lacked confidence and highlighted	Registered nurses challenged by the demands of caring for

				Heideggerian philosophy		personal and professional conflicts. Occupational stress.	FMs in the context of critical illness
Tunlind A et al	ICCN	2015	Sweden	Qualitative 1:1 interviews, content analysis	8 Registered nurses	Technology major tool in life preservation but barrier to patient centred care.	Challenges of humanising a high tech environment.
Vouzavali F	NiCC	2011	Greece	Qualitative, Heideggarian, hermeneutic approach.	12 Registered nurses	Registered nurses develop intense relationships with their patients. This affects how Registered nurses make sense of their world. Core theme of "syncytium".	Registered nurses develop close relationships with patients and their FMs. This has implications for their emotional wellbeing.
Wahlin I et al	ICCN	2010	Sweden	Phenomenological study	12 ICU staff (8 nurses +4 physicians)	Personal knowledge plus supportive atmosphere and team work increases sense of empowerment	Importance of support and team working with AGCCU.
Williams C	NiCC	2005	UK	Qualitative, naturalistic enquiry (video and interviewing)	14Registered nurses	Families can have a positive influence on patient care and recovery, but both FMs and Registered nurses need to be supported to maximise this valuable contribution	Family presence valued by patients and most Registered nurses. Some Registered nurses challenged by FM presence.

2.3 Patient experience in relation to AGCCUs

Name	Journal	Date	Country of origin	Research design	Sample size and population	Focus and findings of study	Relevance to my research questions
Almerud S et al	NiCC	2007	Sweden	Phenomenology	9 patients	Incomprehensible environment, facing mortality, conflict between technology and compassionate care. Strive to join the objectivity and subjectivity of nursing.	Complex and disorientating environment. Delivery of high quality, compassionate care is strived for but may be at a personal cost.
Belanger L and Durcharme F	NiCC	2011	Canada	Literature review	17 articles reviewing patient and nurses experience of delirium	Incomprehension and feelings of discomfort evident overriding theme	Despite NICE CG 103 there is a deficit of knowledge to assess, recognise and intervene in preventing and treating patients with delirium. See also Egerod I (2013) Editorial NiCC

Bergbom I and Askwall A	ICCN	2000	Sweden	Hermeneutic approach	5 patients	Critical illness is a threat to the individual (patient) and also to their world. This threat can be ameliorated by family presence. FMs can give patient courage for survival.	Importance of close proximity of FMs to their loved ones, in sustaining their humanity.
Chaboyer W and Grace J	NiCC	2003	Australia	Quality improvement PDCA cycle (=PDSA)	222 patients with average length of ICU stay 13.9 days	Significant and wide ranging psychological and physiological sequelae.	Clearly articulated in patient interviews. Limited support post AGCCU and post discharge.
Cutler L et al	ICCN	2013	UK	Qualitative literature review	26 qualitative papers	Themes; Unreal experiences and dreams, Proximity to death, Perception of time, Technology and dependence, Communication and relationships with HCPs, Support of family and friends, Transfer and recovery.	All evident in patient interviews.
Deacon K	ICCN	2012	UK	Web based qualitative study. (GT)	35 participants accessed questionnaire via ICU Steps website	3 key needs in the rehabilitation phase; - Information and education Personal support, Assessment and therapy, Community and GP services lack insight into critical illness.	

Engstrom A et al	ICCN	2013	Sweden	Qualitative interviews 6 months post ICU	8 patients	Feeling vulnerable and dependent, struggling to communicate, feeling safe with staff, the "unlikely was reality". Valued ICU diary and follow up clinic	All findings commensurate with patient interviews (not diary as not completed)
Field K et al	Critical Care	2008	UK	Qualitative thematic analysis	40 interviews with patients in their own home post critical illness	Not only physical and emotional stress of transition but poor communication, nutrition, nursing care, ward organization and environment.	Relocation from ICU to ward problematic for most patients interviewed. Staff restricted by physical resources e.g. staff numbers.
Hofhuis J et al	ICCN	2008	The Netherlands	Mixed methods Qualitative semi structure interviews + self-reported questionnaire	11 interviews 50 questionnaires (50% response rate)	Whilst support dominated as a key theme, ICU nurses were perceived as having expertise and technical skills but caring behaviour relieving patient of fear and worries most valued.	Patients and relatives have consistently reported ICU care as being "brilliant".
Johnson P	ICCN	2004	Australia	Phenomenology	9 patients	Themes were "reclaiming the everyday world". Comfort from presence of nurses and FMs. Patients may seek more control of their environment.	Comfort from nurses and FMs evident. Patients wanting to "normalise" e.g. walk, visit bathroom, eat and drink.

Jones C et al	NiCC	2003	UK	Exploratory mixed method	18 male patients- age 21-54 (mean 41)	Life review and reminiscence can be used therapeutically from an early stage to help minimise the negative psychological effects of critically illness.	Patients, FMs and Registered nurses do have access to psychotherapy services.
Jones C et al	NiCC	2015	Sweden	Report (grey literature)		The value of integration of ICU diaries for patients.	No diaries used. NB contrast with Systematic Review Leanne Aikin (2014)
Karlsson V.and Forsberg A	ICCN	2008	Sweden	Phenomenology	8 interviews with patients who had been ventilated and were conscious	Memory loss and communication difficulties. Attempt to "master" the situation with a "yearning for health". Physical presence of nurse or FM made the patient feel safe. Expression of yearning to drink, taste and to go home	All evident in interviews with patients.
Williams S.L.	NiCC	2009	UK	Phenomenology	11 patients	Patients need help to construct their intensive care story to help psychological recovery.	No use of patient diaries.
Lof L et al	ICCN	2008	Sweden	Qualitative content analysis	8 patients interviewed at 3 and 12 months post ICU	Memories of emotions during trajectory of critical illness detailed and strong. Recollections change over time. Unpleasant emotions less intense at 12 months,	Strong and stable recall of emotions evident in patient interviews.

						greater recall of caring by Registered nursesand Drs.	Several codes match patient interviews codes in Lof et al study.
McKinney A and Deeny P	ICCN	2002	UK	Phenomenology	6 patient interviews	Relocation stress evident. Enormity of critical illness impacted post discharge	All evident in interviews with patients.
Misak C	American Journal Respiratory Critical Care	2004	USA	Occasional essay by ex ICU patient and Dr in USA	Reflective account	Profound and distressing delirium; psychosis and paranoia. Muscle loss. Profound sense of own mortality.	Replicated in patient interviews.
Needham D et al	American Journal Respiratory Critical Care Medicine	2012	USA	National longitudinal cohort study from Medicare survey NB 75% mortality rate!! Retrospective analysis		Long term impairment post critical illness includes; depression, immobility, cognitive impairment, neuromuscular impairment. Long term burden for family. Model of survivorship needed to support critical illness journey.	Evidence of physical and psychological sequelae evident in patient interviews. Deficit in follow up care and support in community evident from both patient and FM interviews.
Olsen K et al	ICCN	2009	Norway	Qualitative research + content analysis	11 patients from ICU	Patients reported that they wanted only their closest	FMs need to be with their

					with hypothesis identified.		FMs present with some limitation of visiting. Information for the family helps with the patient's reality orientation. Flexible visiting is challenging for Registered nurses.	relative may be stronger that the patient's need. Registered nurses can be challenged by flexible visiting.
Papathanassoglou E.	NiCC	2010	Greece	Literature review	14 studies of interventions for psychological support of patients in ICU	Literature limited. Registered nurses need to engage in psychosocial support in a systematic way. When interventions occur e.g. guided imagery results are positive	No specific interventions other than "rest periods". Some long term ventilated patients are taken outside.
Ramsay P et al	Journal of Clinical Nursing	2014	UK	Qualitative interviews	20 patients	Sense of "disconnection" due to profound debilitation and dependency. Patients distressed by lack of understanding by ward staff. Significant source of distress for patient.	Confirmation of relocation stress experienced by patients on transfer to ward.
Rattray J	Journal of Clinical Nursing	2014	UK	Literature review	Numbers of articles accessed not declared.	Fatigue, weakness, anxiety, depression, PTSD, delirium and cognitive impairment evident. Need for co-ordinated multidisciplinary recovery and rehabilitation pathway.	All evident in interviews with patients. NICE CG 83 NOT implemented effectively.

Ritmala-Castren M. et al	NiCC	2014	Finland	Quantitative study Retospective analysis of nursing documentation. Pt. survey VAS 5 item questionnaire	Registered nurses (n=90) Patients (n=114)	Nursing documentation of patients sleep quality is poor.	Sleep deprivation and profound fatigue evident in patent interviews.
Roberts B and Chaboyer W	NiCC	2004	Australia	Qualitative – phone interviews	31 patients	74% reported dreaming, majority describing hallucinations 26% patients felt relatives and staff helped them cope with dreams.	All patients interviewed reported abnormal dreams.
Rose L et al	ICCN	2014	Canada	Quantitative – questionnaires	27 patients	Delusional memories, thirst, loss of control, noise and inability to sleep were reported.	All themes evident from patient interviews.
Samuelson K	ICCN	2011	Sweden	Qualitative – two open ended questions	250 patients	81% remembered their ICU stay. 71% described unpleasant memories, 59% pleasant memories. These pleasant memories may alleviate the impact of distressing memories.	All patients interviewed had dreams some pleasant but most distressing. One had no recollection of their stay but powerful recollection of hallucinations.

Storli S et al	NiCC	2008	Norway	Phenomenology	10 patients interviewed 10 years post ICU	Critical illness can leave durable traces even 10 years on. Memories well kept. Panic attacks and anxiety still evident. Some patients still seeking comprehension of the experience. Presence of relatives important resource both at the bedside and in subsequent discovery of lived experience.	Emphasises the long term impact of critical illness.
Strahan E and Brown R	ICCN	2005	Ireland	Phenomenology	10 patients Interviewed 3-5 days post ICU transfer	Sleep patterns problematic, need opportunity to discuss memories and nightmares. Education re diet and rehab needed. Families need to be involved. A follow up nurse would be beneficial.	Confirms transfer to ward as a critical juncture in illness trajectory. Disconnected care evident.
Svenningsen H et al	Journal of Clinical Nursing	2014	Denmark	Quantitative-Memory Tool questionnaire	360 patients were interviewed 1 week post ICU.	Delirium detected in 60% of patients. Need to develop better assessment tools to determine long term consequences of delirium.	No formal assessment of delirium undertaken either on ICU or post discharge.
Tembo A et al	ICCN	2014	Australia	Phenomenology	12 patients Interviewed 2 weeks post ICU discharge + 6-	Overarching theme "Being in limbo", sub themes "Being disrupted", "Being imprisoned" and "Being trapped".	Being trapped, voiceless and imprisoned voiced by

							patients. All evident themes.
					11 months later		
Uhrenfeldt L et al	Journal of Advanced Nursing	2013	Denmark and Norway	Qualitative meta synthesis	14 qualitative papers reviewed	3 categories; - Unpredictable, scary and stressful. Recovery and relief. Sliding into insignificance. Interventional studies and policy development needed.	All 3 themes evident in all interviews (FMs +Registered nurses + patients)
Wade et al	Critical Care	2012	UK	Prospective cohort study	157 patients	55% patients had psychological morbidity. Strongest link was with sedation use.	Psychological interventions and pharmacological interventions may reduce poor outcomes.

2.4 Dyadic and Triadic perspectives

Name	Journal	Date	Country of origin	Research design	Sample size and population	Focus and findings of study	Relevance to my research questions
Agard A.S. et al	ICCN	2012	Denmark	Qualitative GT dyad interviews plus 2 focus groups (patients only + FMs only)	35 interviews at 3 and 12 months post ICU discharge	Struggle for regaining independence and recovering physical strength. Perseverance and hope evident traits in survivors. Physical recovery may precede psychological recovery. NO theory generated	Confirms significant physical weakness of survivors. Relatives vital in supporting the recovery phase.
Castillo et al	Australian Critical Care	2015	Australia and Germany (data collected in Germany but reported in AU)	Article critique of prospective quantitative study using HRQOL questionnaire.	55 dyads (sepsis survivors and their spouses) representing a 9.8% response rate	Care after intensive care treatment should be considered for both patient and FM. No ICU follow up clinics exist in AU.	Confirms psychological sequelae for both FM and patient.
Cypress B	ICCN	2011	USA	Phenomenology	5 patients, 5 Registered nurses and 5 FMs	Affirms mutual influence of FMs, Registered nurses and patients during critical illness. Supports tenets of family centred care and the family as a unit (FM, RN and patient). Specific themes RN=advocacy,	Critical illness has a transformatory effect on patients and FMs (and Registered nurses). Advocating purposeful

						patient=uncertainty, FM=confidence in RN and team.	inclusion of the family in all aspects of care.
Eriksson T et al	ICCN	2011	Sweden	Qualitative, hermeneutic	7 patients and 5 FMs	Patient narratives – recall of real life and unreal life experiences – the latter being more common. FM narrative " on stage" and "back stage" =with the patient and without the patient	Tentative corollaries with category of "dualistic worlds".
Hughes F et al	NiCC	2005	UK	Qualitative Grounded Theory	8 FMs and 5 Registered nurses	Staff perceived relatives' experiences accurately. Issues around information flows. No theory generated.	Information needs evident and largely met by Registered nurses in ICU.
Magnus V and Turkington L (both SLTs)	ICCN	2006	UK	Mixed Method - ordinal scale with inferential statistic -qualitative interviews Grounded Theory	9 staff members (Registered nurses, Drs, Physio) 8 patients	Negative= frustration (staff and patients), lonely, terrifying, feeling like being in prison, powerless. Positive= caring, fantastic when you first hear the speak,	Loss of voice evident in patient interviews. Regaining voice significant juncture in critical illness trajectory. No SLT available on AGCCU.
Tayebi Z et al	NiCC	2014	Iran	Qualitative with thematic analysis of 1:1 interviews	9 Registered nurses, 4 FMs and 2 patients	Iran has restricted visiting polies in ICU of unknown origin. Registered nurses sought to "protect" their	Restricted visiting may occur from a paternalistic "care" of patients.

						patients by imposing visiting restrictions.	
Wahlin I et al	ICCN	2009	Sweden	Qualitative with 1:1 interviews and thematic analysis	11 patients, 12 FMs and 12 ICU staff.	Staff and Registered nurses regard patient as more "unconscious" than the patient. Feeling hope and spiritual experiences disclosed by patients and gave empowerment. Conflict between human closeness and professional boundaries.	Balance between professional distance and developing relationship with family problematic for some Registered nurses

*NiCC = Nursing in Critical Care

**ICCN= Intensive and Critical Care Nursing

Appendix 3 Ontological and Epistemological frames

Consciously or not we bring beliefs and philosophical assumptions to our research. These beliefs are developed through education, socialisation and exposure to life. It is imperative that as a qualitative researcher, beliefs and assumptions are exposed in a reflexive manner (Mason 2002). The ontological frame in qualitative research is that reality is seen through multiple views and perspectives and is dynamic and changing. That which counts as knowledge and that which is knowledge, in the epistemological frame, requires understanding and justification (see Table 3.1). The subjective nature of qualitative research can pose difficulties when viewed externally. However, it is known through the subjective experiences of people. Ontological and epistemological frames cannot be understood in a vacuum – we need to understand our own moral philosophy (aesthetics and ethics) and the logic and reasoning used to make sense of the world (Cresswell 2013). For this reason, my own views and experiences are presented in Chapter 1 and reflexivity is evident throughout the thesis. Table 3.1 outlines the philosophical assumptions related to qualitative research.

Assumption	Questions	Characteristics	Implications for Practice
Ontological	What is the nature of reality?	Reality is multiple as seen through many views	Researcher reports differing perspectives as themes emerge.
Epistemological	What counts as knowledge? Justification? Research and researcher relationship?	Subjective evidence from participants; researcher attempts to lessen distance from participants.	Researcher relies on direct quotation, spends time in the field.
Axiological	What is the role of values?	Researcher acknowledges that research is value laden and biases present	Researcher openly discusses values that shape narrative and include own interpretation

			with participant interpretation.
Methodological	What is the process of research? What is the language of research?	Researcher uses inductive logic, studies the topic within its context using an emerging design.	Researcher works with detail before generalisations, describes in detail context of study, revising questions in relation to field experiences.

Philosophical assumptions in relation to qualitative research (Adapted from Cresswell 2013)

Having outlined the epistemological and ontological frames of a qualitative researcher that relate directly to myself, integration of a theoretical framework for the study follows.

Theoretical frameworks

Philosophical assumptions feed into or indeed underpin the interpretative frameworks which qualitative researchers use to conduct their study. There are many frameworks, including positivism, post-positivism; interpretivism, constructivism, and hermeneutics (Cresswell 2013). Appropriately, such frameworks are constantly evolving. The combination of realist ontology and a constructivist epistemology is discussed by Maxwell (2012), proposing that the real world exists independently of our beliefs but in combination with the knowledge that the world is inevitably our own construction. Michael Crotty claims that meanings are created by humans as they interact with the world and the use of interviewing as a research instrument is, therefore, a co-construction "*Objectivity and subjectivity are brought together and held together indissolubly*" (Crotty 1998 p 48). The social world and natural world are not distinct but one human world, *"it is at one both natural and social"* (Crotty 1998 p 48).

Symbolic Interactionism

Herbert Blumer (1900-1987) devised the term "*Symbolic Interactionism*" and was a student of George Mead (1863-1931) at the University of Chicago. Blumer developed Mead's pragmatic sociological philosophy and the three basic assumptions that underpin Symbolic Interactionism can be summarised as follows (Handberg et al 2015);-

- People strive and act towards what represents *meaning* for them**.**

- Meaning arises out of social interaction. This is achieved via *language*.

- Meaning is being dealt with and modified through interpretative processes – *thought.*

Human behaviour is, therefore, a result of an interpretative process in which people assign meaning to the events and situations they encounter. Given the fluid nature of this process (according to Crotty (1998)), there is no true meaning or valid interpretation but useful interpretations. Social interactions and the sociocultural environment will also influence interpretations and therefore meaning. This social constructionism directs our behaviour and organises our experience.

Appendix 4 Theoretical and Historical background to Grounded Theory

This appendix outlines the theoretical and philosophical foundations of grounded theory with associated context. Recognition of the generational development and variation of grounded theory, and the associated contrasting assumptions, highlighted in Table 3.3 was central to my decision to adopt it as the most suitable version for this research. Reflecting upon the differences and similarities of the objectivist and constructivist approaches together with my own personal perspective has led me to a constructivist approach. In presenting constructivist grounded theory the journey to the development of this method will be outlined.

First generation grounded theory was developed or "*discovered*" by Glaser and Strauss (1967). Their book entitled "*The Discovery of Grounded Theory*" needs to be contextualised to the theoretical perspectives of the 1960s where qualitative research was under attack and realist positivist research dominated. The suggestion was that sufficient outstanding theories had been generated and all that remained was to test them via quantitative research (Urquhart 2013, Ward et al 2015). According to Gibson and Hartman (2014), grounded theory was developed to address an embarrassing '*gap*' in sociology that had developed in the 1960s. The '*gap*' was between so-called armchair sociologists who developed grand theories but did very little empirical research and a large number of empirical studies which did not contribute to theory generation. As such '*The Discovery of Grounded Theory'* sought to generate and ground theory by refocusing on qualitative data rather than quantitative verification of theories. The term '*grounded*' is tied to the '*discovered*' theory which is directly linked with data; hence, the theory is grounded in data (Bryant 2002). The term *'theory'* within this context relates to substantive and formal theories known as '*middle range'* theories. Middle range theories are explanatory and fall between the minor everyday working hypotheses and the all-inclusive *'grand*' theories which are spread across society but cannot be linked back directly to data (Glaser and Strauss 1967 pg. 32-33, Charmaz 2014).

The differing philosophical backgrounds of Glaser and Strauss undoubtedly helped to *discover* grounded theory but may also have generated the ensuing differences of opinion. Strauss was strongly influenced by Symbolic Interactionism coming from the Chicago School of Social Research where both Mead and Blumer studied (Charmaz 2014). In contrast, Glaser was trained in quantitative methods and provides the quantitative propensities associated with early grounded theory (Heath and Cowley 2002). As such Glaser imbued the method with '*dispassionate empiricism*' (Charmaz pg. 9) whilst Strauss brought notions of "*human agency*" and "*an open ended study of action*" (Charmaz pg. 9 2014). The merging of two (arguably) competing philosophical perspectives (Symbolic Interactionism and positivism) may have ultimately led to their acrimonious separation in the 1980s where Glaser stated that Strauss never truly understood grounded theory (Bryant 2002). Undoubtedly this is an oversimplification and Urquhart (2013) states that Glaser and Strauss never claimed a '*correct*' epistemology, indeed Charmaz's (2006) pragmatic view is that grounded theory can be ontologically and epistemologically '*neutral'.* A claim supported by Breckenridge et al (2012) and Glaser (2012) himself. Charmaz (2014) asserts that the text '*The Discovery of Grounded Theory'* (Glaser and Strauss 1967) "…*punctured notions of methodological consensus and offered systematic strategies for qualitative research practice*" (Charmaz 2014 p.7); and is widely accepted as seminal research. Whilst grounded theory has been considered as revolutionary in terms of qualitative research it is also undoubtedly the most disputed and debated research method (Walker and Myrick 2006).

The success of grounded theory is evident by the number of disparate fields that utilise this research design and method such as education, marketing, film making, psychology, sociology and business management (Gibson and Hartman 2014). Indeed, Bryant and Charmaz (2007) state that grounded theory is *claimed* to be the most widely used qualitative research methodology. However it is clearly evident both from the literature review (table 2.4) and my own personal experience (1.4), that many researchers

claim to use grounded theory but in fact utilise only some of the features such as coding or constant comparative method of analysis (Cutcliffe 2005).

Over the last four decades, three major approaches to grounded theory have evolved. Each of these has a differing underpinning philosophy; 'Glaserian' or classic grounded theory is underpinned by positivism (Glaser 1978,1992), Strauss and Corbin's pragmatic – symbolic interactionist approach and latterly Charmaz's constructivist interpretation of grounded theory (Charmaz 2006, 2014). All three are likely to demonstrate the key characteristics set out in Table 3.3.

Key Characteristics of grounded theory method (adapted from Charmaz 2014 pg. 7)
Simultaneous involvement in data collection and analysis
Constant comparative data analysis
Construction of codes and categories from data, not preconceived logically deduced hypotheses
Memo writing to elaborate categories, define relationships
Theoretical sampling aimed at theory construction
Theory development during data collection and analysis

Key characteristics of grounded theory method

Their differing philosophical assumptions will influence coding processes (possibly the crux of the Glaser – Strauss debate) and how the researcher either '*discovers'* or '*constructs*' theory. It is therefore, relevant, if not imperative, to disclose not just the package of methods utilised but the epistemological stance taken. This thesis expounds a constructivist grounded theory approach that includes both the methods used to collect, handle and analyse data (coding, memo-writing and constant comparative analysis) and the theoretical perspective of constructivism as proposed by (Charmaz 2014).

The terms '*constructivism*' and '*constructionism*' are used inconsistently and interchangeably in the literature. Crotty (1998) provides the following distinction; '*constructivism*' refers to the cognitive process that an individual uses to construct meaning and knowledge through interaction with the external world. Whereas '*constructionism*' puts the social dimension at the centre of meaning. The '*constructivist*' approach to grounded theory proposed by Charmaz (2014) appears to be underpinned by social '*constructionist*' epistemology. The constructivist paradigm is characterised by Guba and Lincoln (1994) as having:

> • A relativist ontology where truth, rather than being absolute, consists of multiple realities constructed by individuals in a specific time and place;

> • A subjectivist epistemology in that the interaction between the researcher and participants shapes what emerges from the investigation and knowledge is then created jointly through this interaction;

> • A hermeneutic (interpretative) methodology involving an iterative, dialectic process between all participants and the researcher where understanding can be explored by the researcher and shared with others.

Appendix 5 IRAS Approval Letter

National Research Ethics Service

NRES Committee London - Fulham

HRA NRES Centre Manchester
Barlow House
3rd Floor, 4 Minshull Street
Manchester
M1 3DZ

Telephone: ▇▇▇▇▇▇▇
Facsimile: ▇▇▇▇▇▇▇

21 May 2013

Mrs Pamela Page
Coppers, Vicarage Road
Roxwell
Chelmsford
CM1 4NY

Dear Mrs Page

Study title:	**A descriptive, qualitative appraisal of visiting experiences within adult general critical care units (AGCCUs) utilising a Grounded Theory methodology.**
REC reference:	**13/LO/0798**
IRAS project ID:	**114332**

The Proportionate Review Sub-committee of the NRES Committee London - Fulham reviewed the above application on 20 May 2013.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator, Miss Shehnaz Ishaq, nrescommittee.london-fulham@nhs.net

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, **subject to the conditions specified below.**

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC RandD office prior to the start of the study (see
"Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("RandD approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the RandD office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Other conditions specified by the REC

1.   Please provide the final letter of indemnity from City University London. This letter confirms a favourable opinion for your study, therefore the certificate/letter should be provided and submitted.

2.	Please revise the Consent Form for patients to include the following mandatory statement I understand that relevant data collected during the study, may be looked at by individuals from [company name], from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.'

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You must notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Approved documents

The documents reviewed and approved were:

Document	Version	Date
Evidence of insurance or indemnity	City University London	14 February 2013
GP/Consultant Information Sheets	1 - Patient	24 April 2013
Interview Schedules/Topic Guides	1	24 April 2013
Investigator CV	Mrs Pamela Page	
Letter of invitation to participant	1 - Nurse	24 April 2013
Letter of invitation to participant	1 - Patient	24 April 2013
Letter of invitation to participant	1 - Relative	24 April 2013
Participant Consent Form: Nurse	1	24 April 2013
Participant Consent Form: Patient	1	24 April 2013
Participant Consent Form: Relative	1	24 April 2013
Participant Information Sheet: Nurse	1	24 April 2013
Participant Information Sheet: Patient	1	24 April 2013
Participant Information Sheet: Relative	1	24 April 2013
Protocol	1	24 April 2013
REC application	3.5	08 May 2013

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

information is available at National Research Ethics Service website > After Review

13/LO/0798	**Please quote this number on all correspondence**

We are pleased to welcome researchers and R and D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

Signed on behalf of:

Dr Charles Mackworth-Young Chairman

Email: ██████████████████████████

Enclosures: List of names and professions of members who took part in the review

                         "After ethical review – guidance for researchers"

Copy to: Professor Alan Simpson – City University London
                          Dr Emma-Jane Berridge - City University London
                          Carol Cox – City University London
                          Mr Laween Al-Atroshi, Mid Essex Hospitals NHS Trust

NRES Committee London - Fulham

Attendance at PRS Sub-Committee of the REC meeting on 20 May 2013

Committee Members:

Name	Profession	Present	Notes
Dr Kanagasabai Ganeshaguru	Lay Member	Yes	
Dr Shaun Griffin	Director of Communications and Public Affairs – Human Tissue Authority – Expert Member	Yes	
Dr Charles Mackworth-Young	Physician (Chairman) – Expert Member	Yes	

Also in attendance:

Name	Position (or reason for attending)
Miss Shehnaz Ishaq	Committee Co-ordinator

Appendix 6 IRAS Approval Letter

NHS
Health Research Authority
National Research Ethics Service

NRES Committee London - Fulham

HRA NRES Centre Manchester
Barlow House
3rd Floor, 4 Minshull Street
Manchester
M1 3DZ

Telephone: ▓▓▓▓▓▓▓
Facsimile: ▓▓▓▓▓▓▓

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Other conditions specified by the REC

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4.   Please revise the Consent Form for patients to include the following mandatory statement I understand that relevant data collected during the

351

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information is available at National Research Ethics Service website > After Review

| **13/LO/0798** | **Please quote this number on all correspondence** |

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With the Committee's best wishes for the success of this project.

Yours sincerely

Signed on behalf of:

Dr Charles Mackworth-Young Chairman

Email:

Enclosures: List of names and professions of members who took part in the review

                       "After ethical review – guidance for researchers"

Copy to: Professor Alan Simpson – City University London
                  Dr Emma-Jane Berridge - City University London
                  Carol Cox – City University London
                  Mr Laween Al-Atroshi, Mid Essex Hospitals NHS Trust

NRES Committee London - Fulham

Attendance at PRS Sub-Committee of the REC meeting on 20 May 2013

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Dr Shaun Griffin	Director of Communications and Public Affairs – Human Tissue Authority – Expert Member	Yes	
Dr Charles Mackworth-Young	Physician (Chairman) – Expert Member	Yes	

Also in attendance:

Name	Position (or reason for attending)
Miss Shehnaz Ishaq	Committee Co-ordinator

returned to the patient. A further copy should be placed in the patients' notes and the original placed in the Site File.

Approval for this study is granted on the understanding that you will abide by the requirements of the Research Governance Framework issued by the Department of Health and all other relevant legislation. It is your responsibility to ensure that this project is conducted in accordance with the agreed protocol and that all storage and transfer of data complies with the Data Protection Act 1998. We would be grateful if you would ensure compliance with these instructions and the Trust R&D Operational Policy, which can be found on the Intranet.

For trials involving patients you need to be aware of Trust R&D Policy and the importance of placing a copy of the signed consent form and associated Patient Information Sheet in the patient's main NHS hospital notes. This is to ensure that other clinicians are informed about the patient's participation in the research project, together with documenting any details in the patient's main NHS hospital notes regarding specific research visits, treatments or interventions what are undertaken.

Once the study is underway you will need to keep us informed of its progress. You will be required to complete a Project Annual Status Form issued by the MEHT R&D Department. Additionally, you should be aware that you might be required to participate in the audit of compliance to the Research Governance Framework, which is undertaken in a proportion of the projects each year. Finally when your project has reached completion you will be expected to complete an R&D Project Closure Form.

You will also need to inform the MEHT R&D Department if there are any changes to personnel, the protocol or any other documentation involved in the study. If the Principal Investigator (PI) retires, leaves the Trust or abdicates responsibility for this trial there must be a clear handover to the new PI which much be communicated in writing to the R&D Department. Additionally any adverse events should be reported to the MEHT R&D Department and also via the MEHT electronic Datix system.

Furthermore, please note that any individual or members of a team intending to conduct research within MEHT, in accordance with Trust Policy and Department of Health Research Governance Framework, must have undertaken Good Clinical Practice (GCP) training. This has to be undertaken every two years.

You are reminded that failure to comply with any of the specifics detailed within this formal R&D approval letter could result in withdrawal of R&D approval. If you have any queries about any of the arrangements for this study please contact Mandy Austin, R&D Coordinator on Ext 5136, who will be happy to assist you.

This letter has been sent via email, with a read receipt requested. This will act as acceptance to the conditions outlined above, unless the R&D Department is informed of any issues with this amendment within 48 hours of receipt of this document.

We wish you every success with the project.

Yours sincerely
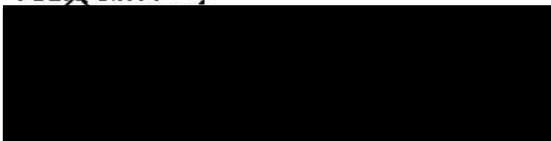
Bruce Philp and Tracey Camburn
R&D Co Directors

Cc   **Laween Al-Atroshi, Chief Research Officer**
       Hilary Bowring, Lead Nurse for Critical Care

Appendix 8 Letter of Access

Mid Essex Hospital Services **NHS**

NHS Trust

Ms Pamela Page
Faculty of Health, Social Care and Education
Anglia Ruskin University
Bishop Hall Road
Chelmsford
Essex
CM1 1SQ

25th June 2013

Dear Pam

Letter of access for research for the study *A Qualitative Appraisal of Visiting within adult critical care units*

This letter confirms your right of access to conduct research through Mid Essex Hospital Services NHS Trust for the purpose and on the terms and conditions set out below. This right of access commences on 14th June 2013 and ends on 31st May 2015 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at Mid Essex Hospital Services NHS Trust has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to Mid Essex Hospital Services NHS Trust premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through Mid Essex Hospital Services NHS Trust, you will remain accountable to your employer Anglia Ruskin University but you are required to follow the reasonable instructions of Hilary Bowring, Lead Nurse Critical Care, your research supervisor, in this NHS organisation or those given on her behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely,

Kay Rainsby
Head of HR Delivery

cc: Mandy Austin, R&D Coordinator, MEHT
      Kate Walker, HR Manager, Anglia Ruskin University

      Hilary Bowring, Lead Nurse for Critical Care MEHT

Appendix 9 Participant Information Sheet for Patients

Participant Information Sheet for Patients

A qualitative appraisal of visiting within adult critical care units.

You are being invited to take part in a research study. Before you make your decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If there is anything you are not clear about or would like more information please feel free to contact **Pamela Page** (contact details overleaf).

What is the purpose of the study?

Patients admitted to Critical Care are extremely unwell. Given that the nurse-patient-relative relationship has a central role in the care of patients, it is important that the concerns and needs of patients and families are recognised and addressed. Patients have a unique point of view of their experiences and it is hoped that by asking you directly, and listening to your experiences of being in critical care, we will get information and understanding that we may not otherwise have known. Discovering what issues were important to you will provide a better understanding of the situation so that relevant interventions might be taken by health care professionals to identify and address the needs of patients and their families within critical care.

Do I have to take part? Your participation in the study is entirely voluntary. If you decide to take part you will be given this information sheet to keep. You are under no pressure to take part and may withdraw from the study at any time without having to explain why. In the event you choose to withdraw, your interview data will be deleted. If you choose not to participate this will not influence the care you will receive.

What will happen to me if I take part?

If you agree to take part in the study, you will be interviewed about your experiences of in critical care particularly in relation to the presence of relatives. The interview is expected to last approximately one hour and will be recorded by digital recorder. It will be conducted in private and

can be stopped at any time. The interview will be arranged at a venue and time convenient for you following your discharge from hospital.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. You can also contact the researcher's supervisors (contact details below). If you remain unhappy and wish to complain formally, you can obtain advice and support from the Patient Advice and Liaison Service (pals@meht.nhs.uk). If you have any clinical concerns these should be directed to the care team as the researcher will be there in a research capacity when you discuss your experiences about the treatment.

Will my taking part in the study be kept confidential?

No other person will be present at the time of the interview and the contents of your interview will remain strictly confidential. This is to preserve your privacy and also to encourage you to speak freely about your experiences. You will not be identified on the digital recording and only the interviewer will have access to your identity. If during the interviews something was said that could indicate harm or malpractice the researcher would be bound by her professional code to disclose this. When the interview is finished, the digital recording will be numbered and kept in a locked cabinet, until its contents are typed up word for word. The recording will be listened and typed up by the researcher or an administrator. All data will be analysed by the researcher. The transcript will remain confidential and be kept in a locked cabinet at Anglia Ruskin University. All extracts will be anonymised so that you cannot be identified. All digital recordings will be stored for up to 3 years once the study is complete and then be destroyed. Any reports or publications made as a result of this study will not identify your name but may contain interview extracts.

What are the possible disadvantages and risks of taking part?

Recalling your experiences of critical care may be upsetting for you. If you become distressed, the researcher will listen to your concerns, provide additional support if required, end the interview temporarily or permanently, encourage you to contact your GP and/or support network (ICU steps or follow up clinician).

What are the possible benefits of taking part?

There are no obvious benefits to you, however we feel it is very important to find out about your experiences within critical care. It is hoped that this information will enable us to change practice and improve patient and relative experience.

Involvement of the General Practitioner/Family doctor (GP)

Version 1 REC ref [13/LO/0798]

Your GP will be informed by letter of your participation in this research with your consent.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed by the London –Fulham Research Ethics Committee.

Who is organising the research?

Pamela Page is the lead investigator and is not involved as a member of the clinical team. This research will form part of a PhD qualification with City University London.

<u>**Contact for further information**</u>

Pamela Page

Anglia Ruskin University

Bishop Hall Lane

Chelmsford

CM1 1SQ

<u>**Supervisors for Research:**</u>

Prof Alan Simpson and Dr Emma-Jane Berridge

School of Health Sciences

City University London

1 Myddleton Street

Northampton Square

London EC1V 0HB

Thank you for taking time to read this information sheet

4 copies required: top copy for researcher; one copy for patient; one copy to be sent to GP and one to be kept with research subject's medical notes.

Appendix 10 Participant Information Sheet for Relatives

CITY UNIVERSITY LONDON
EST 1894

Participant Information Sheet for Relatives

A qualitative appraisal of visiting within adult critical care units.

You are being invited to take part in a research study. Before you make your decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If there is anything you are not clear about or would like more information please feel free to contact **Pamela Page.**

What is the purpose of the study?

Patients admitted to Critical Care are extremely unwell. It is a highly stressful environment for family members visiting their loved ones. Given that the nurse-patient-relative relationship has a central role within critical care it is important that the concerns and needs of patients and their family are understood and addressed. Relatives have a unique point of view of their experiences and it is hoped that by asking you directly, and listening to your experiences of being a relative visiting a family member in critical care, we will get information and understanding that we may not otherwise have known. Discovering what issues are important to you will provide a better understanding so that relevant interventions might be taken by health care professionals to identify and address the needs of patients and their families within critical care.

Do I have to take part?

Your participation in the study is entirely voluntary. If you decide to take part you will be given this information sheet to keep. You are under no pressure to take part and may withdraw from the study at any time without having to explain why. In the event you choose to withdraw, your interview data will be deleted. If you choose not to participate this will not influence the care your relative receives.

What will happen to me if I take part?

If you agree to take part in the study, you will be interviewed about your experiences of critical care particularly in relation to the visiting your family member. The interview is expected to last approximately one hour and will be recorded by digital recorder. It will be conducted in private and can be stopped at any time. The interview will be arranged at a venue and time convenient for you.

Version 1

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. You can also contact the researcher's supervisors (contact details below). If you remain unhappy and wish to complain formally, you can obtain advice and support from the Patient Advice and Liaison Service (pals@meht.nhs.uk). If you have any clinical concerns these should be directed to the care team as the researcher will be there in a research capacity when you discuss your experiences about the treatment.

Will my taking part in the study be kept confidential?

No other person will be present at the time of the interview and the contents of your interview will remain strictly confidential. This is to preserve your privacy and also to encourage you to speak freely about your experiences of visiting the critical care unit. You will not be identified on the digital recording and only the interviewer will have access to your identity. If during the interviews something was said that could indicate harm or malpractice the researcher would be bound by her professional code to disclose this.

When the interview is finished, the digital recording will be numbered and kept in a locked cabinet, until its contents are typed up word for word. The recording will be listened and typed up by the researcher or an administrator. All data will be analysed by the researcher. The transcript will remain confidential and be kept in a locked cabinet at Anglia Ruskin University. All extracts will be anonymised so that you cannot be identified. All digital recordings will be stored for up to 3 years once the study is complete and then be destroyed. Any reports or publications made as a result of this study will not identify your name but may contain extracts from the interviews.

What are the possible disadvantages and risks of taking part?

Discussing your experiences of visiting critical care may be upsetting for you. If you become distressed, the researcher will listen to your concerns, provide additional support if required, end the interview temporarily or permanently, encourage you to contact your GP and/or support network (ICU steps or counselling service or PALS).

What are the possible benefits of taking part?

There are no obvious benefits to you. However we feel it is very important to find out about your experiences of visiting within critical care. It is hoped that this information will enable us to change practice and improve patient and relative experience.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed by the London –Fulham Research Ethics Committee.

Who is organising the research?

Pamela Page is the lead investigator and is not involved as a member of the clinical team. This research will form part of a PhD qualification with City University London.

Contact for further information   **Supervisors for Research:**

Pamela Page   Prof Alan Simpson and Dr Emma-Jane Berridge

Anglia Ruskin University   School of Health Sciences

Bishop Hall Lane   City University London

Chelmsford   1 Myddleton Street

CM1 1SQ   Northampton Square

                                     London EC1V 0HB

████████████   ████████████ ████████████

████████   ████████   ████████

Thank you for taking time to read this information sheet

2 copies required: top copy for researcher; one copy for relative

24th April 2013

Appendix 11 Participant Information Sheet for Nurses

City University London

Participant Information Sheet for Nurses

A qualitative appraisal of visiting within adult critical care units.

You are being invited to take part in a research study. Before you make your decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If there is anything you are not clear about or would like more information please feel free to contact **Pamela Page** (contact details overleaf).

What is the purpose of the study?

Patients admitted to Critical Care are extremely unwell. Given that the nurse-patient-relative relationship has a central role in the management of patients, it is important that the concerns and needs of patients and families are recognised and addressed. Critical Care nurses are exposed to the sickest patients on a daily basis together with distressed and anxious relatives. In order to provide family centred care within critical care and it is important to understand the relationship that nurses have with relatives. By listening to your experiences caring for patients and families in critical care, we will get information and understanding that we may not otherwise have known. By listening to patients, families and nurses we can identify and address the needs of patients and their families within critical care.

Do I have to take part?

Your participation in the study is entirely voluntary. If you decide to take part you will be given this information sheet to keep. You are under no pressure to take part and may withdraw from the study at any time without having to explain why. In the event you choose to withdraw, your interview data will be retained and continued to be used in this research.

What will happen to me if I take part?

If you agree to take part in the study, you will be interviewed about your experiences of nursing in critical care particularly in relation relatives visiting. The interview is expected to last approximately one hour and will be recorded by digital recorder. It will be conducted in private and can be stopped at any time. The interview will be arranged at a venue and time convenient

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for you. A transcript of your interview will be sent to you so that you may check that it is a true reflection of what was said. A stamp addressed envelope will be provided to send this back in the post.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. You can also contact the researcher's supervisors (contact details below). If you have any clinical concerns these should be directed to the care team as the researcher will be there in a research capacity when you discuss your experiences.

Will my taking part in the study be kept confidential?

No other person will be present at the time of the interview and the contents of your interview will remain strictly confidential. This is to preserve your privacy and also to encourage you to speak freely about your experiences about the treatment. You will not be identified on the digital recording and only the interviewer will have access to your identity. If during the interviews something was said that could indicate harm or malpractice the researcher would be bound by her professional code to disclose this. When the interview is finished, the digital recording will be numbered and kept in a locked cabinet, until its contents are typed up word for word. The recording will be listened and typed up by the researcher or an administrator. All data will be analysed by the researcher. The transcript will remain confidential and be kept in a locked cabinet at Anglia Ruskin University. Extracts from participants' interviews may be used when the researcher interviews nurses about their experiences visiting in critical care. All extracts will be anonymised so that you cannot be identified. All digital recordings will be stored for up to 3 years once the study is complete and then be destroyed. Any reports or publications made as a result of this study will not identify your name.

What are the possible disadvantages and risks of taking part?

Working within critical care can be stressful. If you become distressed, the researcher will listen to your concerns, provide additional support if required, end the interview temporarily or permanently, encourage you to contact your GP and/or support network (in-house counseling service or occupational health).

What are the possible benefits of taking part?

There are no obvious benefits to you. However we feel it is very important to find out about the effects of visiting within critical care. It is hoped that this information will enable us to change practice and improve patient and carer experience.

24th April 2013

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed by the London –Fulham Research Ethics Committee.

Who is organising the research?

Pamela Page is the lead investigator and is not involved as a member of the clinical team. This research will form part of a PhD qualification with City University London.

Contact for further information	**Supervisors for Research:**
Pamela Page	Prof Alan Simpson and Dr Emma-Jane Berridge
Anglia Ruskin University	School of Health Sciences
Bishop Hall Lane	City University London
Chelmsford	1 Myddleton Street
CM1 1SQ	Northampton Square
	London EC1V 0HB

Thank you for taking time to read this information sheet

2 copies required: one copy for researcher; one copy for nurse;

Appendix 12 Letter to patient

CITY UNIVERSITY
LONDON

EST 1894

Pamela Page

PhD student

City University London

1 Myddleton Street

Northampton Square

London

EC1V 0HB

Tel. ▓▓▓▓▓▓▓▓▓▓

Email ▓▓▓▓▓▓▓▓▓▓▓▓▓▓

24th April 2013

Dear Mr/s [Surname]

Research Title: A qualitative appraisal of visiting within adult critical care units.

You are being invited to take part in a research study. Before you make your decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the enclosed Participant Information Sheet. If there is anything you are not clear about, or would like more information, please feel free to contact me (use above contact details).

If you would like to participate in this research, you can contact me by telephone or email or complete the attached response form and return in the stamped addressed envelope. Following agreement to be interviewed I will arrange a time, date and venue convenient for us to meet.

As a patient who has been critically ill you may be able to help us understand the role that relatives visiting have in terms of your wellbeing. A Participant Information Sheet is enclosed. It is hoped that by asking you directly and listening to your experiences whilst being a patient in critical care, I will get information and understanding that may not otherwise have been known.

Written consent will be obtained immediately before the interview.

Thank-you for taking the time to consider participating in this research.

Version 1 REC Ref [13/LO/0798]

Yours sincerely

Pamela Page

RESPONSE FORM

Title of Project:. A qualitative appraisal of visiting within adult critical care units.

Name of Lead Investigator: Pamela Page

Please tick which boxes apply to you:

1. I, as a patient previously admitted to critical care would like to participate in the research.

2. I, a patient previously admitted to critical care would not like to participate in the research.

Name:

Contact Details (including Telephone Number):

Version 1 REC Ref [13/LO/0798]

Appendix 13 Letter to relative

CITY UNIVERSITY LONDON

EST 1894

Pamela Page

PhD student

City University London

1 Myddleton Street

London

EC1V 0HB

Tel. ███████████

Email ████████████████

24th April 2013

Dear Mr/s [Surname]

Research Title: A qualitative appraisal of visiting within adult critical care units.

You are being invited to take part in a research study. Before you make your decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the enclosed Participant Information Sheet. If there is anything you are not clear about, or would like more information, please feel free to contact me (use above contact details).

If you would like to participate in this research, you can contact me by telephone or email or complete the attached response form and return in the stamped addressed envelope. Following agreement to be interviewed I will arrange a time, date and venue convenient for us to meet.

As a relative visiting an adult critical care unit you may be able to help us understand the experience of visiting a loved one who is critically ill. A Participant Information Sheet is enclosed. It is hoped that by asking you directly and listening to your experiences of visiting within critical care I will get information and understanding that may not otherwise have been known. Written consent will be obtained immediately before the interview.

Thank-you for taking the time to consider participating in this research.

Yours sincerely

Pamela Page

Version 1 REC ref [13/LO/0798]

RESPONSE FORM

Title of Project:. A qualitative appraisal of visiting within adult critical care units.

Name of Lead Investigator: Pamela Page

Please tick which boxes apply to you:

1. I, a relative visiting within critical care would like to participate in the research.

2. I, a relative visiting in critical care would not like to participate in the research.

Name:

Contact Details (including Telephone Number):

Version 1 REC ref [13/LO/0798]

Appendix 14 Letter to nurse

Pamela Page

PhD student

City University London

1Myddleton Street

Northampton Square

London

EC1V 0HB

Tel. █████████████

Email █████████████████

24th April 2013

Dear Mr/s [Surname]

Research Title: A qualitative appraisal of visiting within adult critical care units.

You are being invited to take part in a research study. Before you make your decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the enclosed Participant Information Sheet. If there is anything you are not clear about, or would like more information, please feel free to contact me (use above contact details).

If you would like to participate in this research, you can contact me by telephone or email or complete the attached response form and return in the stamped addressed envelope. Following agreement to be interviewed I will arrange a time, date and venue convenient for us to meet.

As a nurse working within an adult critical care unit you may be able to help us understand the role that relatives have in terms of patient's wellbeing. A Participant Information Sheet is enclosed. It is hoped that by asking you directly and listening to your experiences of relatives visiting critical care I will get information and understanding that may not otherwise have been known. Written consent will be obtained immediately before the interview.

Thank-you for taking the time to consider participating in this research.

Yours sincerely

Pamela Page

RESPONSE FORM

Title of Project:. A qualitative appraisal of visiting within adult critical care units.

Name of Lead Investigator: Pamela Page

Please tick which boxes apply to you:

1. I, a nurse working within critical care would like to participate in the research.

2. I, a nurse working in critical care I would not like to participate in the research.

Name:

Contact Details (including Telephone Number):

Appendix 15 Consent Form for Patient

CITY UNIVERSITY LONDON

EST 1894

REC Reference Number: [13/LO/0798]

Title of Project: **A qualitative appraisal of visiting within adult critical care units.**

Name of Lead Investigator: Pamela Page

Please initial box

1. I confirm that I have read and understand the information sheet dated 24th April 2013 for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw   at any time, without giving any reason, without my medical care or legal rights being affected.

3.   I agree to the interview being recorded.

4.   I agree to my GP being informed of my participation in the research.

5.   I understand that relevant data collected during the study, may be looked at by individuals from City University London, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.

6.   I agree that anonymous unattributed quotes may be used within the PhD thesis, publications and presentations.

7.   I agree to take part in the above study.

_____   _____
  Name of Research Subject   Date   Signature

(Please print)

_____   _____
  Name of Research Team member   Date   Signature

(Please print)

3 copies required: top copy for researcher; one copy for patient; one copy to be kept with research subject's
medical note

Appendix 16 Consent Form for relative

CITY UNIVERSITY LONDON
EST 1894

REC Reference Number: [13/LO/0798]

Title of Project: **A qualitative appraisal of visiting within adult critical care units.**

Name of Lead Investigator: Pamela Page

Please initial box

1 I confirm that I have read and understand the information sheet dated 24th April 2013 for the above study and have had the opportunity to ask questions.

2 I understand that my participation is voluntary and that I am free to withdraw   at any time, without giving any reason, without my legal rights being affected.

2   I agree to the interview being recorded.

4 I am aware that the study may be audited by Mid Essex Hospital NHS Trust or other professional bodies (if required).

3   I agree that anonymous, unattributed quotes may be used within the PhD thesis, publications and presentations.

4   I agree to take part in the above study.

_____   _____

 Name of Research Subject   Date   Signature

(Please print)

_____   _____

Name of Research Team member   Date   Signature

(Please print)

2 copies required: top copy for researcher; one copy for relative;

*4. This is not a requirement for participation.

Appendix 17 Consent Form for Registered Nurse

CITY UNIVERSITY LONDON
EST 1894

REC Reference Number: [13/LO/0798]

Title of Project: **A qualitative appraisal of visiting within adult critical care units.**

Name of Lead Investigator: Pamela Page

Please initial box

1   I confirm that I have read and understand the information sheet dated 24th April 2013 for the above study and have had the opportunity to ask questions.

2   I understand that my participation is voluntary and that I am free to withdraw   at any time, without giving any reason, without my legal rights being affected.

3   I agree to the interview being recorded.

4   I am aware that the study may be audited by Mid Essex Hospital NHS Trust or other professional bodies (if required).

5   I agree that anonymous, unattributed quotes may be used within the PhD thesis, publications and presentations.

6   I agree to take part in the above study.

_____   _____
 Name of Research Subject   Date   Signature

(Please print)

_____   _____
 Name of Research Team member   Date   Signature

(Please print)

Appendix 18 Prompts and Probes

A qualitative appraisal of visiting within adult critical care units.

Examples of trigger questions for participants, including prompts and probes;-

Phase one

Relatives

- Can you tell me what it is like for visiting ....in critical care?

- What recollections do you have of your first visit?

- How are you coping with the situation?

- How are you getting information about....?

- What has been the most anxious time for you?

Patients

-Can you tell me what you can remember from your stay in critical care?

- Did you have any visitors?

- Do you have any recollections of visitors?

- How did visitors affect your time in critical care?

- How would you describe your experience in critical care? Or transfer to the ward? On discharge home?

- How is your recovery?

Phase two

Nurses

-Can you tell me about your experiences of working in critical care?

- What brought you into critical care nursing?

- What do you consider the needs of family members to be?

- What do you think are the major challenges our emergency admission patients face?

- How are patients and family members prepared for discharge from critical care?

- Do you hear how patients are doing post discharge from critical care?

- Do you get involved in follow up?

- What are you views on visiting?

- How do you assess for delirium?

- How do you find your working environment?

- Do you provide any written information to patients or families on discharge from critical care?

<u>Closure</u>

We have talked about………..is there anything else you would like to talk about?

Maybe something I haven't asked but is really important to you to talk about?

Do you have any questions for me?

Thank-you for your time and sharing your experience with me

Appendix 19 Gantt Chart

ID	Task Name	Start	Finish	Duration
1	Enrolment & subsequent registration on to MPhil pathway with intention to upgrade to PhD	03/09/2012	12/10/2012	30d
2	Groundwork including preliminary literature review	12/10/2012	12/12/2012	44d
3	Completion of research proposal	27/09/2012	27/06/2013	196d
4	Prepare Protocol for ethical approval	04/01/2013	27/06/2013	125d
5	Subject to ethical approval gain access to research participants	02/09/2013	27/03/2015	410d
6	Methodology & Methods chapter	09/01/2015	08/05/2015	86d
7	Literature review	12/01/2015	19/05/2015	92d
8	Undertake interviews –transcription & memo writing	17/09/2013	27/01/2015	356d
9	Concurrent data analysis and coding together with memo writing	17/09/2013	27/03/2015	399d
10	Prepare for upgrade to PhD (publication & presentation)	15/01/2015	10/07/2015	127d
11	Further interviews if required	13/07/2015	29/12/2015	122d
12	Checking for saturation	05/01/2015	10/08/2015	156d
13	Constructing and reconstructing theory	17/05/2013	01/12/2015	663d
14	Early drafts	03/04/2015	28/08/2015	106d
15	Writing up	03/06/2013	30/06/2016	804d
16	Submission September 2016	01/09/2016	01/09/2016	1d
17	Viva	01/12/2016	01/12/2016	1d