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# A HERMENEUTIC PHENOMENOLOGICAL INQUIRY INTO THE LIFE-WORLD OF AN ALTERED STATE OF CONSCIOUSNESS SECONDARY TO ACQUIRED BRAIN INJURY.

**Thesis submitted in partial fulfilment of the requirements for the**

**Degree of Doctor of Philosophy (Nursing)**

**Alison Ruth Buckley**

**January 2022**

**University of**

**Cumbria**

**Word Count: 94,888**

***‘If you don’t know what is wrong with a person, ask him, he may tell you’***

(George Kelly, 1955)

Alison Ruth Buckley University of Cumbria January 2022

Thesis submitted in partial fulfilment of the requirements for the Degree of
Doctor of Philosophy (Nursing)

## ABSTRACT

**Title:** A Hermeneutic Phenomenological Inquiry into the Life-World of an Altered State of Consciousness (ASC) secondary to Acquired Brain Injury (ABI).

**Aim:** To explore the construction and interpretation of meaning of a transitory period of an altered state of consciousness (ASC) in the immediacy of the acute phase of the acquired brain injury (ABI) trajectory in the inpatient, hospital setting from the perspective of the patient and the layperson witness.

**Background:** In the immediacy of the acute phase of the ABI trajectory, the patient presents with clinical neurological sequelae which may result in a transitory period of altered consciousness. Whilst they may return to personal and situational awareness, and orientation, there is a paucity of empirical data which has constructed the meaning of the phenomenon of ASC from the perspective of the patient and the layperson witness.

**Research Design:** The philosophical legacies of Heidegger, Gadamer, Van Manen and Merleau-Ponty, informed the hermeneutic phenomenological study design. Ethical approval was granted by the University of Cumbria.

**Method**: Following discharge from inpatient services, ten participants who self-reported a transitory period of an ASC secondary to an ABI, and eight who were present as the layperson witness were recruited from a United Kingdom charitable organisation. Data collection was conducted via a combination of individual and shared, in-depth semi-structured interviews, to capture first-person accounts of the hermeneutics of the phenomenon of ASC.

**Findings:** The meaning of the phenomenon of an ASC was constructed based upon identification of the existential life-world structures: *spatiality, corporeality, temporality, relationality,* and *discourse*. These life-world experiences independently and collectively influenced participants' perceptions and sense-making regarding the recognition and recovery of the patient's 'self', identity, and personhood along a '*Quest Trajectory'*. This trajectory situated participants between one of two, diametrically opposed narrative positions, defined as '*chaos*' or '*restitution*'. Throughout the '*Quest Trajectory'*, the patient's pre-injury, 'legacy self' was searched for, and privileged. The construction of the patient’s ‘self’, identity and personhood was not solely determined by the pathological changes associated with an ABI but constructed throughout the complex and formative trajectory of ASC.

**Conclusion:** For the participants of this inquiry, the meaning of the phenomenon of ASC is represented by a conceptual model, entitled ‘The Phenomenological Life-World of an Altered State of Consciousness secondary to Acquired Brain Injury: *The Quest Trajectory’*. Understanding the narrative threads which construct the autobiographical experience of an ASC, offers a unique and original contribution to the epistemology of the ABI in the inpatient, hospital setting. The findings of this inquiry have implications for practice, education, and research in the field of clinical neurosciences.

## PUBLIC OUTPUT

### Publications

Barrow, R., Mee, S., Corless, L., and Buckley, A. (2016) ‘Patient Narratives: Defining Patient Boundaries’, *Nursing Times,* 112(16), pp. 18-19.

Buckley, A.R., Corless, l., and Mee, S. (2016) ‘Patient Narratives: Using patent stories to reflect on care’, *Nursing Times,* 112(10), pp. 22-25.

Buckley, A., Corless, L., and Mee, S. (2016) ‘Patient Narratives: Providing Empathetic Care in Nursing Practice, *Nursing Times,* 112(15), pp. 22-23.

Corless, L., Mee, S., and Buckley, A.R. (2016) ‘Patient Narratives: Power Inequality between Patients and Nurses’, *Nursing Times*, 112(12), pp. 12-13.

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Mee, S., Buckley, A.R., and Corless, L. (2016) ‘Patient Narratives: The Meaning behind Communication, *Nursing Times,* 112(14), pp. 22-23.

Nixon, J., Buckley, A., Cheng, A., Dymoke, S., Spiro, J., and Vincent, J. (2016) ‘The ‘Questionableness’ of Things: Opening up the Conversation’. In: McNiff, J. (ed) *Values and Virtues in Higher Education Research: Critical Perspectives*. Routledge, Taylor and Francis, London, pp. 110-125.

Phillips, H., Maw, H., Mee, S., Buckley, A., and Corless, L. (2016) Patient Narratives: How Narratives can Change Nursing Practice, *Nursing Times,* 112(17), pp. 18-20.

### Peer Reviewed Conference Presentations

Third International Conference on Value and Virtue in Practice-Based Research: Influencing Policy Through Enhancing Professionalism, St John University, York. July 2013, *‘Exploring Memories of Acute Confusional State following Intracerebral Haemorrhage: A Patient Narrative’.*

Fourth International Conference on Value and Virtue in Practice-Based Research: Openness and Criticality - Evaluating and Publishing Our Research. St John University, York. July 2014, ‘*Situating Oneself in Narrative Inquiry: A Challenge for the Health Care Practitioner’* (Pre- Conference Seminar Paper)

Fourth International Conference on Value and Virtue in Practice-Based Research: Openness and Criticality - Evaluating and Publishing Our Research. St John University, York. July 2014, ‘*Situating Oneself in Narrative Inquiry: A Challenge for the Health Care*

*Practitioner'*. (Paper)

Post-Graduate Conference, Lancaster University. April 2015, '*Methodological Challenges in Narrative Inquiry: The Illness –Recovery Trajectory'*. (Poster)

Fifth International Conference on Value and Virtue in Practice-Based Research: The Significance of Our Research: Influence and Impact. St John York University, York. July 2015, '*They used to thump the patients, they used to drag 'em'*: *The Impact of the Voice of Experts by Experience in Higher Education'* (Paper)

Doctoral Colloquium, University of Cumbria. July 2015, '*Methodological Challenges in Narrative Inquiry: The Illness –Recovery Trajectory* (Poster)

Post-Graduate Conference, Lancaster University. April 2017, *'Hermeneutic Narrative Inquiry & Moral protection: An Emotional Business'* (Poster)

Doctoral Colloquium, University of Cumbria. July 2017, *'Narrative Inquiry & Moral Protection: An Emotional Business'* (Paper)

Doctoral Colloquium, University of Cumbria. July 2017, *'Hermeneutic Narrative Inquiry and Moral Protection'* (Poster)

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## ACKNOWLEDGEMENTS

First and foremost, I would like to thank the participants of the study for their courage, honesty, and willingness to share their stories. As a practitioner, I have always believed in the power and utility of the illness narrative and hope that in being entrusted with their memories, I have done their stories justice and inspired professionals to privilege the art of listening.

I have been afforded a privileged and personal insight into the meaning of the life-world of an 'Altered State of Consciousness' as sequela to Acquired Brain Injury and am sincerely grateful that the participants shared such meaningful and honest narratives of a formative time in their life histories.

My heartfelt thanks go to Dr Steve Mee who inspired me to value the profound messages which are portrayed through stories of health and illness and encouraged me to begin this journey. I am indebted to my supervisors, Dr Helen Wilby and Dr Tilly Reid, for their patience, support, and unfailing commitment to my work. Your scrutiny has rightly challenged me throughout this journey, not least to develop authority in my writing and have confidence in my ability.

Thank you to the UK national charity and the regional Chairs who support individuals following Acquired Brain Injury. Thank you for embracing my work and affording me the opportunity to work with your members. I am truly grateful to you all, for your energy, commitment, and advocacy you offer those affected by brain injury.

I would like to thank my family and friends for their encouragement throughout this journey and apologise for times when I have declined your social invitations!

Finally, thank you Roy, for showing me how personal stories of illness can shape and inform practice in ways that biomedical text cannot. You enriched my practice both as a nurse and educator in ways you will never know. I remember the occasion when, at a formative time in your illness journey, your simple request for ice in your water was ignored, and when a nurse tried to justify your move to another hospital ward by '*we need your bed for a really poorly patient'.* You had just received a life-limiting diagnosis. Her insensitivity and ill-considered manner will remain with me forever.

As healthcare practitioners, we hold privileged positions and should never forget that the *'little things'* revealed through personal stories, truly matter to those who are entrusted in our care.

With fond memories of a gracious, wonderful, and gentle man. Your story encouraged me to more than simply listen to autobiographies of illness but strive to hear and share the profound messages these stories hold.

## DECLARATION OF AUTHORSHIP

1. I, Alison Ruth Buckley declares that this thesis is my own work and has not been submitted in substantially the same form for the award of a higher degree elsewhere.

2. Aspects of text within sections 3.5.1 and 3.5.2 are reproduced verbatim with kind permission of The Licensor through PLSclear (Licence granted 22.9.21) Buckley, A.R (2016), cited in Nixon, J., Buckley, A.R, Cheng, A., Dymoke, S., Spiro, J., and Vincent, J (2016) 'The Questionableness of Things'. Cited in, McNiff, J (2016) (ed) *Values and Virtues in Higher Education.* London, Routledge, Taylor and Francis Group, pp. 118-120.

## ORGANISATION OF THESIS

The thesis is organised over seven chapters.

Chapter One orientates the reader to the aim of the inquiry and provides an overview of the spectrum of disorders of consciousness and the ensuing synonymic challenge in defining and clarifying the diagnosis and presentations of levels of consciousness. The aim of the study is contextualised with reference to the existing body of evidence relating to the phenomenon of an 'Altered State of Consciousness' (ASC), as a neurological sequela of an Acquired Brain Injury (ABI).

Chapter Two takes its point of reference from a scoping review of the empirical and theoretical literature which explores the lived experience of an ASC independent of the pathological cause, from the perspective of the patient, layperson, and healthcare professional. The discussion develops with a critical review of the utility of the illness narrative and its associated trajectory and provides a discussion of narrative typologies. The potential for an ABI to affect an individual's sense of identity, self, and personhood in the acute phase of care and upon discharge from services is considered. The chapter is summarised by highlighting the methodological gaps relating to the phenomenon of ASC in the context of the post-injury, ABI trajectory, and identifying the research aim and questions.

Chapter Three presents a critical discourse of the philosophical and historical influences of hermeneutic phenomenology and defends its adoption as the methodology for this empirical inquiry. The philosophical life-world approach to the meaning and construction of illness is presented along with a reflexive discourse of my positioning as the researcher with a historical background and fore-groundings as a nurse.

Chapter Four presents the study design and methods which grounded the tenure of the study, provides a critical debate and exposition of the ethical challenges, defines the participant sample, the conduct of the interview, and the philosophical approach and procedural steps to hermeneutic data analysis.

In Chapter Five, the findings of the study are presented in the context of the '*meaning structures*', which independently and collectively, emerged as influencers on the construction and interpretation of the meaning of the lived experience of the life-world of ASC from the perspectives of both participant groups. The verbatim narratives of the participants support the presentation of findings.

Chapter Six analyses the findings of the study, with reference to the extant empirical and theoretical literature. The discussion is structured by addressing each of the emerging life-world '*meaning structures'*, from the perspective of both participant groups, considers the inter-subjectivity of the phenomenon of ASC, and influence of ASC on the recognition and potential transformation of the patient's pre-injury, 'legacy self'.

Chapter Seven presents a critical discourse of the study's findings as an original contribution to knowledge. The development of a model which conceptualises the life-world of the phenomenon of ASC, defined as 'The Phenomenological Life-World of an Altered State of Consciousness secondary to Acquired Brain Injury*: The Quest Trajectory'* is presented. The inquiry's limitations of method, recommendations for practice, education, and research in clinical neurosciences, and the dissemination plan and pathway to impact are considered.

## GLOSSARY OF TERMS & ABBREVIATIONS

| | |
|---|---|
| Acquired Brain Injury (ABI) | '*ABI is an umbrella term, encompassing a wide spectrum of brain injuries that generally includes traumatic and non-traumatic aetiologies such as cerebral concussion, brain contusions, subarachnoid haemorrhage or other acquired problems'* (Teasell *et al*., 2007, p. 107). |
| Coma | Defined as a '*state of unrousable unresponsiveness, lasting more than six hours in which a person is unconscious and cannot be awakened, fails to respond normally to painful stimuli, light or sound, lacks a normal sleep-wakefulness cycle and does not initiate voluntary actions'* (Royal College of Physicians, 2020, p. 25). |
| Critical Care Unit / Intensive Care Unit | An inpatient, hospital setting which admits patients with critical care needs. Referred throughout the thesis as the 'Intensive Care Unit' and abbreviated as the 'ICU' |
| Delirium | '*Delirium is characterised by disturbed attention (ie. reduced ability to direct, focus, sustain, and shift attention) and awareness (ie. reduced orientation to the environment) that develops over a short period of time and tends to fluctuate during the course of a day, accompanied by other cognitive impairment such as memory deficit, disorientation, or impairment in language, visuospatial ability, or perception. Disturbance of the sleep-wake cycle (reduced arousal of acute onset or total sleep loss with reversal of the sleep-wake cycle) may also be present. The symptoms are attributable to a disorder or disease not classified under mental and behavioural disorders or to substance intoxication or withdrawal or to a medication'* (World Health Organisation, 2018). |
| Delusion | '*A delusion is a belief that is clearly false and that indicates an abnormality in the affected person's content of thought'* (Kiran and Chaudhury, 2009, p. 3) |
| Disorder of Conscious | A state in which normal consciousness is disordered. May be defined as a temporary or prolonged state. Abbreviated as DOC. |

| | |
|---|---|
| Hallucination | *'A perception in the absence of external stimulus, that has qualities of real perception. Hallucinations are vivid, substantial, and are seen to be located in external objective space. A disorder characterised by a false sensory perception in the absence of an external stimulus. Hallucinations can be caused by nervous system disease, certain drugs or mental disorders'* (ICD-10-CM, World Health Organisation, 2014). |
| Illusion | *'A perceptual experience(s) in which information arising from 'real' external stimuli leads to an incorrect perception or false impression of the object or event from which the stimulation occurs'* (West, 2017). |
| Layperson, Bedside Witness | In the context of this inquiry, the '*layperson, bedside witness'* is the spouse, relative, friend or significant other of an individual who is admitted to the acute, inpatient hospital facility following an Acquired Brain Injury (ABI).<br>Because of the nature of their relationship, they were witness to, and able to provide testimony of the individual's transitory period in an Altered State of Consciousness (ASC), during the acute phase of the ABI trajectory. The individual will be defined through the inquiry as the 'witness *of-ASC'* |
| 'Legacy Self' | Conceptualises the recognisable character, personality traits, and behaviours of the patient's self, identity, and personhood prior to the Acquired Brain Injury |
| Patient | An individual who is admitted to the inpatient hospital setting and is in receipt of care |
| Post-Traumatic Confusion (PTC) | 'A *transient organic mental syndrome with acute onset characterised by a global impairment of cognitive functions with a concurrent disturbance of consciousness, attentional abnormalities, reduced or increased psychomotor activities and a disrupted sleep/wakefulness cycle'* (Stuss *et al.*, 1999, p. 640). Abbreviated as PTC. |
| Professional | An individual who by virtue of experience, training and education is employed within the inpatient, hospital setting.<br>In the context of this inquiry, unless otherwise stated, the discipline to which the professional belongs is not identified. |
| Prolonged Disorder of Consciousness (PDOC) | Characterised by one of two clinical presentations:<br>'Vegetative State' (VS): '*A state of wakefulness without awareness in which there is preserved capacity for spontaneous or stimulus-induced* |

| | |
|---|---|
| | *arousal, evidenced by sleep–wake cycles and a range of reflexive and spontaneous behaviours. VS is characterised by absence of behavioural evidence for self or environmental awareness'*.<br>Minimally Conscious State (MCS): '*A state of severely altered consciousness in which minimal but clearly discernible behavioural evidence of self or environmental awareness is demonstrated. MCS is characterised by inconsistent, but reproducible responses above the level of spontaneous or reflexive behaviour, which indicate some degree of interaction with their surroundings*.'<br>(Royal College of Physicians, 2020, p. 24) |
| Sequela(e) | '*A condition(s) which is the consequence of disease or illness*' (Oxford English Dictionary). |

# CHAPTER ONE: BACKGROUND and CONTEXT OF THE STUDY

## 1.1 Orientation to the Research

> ***'To ask a question means to bring into the open. The openness of what is in question consists in the fact that the answer is not settled'.***
>
> **(Gadamer, 2004, p. 392)**

An 'Acquired Brain Injury' (ABI) is defined as a neurological insult to the brain resulting directly from trauma, neuropathology, metabolic, toxic, or hypoxic injury (Teasell *et al.,* 2007; Royal College of Physicians, 2020; Sherry, 2006). Analysis of Hospital Episode Statistics (NHS Digital, 2017) for England and datasets from elsewhere in the UK (Headway, 2016-17) reported that 348,453 adults, representative of an incidence rate of 543 per 100,000 of the population, were admitted to hospital with a primary diagnosis of an ABI.

Secondary to a diagnosis of an ABI, patients admitted to the inpatient, hospital facility are likely to present with a disorder of consciousness (Godbolt *et al.*, 2013; Keelan *et al*., 2019; Kim *et al*., 2007; Stuss *et al*., 1999) and varying degrees of cognitive, neuro-behavioural, and functional impairments (Giacino *et al*., 2014; Ommaya and Gennarelli, 1974; Rabinouitz and Levin, 2014). Functional and cognitive neurological sequelae along with the associated clinical presentations are variable, with recovery reflective of the underlying neuropathology and the severity of neuronal injury sustained at the time of the insult (Bigler, 2019; Hilton, 2005; Wu *et al*., 2015).

Whilst recovery may be realised and the patient returns to a world of personal and situational awareness and orientation, there is a paucity of empirical data which seeks to understand the first-person meaning of an individual's lived-through experiences during a disorder of consciousness (DOC), as they become unexpectedly embroiled in the complex trajectory of an ABI within the acute inpatient clinical setting.

## 1.2 Situating the Study: A Professional and Personal Reflection

The professional and personal motivations for this inquiry evolved from my clinical experience in neuroscience nursing practice and subsequent work in Higher Education. Frank's (1995) '*Wounded Storyteller'*, and the works of Charon (2006) and Sacks (2012, 2015) captured my imagination. These seminal text privilege the utility and influence of the illness narrative, and challenge those embedded in positivistic medical discourse to think differently about stories of health and illness.

As an educator, involvement with one person was formative in challenging my view of the subjective experience of someone whose level of consciousness is transiently impaired. I invited her to share her experiences with a group of pre-registration nursing students. 15 years after a spontaneous intracerebral haemorrhage, her memories remained profound. The poignancy of her story engaged us, as she recounted florid hallucinations, illusions, and perceptual disturbances, admitting that whilst she had recovered functionally, she continued to struggle to reconcile her experiences. Her distress was palpable as she recalled how, within the hallucinogenic and illusional landscape, familiar characters and family members morphed into sinister mythical beings who tried to communicate with her. She found herself residing in a dark, lonely, and uncompromising reality, which left her feeling paranoid and vulnerable. She also described her mother's distress. Seated at the bedside she had been witness to her daughter's paranoia, childlike behaviours, random communication, and the seemingly nonchalant and uncharacteristic way she engaged with others.

Following her visit, I reflected on the occasions I had supported patients following an ABI within the acute, inpatient clinical setting. I was of the initial and somewhat naive view that patients whose level of consciousness is transiently impaired would be unable to recall memories of this time once lucid, or if reminiscence was to be encouraged, it was potentially maleficent or futile. Listening to her account was a defining experience for me. I had never thought to enquire as to a patient's experience on emergence, nor recognised that a patient's trajectory through illness, and particularly during a period of compromised consciousness would, on discharge, continue to hold such a defining *'central role in their larger life story'* (Haidet, Kroll and Sharf, 2006, p. 325).

As a practitioner, I had adopted Husserl's philosophical position of the '*natural attitude'* (Husserl, 1970, 1980; Moran and Mooney, 2002, p. 5), a taken-for-granted, pre-reflexive understanding (Dahlberg, Drew and Nyström, 2001; Van Manen, 1990) of the patient's experience of illness. On reflection, I had privileged the clinical, diagnostic assessment of consciousness through objective measurements and focused on the therapeutic efficacy of management strategies, rather than acknowledging the potential and transformative nature of the lived experience. Her narrative left me questioning how a sudden and unexpected state of disordered consciousness is qualitatively lived through, as a transitory yet seminal interruption in one's life trajectory. Van Manen's (1990, p. 8) definition of phenomenological inquiry resonated with me, in that phenomenology makes us '*thoughtfully aware of the consequential in the inconsequential, the significant in the taken-for-granted'.*

### 1.3 Definition of Terms: Disorders of Consciousness - A Synonymic Challenge

Historically, there has been a lack of consensus in explicating the nature of consciousness, with philosophers, scientists and clinicians proposing varied definitions and positions. However, there is broad consensus that consciousness fundamentally comprises two dimensions, *'wakefulness'* and '*awareness'* (Posner *et al*., 2007; Royal College of Physicians, 2020; Zeman, 2001).

Structural, toxic, or metabolic injury to the Reticular Activating System and its afferent projections to the cerebral cortex and thalamus are known to influence an individual's state of consciousness, resulting in coma, defined as '*a pathological state of eyes-closed unresponsiveness in which the patient lacks both wakefulness and awareness'* (Bernat, 2006, p. 1181). A 'Disorder of Consciousness' (DOC), with coma being one example, is clinically categorised by the degree to which an individual demonstrates arousal or alertness, cyclical wakefulness, behavioural evidence of an individual's awareness of self and their environment, along with other qualitative clinical findings (Royal College of Physicians, 2020). True coma rarely persists for longer than a month following onset, after which the individual either regains awareness or is diagnosed with one of two Prolonged Disorders of Consciousness (PDOC): Permanent Vegetative State (PVS) and Minimally Conscious State (MCS) (Bernat, 2006; Royal College of Physicians, 2020). The criterion for diagnosis and the repertoire of neurological presentations seen with a PDOC have been debated and refined over time (Edgar, Kitzinger, and Kitzinger, 2014; Royal College of Physicians, 2020). In brief, 'Persistent Vegetative State', was originally defined by The Multi-Society Taskforce in 1994 and redefined as 'Unresponsive Wakefulness Syndrome' by the European Taskforce on Disorders of Consciousness (Laureys *et al*., 2010) because of clinical disquiet about the pejorative term 'vegetative'. However, a review by the Royal College of Physicians (2020) has retained the term, 'Vegetative State' (VS), for the present. Patients diagnosed with VS present in a '*state of wakefulness without awareness*' with '*spontaneous or stimulus-induced arousal'* (Royal College of Physicians, 2020, p. 25).

Patients may recover from VS and progress to a Minimally Responsive or Minimally Conscious State (MCS) (Royal College of Physicians, 2020), defined as a '*severely altered consciousness in which minimal but definite behavioural evidence of self or environmental awareness is demonstrated*' (Giacino *et al.,* 2002, p. 350). Although debate continues as to the characterisation of emergence from MCS, it is indicated by variable yet increasing conscious awareness with evidence of personal and situational orientation (Bodien *et al.,* 2020; Giacino and Kalmar, 1997; Giacino *et al.,* 2002; Giacino *et al*., 2014; Laureys, Owen and Schiff, 2004; Laureys and Boli, 2008; Nakase-Richardson *et al.,* 2009; Taylor *et al.,* 2007).

In the immediacy of the post-ABI injury trajectory, individuals may present with fluctuating patterns of disorientation, confusion and cognitive limitations, with attentional deficits and disturbances in perception and consciousness. This constellation of symptoms was collectively defined by Russell in 1932 as 'Post-Traumatic Amnesia' (PTA). However, Stuss *et al*., (1999) redefined the syndrome as 'Post-Traumatic Confusional State (PTCS), to reflect clinical presentation more accurately.

To further complicate the diagnostic picture, delirium is another categorisation of an acute, yet reversible disturbance of consciousness which manifests as confusion, attentional deficits, perceptual and cognitive changes (American and Psychiatric Association, 1994; World Health Organisation ICD-11, 2018). Delirium is acknowledged as the most prevalent cause of cognitive dysfunction in the hospitalised patient (Bergeron *et al*., 2001; Ely, Siegel, and Inouye, 2001a; Meagher *et al*., 1998; Rood *et al.*, 2018) affecting 11-87% of critically ill adults admitted to ICU (Aldemir *et al*., 2001; Ely *et al*., 2001b; Ely *et al.*, 2001c; Ouimet *et al.*, 2007; Rood *et al.*, 2018; Svenningsen and Tønnesen, 2011). It was first described as early as 1966 by McKegney (1966, p. 636) as a '*new disease of medical progress'*, a plethora of symptoms defined collectively as '*madness*', with later definitions recognising the complex nature of clinical presentation. Since the 1980s, studies have focussed on delirium as a medical nuance and attempted to define and explain the clinical presentation, diagnostic criteria, and assessment strategies to validate its presence as a phenomenon. Evidence suggests that the trajectory of delirium is associated with increased mortality (Rabins and Folstein, 1982), severe neurocognitive morbidity, and psychological sequelae (Cuthbertson *et al*., 2004; Dimartini *et al*., 2007; Francis and Kapoor, 1992; Griffiths and Jones, 2007; Grover *et al.*, 2019; Grover and Shah, 2011; Hopkins *et al.*, 2005; Kiekkas *et al*., 2010; Lee-Steere *et al*., 2020; Nouwen *et al*., 2012; Pollard, Fitzgerald and Ford., 2015; Ringdal *et al*., 2006; Ringdal *et al*., 2009; Rotondi *et al*., 2002; Schnyder *et al*., 2001; Stoll *et al*., 1999).

Whilst criteria attempt to provide some level of clinical consensus to inform diagnosis and prognosis, there continues to be subjective bias in the clinical assessment of disorders of consciousness which risks misdiagnosis, and makes formal classification difficult (Di Perri *et al*., 2014; Sherer *et al*., 2005; Sherer *et al*., 2009; Vaitl *et al.*, 2013). Niedermeyer's early works (1994, 1999) defined coma as a state of being resulting in the loss of vigilance, mental contents or experience and selective attention. In 2013, Vaitl *et al.,* conceptualised coma as affecting '*activation*', which refers to one's level of arousal, alertness and a sense of responsiveness, '*awareness span'*, '*self-awareness'* and '*sensory dynamics'.* This latter characterisation reflects a more subjective dimension to disordered consciousness. Some individuals can recall their time in coma, describing it as a rich and varied sensory and perceptual experience (Vaitl *et al*., 2013). In support, the introduction of advanced functional neuroimaging techniques has challenged the view that despite the perceived reliability of formal clinical assessments of wakefulness and responsiveness, individuals assessed as lacking awareness, may have experiences 'within' the coma state. Functional imaging has provided evidence of significant cortical activation which may suggest an ability for integrated information and cognitive processing (Corrigan, Smith-Knapp, and Granger, 1997; Laureys *et al*., 1999; Laureys and Boly, 2008; Laureys and Schiff, 2011). Sherer, Yablon and Nakase-Richardson (2009) recognised that one's subjective, self-reported experiences in coma, particularly time in coma challenges the accuracy of empirical, clinically recorded data. Whilst the authors acknowledge that the cognitive capacity of the patient may have influenced their perception of reality, the study nevertheless highlighted experiences throughout the trajectory of coma are so uniquely felt, that formal diagnostic measures of consciousness may be limiting in their application and fail to reflect the reality of one's experience. Undoubtedly, continued work in this area will provide evidence to challenge thinking, redefine diagnostic and prognostic outcomes and enable brain functionality to be correlated with disordered consciousness.

Whilst established assessment tools including the Glasgow Coma Scale (GCS) (Teasdale and Jennett, 1974), the Sensory Modality Assessment Rehabilitation Technique (SMART) (Gill- Thwaites, 1997; Gill-Thwaites and Munday, 2004), the Wessex Head Injury Matrix (WHIM) (Majerus, Van der Linden, and Shiel, 2000; Shiel *et al*., 2000; Wilson *et al*., 2009) and the JFK Coma Recovery Scale – Revised (CRS-R) (Giacino, Kalmar and Whyte, 2004; Seel *et al.,* 2010) define and categorise the clinical and behavioural characteristics of consciousness, differential diagnosis remains challenging. Following ABI, patients present with varied and unpredictable fluctuations in wakefulness, cognitive behaviour and arousal which make the construction of an encompassing and collective 'state of being' challenging. This is particularly evident in the acute phase post-ABI, where it is difficult to establish whether these symptoms are representative of the neuropathology of ABI, or delirium secondary to other causes. The use of diagnostic labels which classify disorders of consciousness, make little contribution to the layperson's understanding of the individual's presentation during the trajectory of ABI, and affect dialogue between relatives and clinicians, hindering the articulation of prognostic and management goals (Edgar, Kitzinger, and Kitzinger, 2014). In support, Formisano, Pistoia and Sarà (2011, p. 638) are reserved in their use of diagnostic terms, deeming the assessment of consciousness as highly subjective.

Recognising the interpretive tensions in establishing a clinical diagnosis of consciousness post-ABI, Block (1995, 2001) proposed 2 distinct classifications. Firstly, '*primary* *phenomenal consciousness'* (Block, 1995, p. 227) is defined as the immediate, subjective experience of being conscious. The second notion of consciousness is '*reflexive consciousness'* (Block, 2001, p. 205) whereby individuals focus on their primary experience of consciousness as an '*object for further conscious reflection or reflective thought'* (Revonsuo, Kallio and Sikka, 2009, p. 189). In this context, it could be argued that any medically derived diagnostic criterion for disordered consciousness limits understanding of the phenomenon as a unique, subjective experience. Perhaps then, disordered consciousness can only be described reflexively by those who have experienced it as simply a transitory state of 'altered consciousness', defined as '*an alteration in the informational or representational relationships between consciousness and the world'* (Revonsuo, Kallio and Sikka, 2009, p. 187).

### 1.4 Clarification of the Study Focus

The aim of this hermeneutic, phenomenological inquiry was to explore how a transitory period of disordered consciousness is constructed and interpreted in the immediacy of the acute phase of the ABI trajectory in the inpatient, hospital setting, from the perspective of the patient and the layperson witness.

There remains a lack of consensus by healthcare practitioners who, in the context of neuropathology, adopt differing synonyms when referring to alterations in consciousness. To the uninitiated lay public, it is not surprising then, that the clinical spectrum of disorders of consciousness and associated classifications are poorly understood (Brogan and Provencio, 2014; Edgar, Kitzinger and Kitzinger, 2014; Eeles, Pandy and Ray, 2013). For the purposes of clarifying the inclusion criteria of the study, it was necessary to identify a 'state of being' which would be universally and broadly recognised by potential participants. This was affirmed during an introductory meeting at a regional charitable, network group which supports individuals and families following an ABI. I discussed my interest in speaking to individuals who had experienced a transitory period of a loss of consciousness secondary to ABI. Those who remembered such experiences described themselves as being in, or recovering from 'coma' or 'unconsciousness', failing to recognise 'disordered consciousness' or any of the other previously cited synonyms as a clinical diagnosis relevant to them. Following the meeting, I reflected on the participant inclusion criteria and felt I might adversely limit recruitment of participants by characterising individual experiences by using defined diagnostic labels.
Independent of pathological cause and clinical presentation, understanding a loss of consciousness, disordered consciousness, delirium, Post-Traumatic Confusional State or indeed coma, as collective and rich representations of an '*Altered State of Consciousness'*

(ASC) refined the inclusion characteristics of the study group.

# CHAPTER TWO: LITERATURE REVIEW

## 2.1 Adopting a Hermeneutic Stance

For the hermeneutic phenomenological researcher, Van Manen (1990, p. 76) advocates that one needs to be cautious of examining existing literature at the commencement of the research study as it '*may be more difficult to suspend one's own interpretative understanding of the phenomenon'*. Whilst there is consensus in the academic community that the review serves to introduce the reader to the empirical and theoretical body of work relative to the phenomena under study, Smythe and Spence (2012, p. 23) advocate it should not be exhaustive but rather, a '*dialogical partner'*, which seeks to portray the *'taken-for-granted meanings that make up the knowing of practice'* (Smythe, 2012, p. 50).

Gadamer (2001, p. 113) posits that when engaging in phenomenological inquiry, one ought to work '*descriptively', 'creatively'* and '*intuitively*' so that concepts come '*forward in movements of thought, springing from the spirit of language'.* Such an iterative approach to the review provided interpretive and scholarly prompts throughout the study and engendered a more *'conversational partnership'* (Van Manen, 1990, p. 76) with the body of evidence, shaping the thesis as the phenomenon of ASC began to emerge.

## 2.2 Search Focus

Adopting a systematic approach, a scoping review (Arksey and O'Malley, 2005; Tricco *et al.*, 2018) was undertaken of the historical and contemporary empirical and theoretical evidence base which examined the subjective and biomedical perspectives of altered states of consciousness (ASC) secondary to neuropathology. The nature of 'self', personhood, and identity transformation, commonly seen as sequelae to ABI, both in the immediacy of the acute inpatient setting and throughout the ABI post-injury trajectory were appraised. The scoping review also presented a discourse of the influence and utility of the illness narrative, as a way of theorising and *'living with stories*' (Frank, 1995, p. 23). The seminal works of authors who have challenged the reductionist view of medicine and privileged the art of narrative as an emerging evidence base for clinical practice were reviewed.

It is noted that the initial scoping review was not exhaustive nor reflective of the extent of published works across all the subject headings (Smythe and Spence, 2012), but rather provided a contextual map and narrative synthesis of the existing body of works with respect to the aims of this empirical inquiry (Tricco *et al.*, 2018).

For each of the subject headings, identified in the search strategy (section 2.3), the four-stage methodological process of a scoping review proposed by Arksey and O'Malley (2005, p. 23) was undertaken. Following the identification of the research questions, the second stage of the scoping review advocates an initial evaluation across the subject headings to gain a *'sense of the volume and general scope of the field*' (Arksey and O'Malley, 2005, p. 23) under study.

## 2.3 Search Strategy

A systematic search of selected peer-reviewed primary research, discursive and position papers, systematic reviews and secondary reference sources, and the theoretical evidence base was conducted from 1990-2022, using Academic Search Complete (EBESCO), Academic Complete ProQuest eBook collection (ProQuest), CINAHL Plus with Full Text (EBSCO), EBSCOhost Academic eBook Collection, World Wide (EBSCO), MEDLINE with Full Text (EBSCO) ProQuest Archives, ScienceDirect (Elsevier), PsycARTICLES (American Psychological Association), Cochrane Library (John Wiley and Sons) and Google Scholar databases.

The search was broad based to include index keywords and threads, cited as: *disorders of consciousness, delirium, hallucinations, delusions, acquired brain injury (adult), Post-Traumatic Confusional State (PTCS), Post-Traumatic Amnesia (PTA), psychosis, confusion, 'self', personhood, identity, intensive / critical care, lived experience, caregivers, family, patient, and phenomenology / hermeneutic phenomenology*. The Boolean Operators, *'and*'. '*or'* and '*not',* refined the search. The references and citations published in the research studies, particularly the systematic reviews and meta-summaries were also examined. The search captured early works, pre-1990, if they were deemed seminal works and important in establishing historical positions. Exclusion criteria included paediatric participant studies related to ABI, near-death experiences, the long-term trajectory of ABI, prolonged disorders of consciousness (PDOC), and the management protocols and interventions post-ABI. No restrictions were made on the aetiology or classifications of ABI. Rather, a pragmatic decision was made to focus on the presentations of neuropathology, which included perceptual disturbances and disorders. Combining different search threads retrieved a breadth of papers, so a decision was made to include those studies which made significant contributions to the evidence base. No limits were made to a specific inpatient, hospital setting where patients with ABI were admitted. Limits were applied to publications in English language, although no exclusions were made on the country of origin.

After initial screening of the published works under each of the broad subject headings, the third stage of the scoping review appraisal framework (Arksey and O'Malley, 2005) required the systematic analysis of the empirical and theoretical findings to ascertain relevance to the research question. The adoption of Tricco *et al.,*'s (2018) PRISMA-ScR (Preferred

Reporting Items for Systematic Reviews and Meta-Analyses – Scoping Reviews) for a scoping review adapted from the PRISMA statement (Moher *et al.,* 2009) guided this stage. Following the review of the titles and abstracts, the empirical studies deemed relevant were sourced as full-text publications to appraise the methodology, establish eligibility and relevance. A PRISMA-ScR (Tricco *et al.,* 2018) flow diagram was constructed for each of the scoping review subject headings which detailed the number of sources of evidence screened, eligibility criteria and exclusions and inclusions at each stage of the review process. An illustration of the outcome of the scoping review which focused on the patients' perspectives of an altered state of consciousness, can be found in Appendix 2.

The final stage (Arksey and O'Malley, 2005) advocates the charting of the empirical datasets in a bibliographic and methodological matrix summary table. The citations captured the characteristics, intervention types, methodological design, and findings of the studies (Tricco *et al.,* 2018). Such a consistent approach allowed for the comparison of findings across the datasets and the identification of methodological gaps in the published evidence base. An illustration of the matrix summary table which focused on the patients' perspectives of an ASC, can be found in Appendix 3.

## 2.4 The Patients' Perspectives of an Altered State of Consciousness

***'It is much more important to know what sort of patient has a disease, than what sort of disease a patient has'***

**(Osler, 1961, p. 105)**

As a preface to this scoping review and henceforth, in the context of this inquiry, the patient is defined as an individual, who accesses healthcare services. Whilst debate continues as to the potential homogenising and labelling effect of the descriptor '*patient*' and the preferences for the adoption of '*client*', '*service user'*, '*consumer*', '*survivor*' as examples, Costa *et al.,*'s (2019) scoping review found those who are recipients of health care preferred, the term, '*patient*'.

Published works have focused on the prevalence, diagnosis and prognostic indicators of an ASC secondary to ABI, the development of evidence based guidelines to manage neuropathology (Royal College of Physicians and Society of Rehabilitation Medicine, 2003; Brain Trauma Foundation, 2016; National Institute for Clinical and Health Care Excellence, 2019) and the utility, reliability, and validity of assessment tools to assess differing levels of consciousness (Majerus, Van der Linden, and Shiel, 2000; Seel *et al.,* 2010; McAleese *et al.,* 2018). However, because '*consciousness cannot be directly observed'* (Seel *et al.*, 2010, p. 1796), limitations in the formal, clinical assessment of consciousness are such that inferences are inevitably drawn about the behavioural and neurological presentations seen in patients (Laureys *et al.*, 2005; Giacino and Smart, 2007). It is not the remit of this review to appraise the reliability and validity of behavioural assessment tools, the duration and functional basis of Post-Traumatic Confusion post-ABI, nor challenge the neuro-behavioural basis or factual accuracy of memory recall. Rather, the scoping review provides a critical discourse of the emerging body of inductive, empirical, and theoretical evidence which seeks to reveal the content and meaning of the lived experience of ASC in the hospitalised patient.

Empirical studies which capture first-person accounts of the phenomenon of ASC are largely descriptive in nature, focusing on autobiographies of the experience of critical care and the acute inpatient hospital setting following a diagnosis of ASC, secondary to neurological trauma, toxicity, metabolic disturbances, or induced by medication for the purposes of clinical management. Despite the heterogeneity of aetiology and behaviours observed *in-ASC*, empirical findings report a range of subjective, qualitative experiences which include, but not exhaustive of, a patient's residency in an alternate reality.

Although prevalence data of a delirium presentation is difficult to establish due to the inconsistency and reliability of assessment (Bowker, 1995; Eisendrath, 1980; Ryan *et al.,* 2013; Koirala *et al.,* 2020), and hesitancy in disclosure, for fear of not being believed or labelled as '*crazy*' (Granberg, Bergbom-Engberg and Lundberg, 1999), patients are able to recall a rich landscape of delusional and factual memories (Bergbom-Engberg and Halijamae, 1988; Capuzzo *et al*., 2004; Dasta *et al.*, 1985; Granberg, Bergbom-Enberg and Lundberg, 1998; Jones *et al.*, 2001; Kvale, Ulvik and Flatten, 2003; Miller and Ely, 2006; Oldenbeuving *et al.,* 2007; Palmieri, 2003; Roberts and Chaboyer, 2004; Rotondi *et al*., 2002; Sorensen Duppils and Wikbald 2007; Whitehorne *et al.*, 2015). Debate ensues as to the content of memories during ASC, with Papathanassoglou and Patiraki (2003) preferring to describe patients' experiences as illusions or dreams whilst others are described as hallucinations, unreal experiences, or hypnagogic states (Maddox, Dunn and Pretty, 2001). Whilst it could be argued that the heterogeneity of perceptual disorders poses methodological limitations in study design, independent of the content of experiences of ASC, these temporary states collectively result in a deviation '*from the natural world (world-consciousness) in such a way that the world and or self tend to be misrepresented'* (Revonsuo, Kallio and Sikka, 2009, p. 194). These misrepresentations may involve, but are not limited to, sensory, cognitive, and affective processes: a constellation of symptoms unique to the individual.

Retrospective, autobiographical accounts are rich in descriptions and offer invaluable insights of the perceptual disturbances which accompany ASC. Longitudinal studies (Kvale, Ulvik and Flatten, 2003; Cuthbertson *et al*., 2004; Svenningsen *et al*., 2014; Instenes *et al*., 2017; Roberts *et al.,* 2007) support the view that whilst factual memories of the hospital experience may diminish over time, the delusional memories, particularly those associated with delirium remain intrusive and persistent. The content of the hallucinogenic and delusional landscape is largely remembered as persecutory, profoundly psychotic, and interspersed with paranoia and animistic dreams (Belanger and Ducharme, 2011; Breitbart *et al.,* 2002; Crammer, 2002; Daffurn *et al.,* 1994; Gaete Ortega, Patathanassoglu, and Norris, 2020; Instenes *et al.,* 2017; Jones, Griffiths, and Humphries, 2002; Lange *et al.,* 2022; Magarey and McCutcheon, 2005; McCurren and Cronin, 2003; Richman, 2000).

Whilst recognising the limits to generalisability of small scale, qualitative studies, personal accounts provide a rich and unique contribution to the body of evidence which inform clinical practice (Morse, Hutchinson and Penrod., 1998). Richman (2000, p. 24), a sociologist and anthropologist, developed delirium following critical illness. His distress is palpable as he negotiated his way through a '*gigantic kaleidoscope'* of psychotic symptoms, animistic hallucinations, collectively described as '*dreams of affliction'.* He was *'accompanied by beasts that I did not recognise but with whom I could converse, impending danger was constant, and I had no notion of body and self'.* Feelings of isolation persisted on recovery as he left the *'anomie of inner space and time to a trivial world of awakening with fixed routines of meals and medications'.* A similar account is presented by Crammer's (2002) autobiography of fluctuating consciousness secondary to delirium. Whilst the limits of generalisability in self-reported case study design should be acknowledged, he presents a vivid description of the hallucinogenic landscape along with persecutory and disturbing delusions. A degree of resolution was achieved when he was able to rationalise his experiences in the context of contemporaneous events within the unit and because of his prior experiences as a psychiatrist.

Independent of the aetiology, patients frequently describe their emergence from the depths of ASC as a transitory, yet equally disturbing experience. The concept of a liminal space is experienced by the patient both during a period of ASC, and on gaining situational and personal awareness. In other studies, it is defined as a '*borderland*' (Andersson *et al.,* 2002), a '*twilight zone'* (Instenes *et al*., 2017), whereupon, on the *'threshold of consciousness*' (Darbyshire *et al.,* 2016, p. 6), the boundaries of reality and perceptual disturbances remain distorted (Andersson *et al.,* 2001; Andersson *et al.,* 2002; Darbyshire *et al.,* 2016; Laitinen, 1996). Reconciling the reality of the factual and delusional memories, making sense of the content of experiences, and searching for clarity are consistent themes within the literature (Andersson *et al.*, 2002; Boehm *et al.,* 2021; Doig and Solverson, 2020; Duppils and Wikbald, 2007; Magarey and McCutcheon, 2005;

Samuelson, Lundberg and Fridlund, 2007; Samuelson, 2011; Wade *et al.*, 2015). Patients attempt to impute meaning to the factual content of their perceptual disturbances. This pursuit is described as *'making the incomprehensible comprehensible'* (Andersson *et al.*, 2002, p. 661) or developing *'a sensible story out of it'* (Andersson, Norberg and Hallberg, 2001, p. 313). Sense-making appears to foster a degree of resolution and justification for the abhorrent and bizarre experiences associated with ASC, but this is not without its challenges. External events influence the content of the patient's experience, and they have difficulty in determining what was real or unreal. Distress is further compounded when the perceptual disorders associated with ASC include derangements in time, place, and motion (Svenningsen, Egerod and Dreyer, 2016; Weir and O'Brien, 2019). For others, independent of the cause of ASC, the individual's quality of life is affected (Van Rompaey *et al.,* 2016) and they risk significant psychological morbidity and vicarious trauma on recovery (Daffurn *et al.*, 1994; Ely, Siegel and Inouye, 2001a; Kiekkas *et al.,* 2010; Lee-Steere *et al.*, 2020; Mackenzie and Popkin, 1980; O'Malley *et al.,* 2008; Wacker *et al.,* 2006; Wade *et al.,* 2015).

In a large multi-centre study, Ringdal *et al.,* (2006) sought to understand the extent of factual and delusional memories of patients (n=239) admitted to the ICU and correlated the context of memory with psychological complications on discharge. Although the researchers acknowledged that it was difficult to validate and differentiate memory types, 83% of patients were able to recall factual memories of family visits, with 26% describing delusional memories. However, it was the latter group who statistically were more likely to report long-term psychological sequelae. These findings are commensurate with Ringdal *et al.*'s (2009) prospective, longitudinal cohort study, which reported delirium as significant risk factor for reduced health-related quality of life indicators. Whilst the data could not establish a predicted risk of Post-Traumatic Stress Syndrome, interventions to optimise security and comfort were recommended to minimise the risk of adverse sequelae during admission. In contrast, Roek, Arjen and Slooter (2012) undertook a systematic review (n=14) to establish the correlation between delirious experiences and emotional consequences. Whilst findings were heterogenous and long-term outcomes could not be predicted with any degree of certainty, the emotional burden reported on recovery reflected the loneliness and estrangement felt whilst delirious.

Whilst a significant number of accounts of ASC are distressing and leave individuals with a sense of uncertainty and bewilderment, other studies lend towards optimism. Adopting hermeneutic phenomenology, Papathanassoglou and Patiraki (2003) interviewed eight individuals who experienced a period of perceptual disorientation during critical care. Conceptualised as a '*cocooning phase'*, the participants emerged with a renewed sense of ‘*transcendence and rebirth’.* Their dream-like experiences had a transformative, almost spiritual effect. Findings are reflective of those described by Johnston (2011). Following a cardiac event which necessitated a prolonged period of hospitalisation, he described his hallucinogenic experiences as an opportunity for ‘*change and rebirth’* (2011, p. 375) and time to ‘*rework and master past developmental traumas*’ encountered prior to the illness. However, on his recovery it became evident that his wife was unable to validate and accept the profound and affirmative impact of his hallucinations. In contrast, her narrative focused on the unpredictable and fragile nature of his illness, and the profound sense of impending loss, captured as an ambiguous, ‘*liminal space between life and death’* (Johnston, 2011, p. 377).

Andersson, Norberg and Hallberg’s (2001) study sought to establish whether a patient’s behaviours manifested during a period of delirium are reflective of intentional actions and internal experiences at the time. The findings highlighted that the patient recalls oscillating between awareness and unawareness and attempts to seek control by offering justifications for their reported behaviours. Whilst findings resonate with that of other studies, observational methods potentially risk observer interpretation bias, and one needs to be cautious of making inferences about the origins of behaviours (Hogg, 2002).

The way patients relate to others and interact with their environment during ASC is revealing. Stenwall *et al*., (2008a) examined the patient’s memories of encounters and engagement with professional carers and close relatives. Unable to communicate, they were left feeling ‘*lonely within the perceived reality’,* as they ’*hovered’* at the border of two distinct realities, that which was ‘*perceived within the coma’* and the ‘*ordinary reality’.* Not only did patients search for understanding and sense-making, but they also reported feeling ‘*at the mercy of the person they encountered’* and ‘*objectified*’ by others within the relationship. This sense of loneliness and isolation was compounded when they recalled feeling rebuked or berated for their behaviours (Lingehall *et al*., 2015). Once lucid, patients were left with feelings of incomprehensibility and psychological distress (Belanger and Ducharme, 2011; Breitbart *et al.,* 2002; Fagerberg and Jonhagen, 2002; Fuller, 2016; Griffiths and Jones, 2007; Harding, Martin, and Holmes, 2008).

The most comprehensive systematic review and meta-summary to date synthesised the empirical findings of 24 qualitative and mixed-method studies of the delirium experience (Kuusisto-Gussman *et al*., 2021). The study reported the overwhelming and distressing nature of the delirious state, the effect on personal and professional relationships and the risk to psychological morbidity. Recommendations included the need for the development of a theoretical model of delirium and a strategically informed management plan, to support patients and their relatives during hospitalisation and on discharge.

Whilst storied, descriptive accounts focus on the qualitative features of self-reported ASC experiences, the reductionist nature of such inquiries limits understanding as to how one's sense of self or personhood is perceived or transformed throughout the trajectory of an ASC. The interpretation of the perceptual disturbances experienced during psychiatric illness, particularly psychosis, go some way in bridging this methodological gap. Whilst the lived experience of psychosis reflects the findings of other presentations of ASC in that individuals describe residency in a transitory, yet disturbing hallucinogenic and delusional landscape (Boyd and Gumley, 2007; Boydell *et al.*, 2010; Dilks, Tasker and Wren, 2010; Geekie *et al.,* 2011; Geanellos, 2005; Gould, DeSouza and Reeiro-Gruhl, 2005; Hirschfeld *et al*., 2005; Jarosinski, 2008; Kilkku, Munnukka and Lehtinen., 2003; Kiran and Chaudhury, 2009; Mancini *et al.,* 2014; Mauritz and Van Meijel, 2009; Pienkos, Silverstein and Sass, 2017; Robertson and Lyons, 2003; Shea, 2010; Tosch, 1988), other studies have adopted a more philosophically informed, interpretive approach to understand the perceptual disturbances experienced. McCarthy-Jones *et al.*, (2013) undertook the first meta-synthesis of inductive, qualitative studies which examined the subjective experiences of psychosis. Like the perceptual disorders seen with delirium, one of the overarching themes which emerged from the analysis was the loss of consensual reality whilst psychotic. The legacy of psychosis highlights how the loss of one's sense of restored self and agency affects the future relationships with others. Reflecting on behaviours whilst psychotic resulted in feeling of guilt, shame and remorse, findings substantiated by studies of delirium (Lingehall *et al*., 2015; Pollard, Fitzgerald and Ford, 2015). In challenging the biomedical construction of mental illness, Larsen (2004) purports that the hegemony of the mental health institution constrains the emergence of sense-making for those who experience a first episode of psychosis. Drawing on social anthropology and adopting an ethnographic methodology, he found that in attempts to make sense of a psychotic experience, participants draw on a repertoire of social and cultural resources to maintain a sense of agency.

Moving away from the dominant, cartesian view of the body, there is an emerging commitment to understand the body in illness from a philosophical position. Merleau-Ponty's (1962, p. 153) concept of embodiment as *a 'grouping of lived through meaning'* encapsulates how the 'self' is changed within the complex milieu of illness and the positioning and re-positioning of 'self' within the social and cultural context in the present and future. In support, Levin and Solomon (1990, p. 515) believe that the emergence of behavioural medicine has furthered this paradigm shift in medical discourse, re-conceptualising the body as the '*phenomenological body of experienced meaning'.* The concept of embodiment grounded Danon's (2016) narrative analysis of 17 individuals and revealed an interesting dichotomy of one's corporeal existence in coma. Reflecting on their coma experiences, patients were neither present nor absent, existing simultaneously in an '*earthly and unearthly'* realm, neither *'dead'* nor *'alive'.* Whilst studies which have conceptualised the phenomenological body-in-coma are limited, the work of Sivertsen and Normann (2015) offers a similar perspective of one's embodied self. Interviews with three men who sustained traumatic brain injuries as young adults, recognised that privileging the body-as-object, a body defined by functional performance and ability, commonly assessed during the rehabilitation phase, limits sight of the body-as-subject, that which is personally '*experienced and expressed'.* However, privileging the functional limitations post-ABI fails to acknowledge the profound impact of the loss of agency (Sivertsen and Normann, 2015), and risks leaving the individual's sense of self, exposed, vulnerable, and marginalised (Darbyshire *et al*., 2016).

In summary, during the acute phase of the inpatient admission, for those diagnosed with ASC secondary to neuropathology, the trajectory is complex. Prognosis is uncertain and the path of recovery, undulating and unpredictable. There is limited evidence that opportunities are afforded to patients to describe their experiences as they become increasingly lucid and gain personal and situational awareness. Rather it is the behaviours and actions of those *in-ASC* which are commented upon and appear to define the person henceforth. Whilst the lived narrative of ASC, independent of the cause, is uniquely experienced, individuals describe similar and consistent themes. Memories of perceptual disturbances which accompany a transitory residency in the liminal and isolated reality of ASC remain intrusive, incomprehensible, and overwhelmingly disturbing on recovery. Reflecting on their experiences, individuals have a limited sense of reality, and strive for reconciliation and sense-making.

### 2.5 The Laypersons' and Healthcare Professionals' Perspectives of an Acquired Brain Injury, Altered State of Consciousness and Interventions.

Journeys through illness are not experienced exclusively by the patient but by those who find themselves unexpectedly embroiled in what will inevitably be a formative and seminal life event post-injury (Hyden, 1997). There is a wealth of evidence that life threatening illness particularly that associated with brain injury has a profound and enduring impact on family members and relational dynamics (Cruzado and Elvira de la Morena, 2013; Florian and Katz, 1991; Giovannetti *et al.,* 2015; Lezak, 1978; Perlesz, Kinsella and Crowe, 1999; Soeterik, 2017; Soeterik *et al.,* 2017; Whiffin, 2012; Whiffin *et al*., 2015; Whiffin *et al*., 2017; Whiffin, Gracey and Ellis-Hill, 2021).

Published works relating to the family's perspective, focus on the witness' emotional and psychological responses, and vicarious trauma resulting from the experiences of critical illness and traumatic brain injury (Ashana, Lewis and Hart, 2020; Assa, Wicks and Umberger, 2021; Bijttebier *et al*., 2001; Coco *et al*., 2011; Daley, 1984; Davidson, *et al.*, 2017; Fins, 2013; Gholamzadeh *et al*., 2012; Lewis and Taylor, 2017; Verhaeghe *et al*., 2005; Verhaeghe *et al*., 2007; Whiffin *et al*., 2015), and the practical strategies which are employed by clinical teams to identify the priorities of care and support needs for relatives (Engli and Kirsivali-Farmer, 1993; Maxwell, Stuenkel and Saylor, 2007; Molter, 1979; Tin, French and Leung, 1999).

The immediate and longer-term care burden of ABI and consequences for family dynamics, role adaptation and the lack of focused and managed support particularly on discharge, are well represented in the literature (Duff, 2002, 2006; Laratta *et al*., 2020; Maggio *et al.*, 2018; Soeterik *et al.,* 2017; Soeterik, Connolly and Riazi, 2018; Tramonti *et al.*, 2019). Families are thrown into uncertainty, having to navigate their way through an unpredictable and somewhat trepid path as they struggle to adjust to the individual's prognosis and the psychosocial and emotional impact of an ABI. This is particularly seen for those who have spousal and caregiver responsibilities for a family member, whose executive functioning, cognitive and functional abilities, and behaviour are compromised significantly by the injury. Family roles have to be re-negotiated and re-evaluated as the extent of the individual's limitations are realised (Choustikova *et al*., 2020; Chwalisz and Stark-Wroblewski, 1996; Clark-Wilson *et al*., 2016; Covelli *et al.,* 2016; Holloway and Fyson, 2016; Jumisko, Lexell and Söderberg, 2007; Kitzinger and Kitzinger (2014): Manskow *et al*., 2018; Nalder *et al*., 2013; Oyesanya, 2017; Perlesz, Kinsella and Crowe, 1999; Ryan *et al*., 2016; Soeterik, 2017; Testani-Dufour, Chappel-Aitken and Gueldner, 1992).

However, there is a paucity of research which explores the extent to which family members experience a transitory period of an ASC secondary to ABI in the immediacy of the acute, inpatient environment. Little is understood as to how the behaviours and the clinical manifestations associated with a presentation of an ASC are interpreted, as the witness finds themself a spectator in the unfamiliar and unpredictable territory of ASC. Some insight is gained from studies which have explored the family member's perception of delirium (Bohart, Merete, and Forsyth, 2019; Huang *et al.,* 2021). Adopting phenomenology as a methodology, Day and Higgins (2015) interviewed 14 females whose spouses presented with delirium. Whilst believing their loved one remained corporeally present, they were deemed to be '*existentially absent'.* Staff appeared to offer little justification for the bizarre and uncharacteristic behaviours associated with delirium which left the witness feeling uninformed, marginalised, and isolated. Schmitt *et al.*,'s (2019) qualitative study captured the overarching burden profile of delirium, experienced by 16 spousal caregivers. The adverse and unpredictable presentation of delirium, the caregiver's feelings of fear, guilt and helplessness and the situational burden compounded by a lack of knowledge, safety concerns and the inattention of staff, significantly contributed to their distress.

Whilst psychological distress and helplessness are unifying themes which emerged in other works (Buss *et al*., 2007; Fernandes, 2018; Lawlor, Fainsinger, and Bruera, 2000; Morita *et al*., 2007; Martins *et al.*, 2018), the witness' subjective experience of delirium is compounded if it is a prelude to clinical deterioration or a terminal diagnosis (Breitbart *et al.*, 2002). An integrative literature review undertaken by Finucane *et al.*, (2017) explored the experience of caregivers of terminally ill patients. Due to the irreversible nature of the delirium presentation, caregivers were unlikely to re-establish the caregiver relationship prior to death which heightened feelings of distress. These findings however, contrasted with those of Namba *et al.*,'s (2007) earlier study, in which delirium was welcomed as a timely distraction from the inevitable pain experienced and imminent mortality.

Whilst there is increasing commitment to understand the family's perspective of ABI during the acute phase of the presentation through to rehabilitation and discharge, there remains a lack of storied evidence to elicit the meaning of the lived experience of an ASC, as a recognised feature of post-ABI clinical presentation. Similarly, there is a paucity of published research which examines the lived experience of an ASC from the practitioner's perspective. The existing body of literature privileges a pragmatic approach to evaluate the implementation, reliability and validity of assessment tools which inform the diagnosis and prognosis of the clinical presentation of the ABI, and the associated impairments in consciousness and neurological function.

The practitioner's experience of ASC is largely evidenced by studies which again focus on delirium, and the prolonged and irreversible dementia syndromes. Adopting critical discourse analysis and a period of participant observation in clinical practice, Schofield, Tolson, and Fleming (2012) explored nurses' perceptions of working with the older person diagnosed with dementia. Analysis revealed that patients were defined by their altered behaviours and in doing so, they were '*disembodied and dehumanised'.* The nurse's engagement with patients was limited to '*containment*' and '*surveillance*', to purportedly minimise the patient's exposure to risk. However, once lucid, patients were viewed differently, '*as persons with human dignity to preserve and protect'.* Perceiving the patient to be distant and difficult to '*reach'* as they resided in an alternate reality, was a theme which emerged from Andersson *et al.*,'s (2002) study. Nurses were increasingly suspicious and cautious as to the patient's motivations and tended to make assumptions about the aetiology of the patient's behaviour.

Whilst the utility and efficacy of intervention and management strategies have been extensively examined within the delirium literature, these are largely constructed from epistemological foundations. Despite the development of clinical guidelines which recommend best practice (National Institute for Health and Care Excellence, 2019), evidence suggests that organisational, educational and resource issues present as barriers to successful implementation (Abrahamson, Fox, and Doebbeling, 2012; Emme, 2020; Kotfis, Marra, and Ely, 2018; Trogrlić *et al.*, 2015; Van de Steeg *et al.*, 2014). In addition, the reliability and validity of assessment tools and non-pharmacological interventions to address the clinical presentation of delirium rely on observer judgement which risks the introduction of subjective bias. Care is perceived as burdensome, particularly during occasions when the patient presents with aggression, hyperactivity and is uncooperative (Lou and Dai, 2002; McDonnell and Timmins, 2012; Thomas, Coleman and Terry, 2021). The behaviours seen in the delirious patient are perceived as difficult to manage amongst other competing workload demands (Adriaenssens, *et al*., 2011; Belanger and Ducharme, 2011; Brooke and Manneh, 2018; Kristiansen, Konradsen and Beck, 2019; LeBlanc *et al.*, 2018; McDonnell and Timmins, 2012; Schmitt *et al.*, 2019; Yang *et al.*, 2020).

The formal assessment of cognitive status associated with perceptual disturbances experienced in the acute hospital setting appears to be inconsistent and poorly undertaken, with management strategies focusing on risk reduction and the prevention of the negative sequelae of impaired consciousness (Yevchak *et al*., 2012). The strategies presently employed in practice range from reality re-orientation (Inouye, 2000) to validation therapy (Feil, 2002). Reality re-orientation is an approach which attempts to re-orientate patients to the 'here and now', the aim of which is deemed to minimise factors which may contribute to and perpetuate confusion. Alternatively, validation therapy, an approach developed by Naomi Feil (2002) advocates the endorsement and acceptance of the patient's reality and therefore 'validates' confusion, recognising it is a 'real' for the patient, the outcome of which is believed to reduce the distress caused by challenging the patient's narrative. Clinicians have historically advocated both these therapies, despite their conflicting approaches with Millisen, Steeman and Foreman (2004) suggesting that they make a '*valuable contribution'* to the management of delirium in the acute setting. It needs to be acknowledged however, that historically these approaches were adopted in the care of clients with protracted, long term and irreversible dementia states with associated cognitive impairment. However, a Cochrane Systematic Review (Neal and Briggs, 2003) reported that whilst validation therapy may facilitate the restoration of a patient's self-worth and reduce distress and anxiety, there was insufficient evidence to allow any substantive conclusions about efficacy and outcome. Furthermore, Spector *et al*., (2000, 2003) reported that whilst re-orientation therapy may be modestly effective in certain patients, the effects were indeed transient and may result in increased confusion and distress. Such interventions tend to be evaluated from an external perspective by assessing a patient's behaviour or perceived responses during ASC. Despite a commitment to the development of evidence-based protocols to inform management of those who present with an array of perceptual disturbances in the acute setting, the evaluation of the utility and efficacy of interventions from the patient's and layperson's perspective is limited. Several studies cited earlier, recommend practitioners develop strategies which do not simply assess risk of ASC and interventions to reduce the distressing symptoms manifest but encourage dialogue and the sharing of experiences. This would establish understanding of the immediacy of experience as well as long term burden risk.

In summary, whilst there is increasing commitment to understand the layperson's perspective of ABI during the acute phase of the presentation through to rehabilitation and discharge, there remains a lack of storied evidence to elicit the meaning of the lived experience of ASC as a recognised feature of post-ABI clinical presentation. Support focuses on prognostic indicators, diagnosis, and treatment intentions with limited acknowledgement of the personal impact of the ASC trajectory. For the practitioner, the physical manifestations of ASC and the presenting, associated behaviours are deemed burdensome and 'managed' with little attention paid, on recovery, to the patient's lived experience *in-ASC*.

### 2.6 The Illness Trajectory and Narrative Typologies: Transformation of 'Self', Identity and Personhood in ABI and Perceptual Disorders

**'*Telling stories of illness is the attempt, instigated by the body's disease, to give a voice to an experience that medicine cannot describe'***

**(Frank, 1995, p. 18)**

Since the seminal works of James (1890), Jung and De Laszlo (1959), Locke and Winkler (1996) and Maslow (1943) who pursued scholarly interest in concepts of 'self', there has been a plethora of published literature which propose varied definitions and constructs. From Goffman's (1963) early work, 'self', personhood, and identity have been the subject of philosophical, sociological, and psychological debate and contradiction (Neisser, 1998; Sartre 1943 / 1958; Ricouer, 1992; Zahavi, 2000). In its basic form as a concept, 'self' deals *'chiefly with the interior world and one's perception of it'* (Hammock, 2010, p. 12) and is '*altogether individual'* yet *'intrinsically social'* (Jenkins, 1996, p. 50). 'Self' manifests and is constructed through the first-person narrative (Zahavi, 2000), *'a self-present, single, temporally persistent, bodily and bounded subject of experience'*

(Henriksen and Parnas, 2014, p. 544). An individual's presentation of 'self' to the exterior world, referred to as one's 'identity', is frequently and purposefully manipulated so that one maintains *'internal coherence and continuity' (*Hammock, 2010, p. 12). Etymologically, 'identity' arises from Latin roots, the *identitas*, from *idem*, meaning 'the same', a concept later developed by Ricouer (1992) as *'identity idem' (identity as sameness)*. This is an identity which remains constant over time (Venn, 2000) but becomes an '*identity ipse'* or *'identity as selfhood'* (Ricouer, 1992) when one's construct is affected by others (Jenkins, 1996) and their '*dialectical relationship with society'* (Berger and Luckmann, 1966, p. 194). Crossley (2000, p. 21) espouses that the self-concept is multifaceted and inextricably influenced by linguistic, historical, and social structures. One's construction of 'self' is also temporally influenced wherein the contemporaneous, past, and future projections of 'self' contribute to the narrative of 'self' and identity. Aligned to this notion of identity is the narrative: '*the story we tell of ourselves, is also the story that others tell of us'* (Sarup and Tasneem, 1998, p. 3).

Narrative discourse and autobiographical accounts have advanced understanding of the effects of illness on one's construct of self. Since the influential works of Charon (2001, 2004, 2006), Charon and Wyer (2008), Frank (1995), Kleinman (1989) and Svenaeus (2000), there has been increasing recognition that narrative-based medicine has the potential to provide invaluable insights into the illness-recovery trajectory (Bury, 1982; Department of Health, 2005; Fioretti *et al.*, 2016; Greenhalgh, 1999; Greenhalgh and Hurwitz, 1999; Hyden, 1997; McLellan, 1997; Mishler, 1984; Wilcock *et al*., 2003) with Kleinman (1989, p. 49) recognising the important contribution illness stories have in outlining '*the distinctive events and long-term course of suffering'.* However, it is argued that the emergence of the illness narrative has been consumed by the dominant voice of medicine which is seen to pathologise illness and define disease by clinical presentation, subjugating the lived experience of illness as a '*silent emblem of a covert reality that is usually dealt with either indirectly or not at all' (*Kleinman, 1989, p. 9). Disillusioned by this positivist paradigm, social psychology and anthropology have attended to the utility of the biographical experience to contextualise the intricacies and nuances of health, illness, and health care relationships within personal, social, cultural and at times, political contexts (Hyden, 1997; Murray, 1999; Polkinghorne, 1988; Stephens, 2011). It was not until a distinction was made between disease and the suffering espoused by illness, that the '*foundation was laid for conceiving the patient's speech as a voice that was strong enough to stand up against the voice of medicine'* (Hyden, 1997, p. 49).

The utility of stories and narrative construction lie in the premise that, *'stories are* *performative: through them we initiate, suggest, and call for responses'* (Martin, 2007, p. 54) particularly when life transition and change require the reshaping and managing of the '*shifting ground of our lives*' (Bingley *et al.*, 2008, p. 655). This discourse rests on the belief that the illness narrative captures different perspectives not aligned to the traditionalist biomedical paradigm by giving '*disease a personal history'* (Murray 1999, p. 58). In defending the utility of storytelling, Bury (2001) who has published widely in the field of the social psychology of illness, provides a critical discourse of the tension which underlies the academic debate between the traditional biomedical and reductionist forms of inquiry, and inductive approaches. His conclusions are encouraging, in recognising the move from the paternalistic discourse of medicine to a position in which, through narrative, illness '*suddenly finds a new voice'* (Bury, 2001, p. 268). Working with autobiographies of chronic illness, he developed a narrative classification. Firstly, he describes the *'contingent narrative'*, a narrative informed by the cultural and societal context of illness and beliefs held by the individual at the onset of diagnosis through to disease progression, when the effects of the illness are realised. Secondly, the '*moral narrative'* situates the individual, the narrator, within a changing and dynamic landscape, and recognises the effect of illness on one's agency and social identity. The final narrative form, defined as the '*core narrative'* explores the deeper socio-cultural and sociological meaning one attaches to illness and suffering.

For Frank (1995, p. xii), testimonies of illness provide the storyteller with a '*voice that illness and it's treatment often take away'*, and '*is for an other, just as much as it is for oneself*' (Frank, 1995, p. 17). He defines three typologies of the illness narrative, *chaos, quest, and restitution*. For those who begin a journey of illness and suffering, 'r*estitution'* is the preferred narrative, reflected in the storyline: '*Yesterday I was healthy, today I am sick, but tomorrow I will be healthy again'* (Frank, 1995, p. 77). The *chaos* narrative acknowledges that illness is inherently disruptive and the myriad uncertainties which accompany diagnosis and prognosis, the loss of control and its unpredictable trajectory collectively threaten one's sense of agency and action. Whilst this narrative typology which accompanies illness is, at times, difficult to both tell and hear, it nevertheless affords the '*ill their most distinctive voice*' (Frank, 1995, p. 115). In contrast, in acknowledging the limits of medicine, the narrator in the *quest* narrative embarks on a journey characterised by transformation, adaptation, and the regaining of control and self-agency despite what might be an unfavourable prognosis.

The empirical and theoretical literature (Anderson and Bury, 1988; Bury 1982, 1988, 1991, 1997, 2001; Charmaz, 1983, 1995, 2002, 2009, 2010; Egnew, 2008; Garro, 1992; Kelly and Field, 1996; Leventhal, Idler and Leventhal, 1999; Radcliffe, Lowton and Morgan, 2013; Thomas, 2007; Toombs 1995; Williams 1984, 1996, 1999, 2000) attend to the travails of chronic illness as a rich source of data, partly because of the protracted and irreversible nature of disease. The abiding theme reflects how 'self' and identity as cognitive constructs are constantly re-appraised and re-evaluated, as one's integrity of 'self' is threatened during the trajectory of chronic illness (Charmaz, 1995; Kelly and Field, 1996; Kestenbaum, 1982). Individuals are forced to rethink their life journey when disablement and disability risk their present construct of 'self', conceptualised by Bury (1982, p. 167) as '*biographical disruption'.* This position reflects William's (1984, p. 197) notion that chronic illness '*assaults the taken-for-granted world*', the self-narrative is reconstructed and a journey of a '*never-ending cycle of biographical appraisals and reappraisals'* begins (Williams, 2000, p. 5).

Whilst one might assume that the temporal nature of the acute deterioration of health, unlike chronic illness, is such that the extent of bodily and disruption of one's 'self' construct is limited, recovery is realised and there is a degree of '*restitution*' (Frank, 1995), empirical findings suggest otherwise. Following critical illness, the '*restitution'* narrative imposes limitations as one searches for coherence, reconciliation, and validation (Ellingsen *et al.,* 2021; Etherington, 2003; Gajic *et al.,* 2018; Hashem *et al.,* 2018; Toombs, 1987). Adopting ethnomethodology, Rosenfeld (2006) found that the experience of acute illness and injury, independent of the cause, challenges one's '*embodiment*' and has significance for the future maintenance of a '*morally, socially and culturally competent self*' (Rosenfeld, 2006, p. 77), with Papathanassoglou and Patiraki's (2003) earlier findings supportive of the premise that '*rich in symbols of transformation'*, self and to some extent personhood is under perpetual reconstruction.

The research is replete with evidence that pathological changes secondary to an ABI result in disorders of cognition, executive functioning, personality, behaviour, and neurological function which affect one's perception of 'self' and self-performance (Cloute, Mitchell and Yates, 2008; Gracey *et al.*, 2008; Morris, 2004; Ownsworth, 2014; Power *et al.*, 2020; Ylvisaker and Feeney, 2000). There is a recognition too, that the patient, independent of their cognitive status, experiences a profound loss of selfhood which impacts significantly on their subjective experience, relationship with others and personal identity (Caddell and Clare, 2010; Morris, 2004; Naue and Kroll, 2009; Sabat and Harre, 1992). Feldhaus-Weber's work (2003, p.51) poignantly captures one's dissonance with an individual's sense of 'self' post-ABI: '*I felt like someone, but not like any one I knew. I was a stranger to myself*'.

Following the seminal work of Goldstein (1959), who highlighted the importance of addressing the neuropsychology of rehabilitation, empirical studies (Fraas, 2015; Nochi, 1998, 2000; Power *et al.,* 2020) have attempted to quantify the extent to which limitations of neurological and cognitive functioning and performance affect an individual's construct of 'self' and identity. Analysing the discourse from ten individuals following a traumatic brain injury, Nochi (1998), summarised the loss of self as multi-faceted, conspicuous when comparisons were made of their pre-injury capacities and threatened further by social labelling, with a later study (Nochi, 2000) adopting grounded theory to reveal several contingent narratives aligned to self which included the '*grown', 'recovering' and 'protesting'* self. Ownsworth (2014, p. 1) offers a comprehensive account of the psychological and cognitive influences on the identity of 'self', following brain injury. She views the aim of rehabilitation not as a reconstruction of 'self' but rather the '*personal meaning that individuals derive from their post-injury experiences'.* In presenting a schematic representation, she recognises that one's autobiographical 'self' is continually under construction and adversely affected when physical, cognitive, and behavioural impairments arise following brain injury. Gracey *et al*., (2008, p. 642) found that individuals whose construct of 'self' and identity were affected by brain injury, were particularly '*concerned with the personal meanings and feelings associated with activity, both practical and social'.* Using discourse analysis, Cloute, Mitchell and Yates (2008) explored how identity was co-constructed by individuals who sustained a traumatic brain injury and their informal carers. Firstly, the participants felt passive in their role as patients, they were simply recipients in a medical narrative. When they lacked a coherent memory of their time in coma, this served to compound their feelings of isolation and disempowerment. Patients also felt that their functional limitations and cognitive deficits resulted in dependency which exacerbated their feelings of passivity and disability. It was primarily the medical discourse that created a sense of dependency and as a result adversely influenced the participant's return to a sense of selfhood.

The nature of 'personhood' and relational dynamics due to more long-term deterioration in cognition and perceptual orientation seen with dementia, have been explored by Smebye and Kirkevold (2013). Adopting hermeneutic methodology, the inter-relational content and context of communications were analysed between the family, professional caregiver, and the patient. The findings revealed a broad interpretation of the nature of relationships which impacted both positively and adversely on the client with dementia. When care was focused on pragmatic, physical tasks, there was a distinct diminishing of personhood, whereas care which embraced collaboration and reciprocity centralised the patient and '*bestowed'* a sense of personhood on the client, particularly when care was not deemed to be duty bound or ritualistic. The perspectives of the family member as a witness to both the immediate and longer-term burden of changes to self, identity, and personhood secondary to neuropathology have been advanced by authors in the clinical neurosciences. Soeterik, Connolly and Riazi (2018) adopted interpretative phenomenological analysis to explore the experience of nine female caregivers for a family member diagnosed with a disorder of consciousness. Despite the individual being corporeally present, there was an enduring sense of loss, conceptualised as '*loss without a name'* and *'relationship without a title'* which served to re-define relationships henceforth. Anecdotally, within clinical practice, I have seen how family members 'search' for the familiar character and personality traits reminiscent of the person's 'self' prior to the ABI, as evidential indicators, or signifiers of an individual's recovery. It is this apparent 'searching' which suggests that concern lies in the possibility that some aspects of the person's previous 'self' has been irretrievably lost. This pursuit by family members to recognise character traits reminiscent of the individual during the recovery phase of an ABI, is defined as '*biographical attendance'* (Whiffin, 2012, p. 202; Whiffin *et al.,* 2017).

In summary, there is a wealth of empirical evidence of the neurocognitive, psychosocial, and physical sequelae following ABI. Through the lens of narrative, the autobiographical account captures the complexities and nuanced understanding of the illness trajectory, and in the context of narrative-bound research '*gives voice to an experience that medicine cannot describe'* (Frank, 1995, p. 18). In the immediacy of the post-ABI trajectory and upon discharge from services, the presentation of 'self' is appraised. The neurological complications associated with the ABI, risk the reconstruction of future self and identity.

## 2.7 Summary

This scoping review has recognised that as an anticipated sequela of an ABI, ASC is primarily measured clinically through the assessment of wakefulness, arousal, and awareness to establish levels of consciousness, along with the appraisal of other observable physical and cognitive presentations. Diagnostic tools serve to guide decision making, characterise clinical presentations and establish the extent to which recovery is realised. However, whilst the direct observation and assessment of the person who experiences a transitory period of an ASC contributes to the body of empirical evidence to inform practice, this positivistic discourse limits the ASC to a set of somatic responses and symptoms with limited attention afforded to the phenomenon's experiential and qualitative dimensions and an understanding as to how one negotiates their way through the ASC within the acute inpatient hospital setting.

Minkowski's seminal work on the philosophical conceptualisation of schizophrenia identified the disorder as a *'trouble générateur'*, a '*generative or generating disorder'* (Urfer 2001, p. 281). Grasping the *'generative disorder'* of disease seeks to reveal the '*intimate transformation of subjectivity underlying the manifold symptoms'* (Stanghellini, 2010, p. 322). The biomedical construct of an ASC comprises such ‘*manifold symptoms*’ deemed a collective representation of the disorder, and it is this narrative which dominates the clinical discourse. The cognitive and behavioural sequelae of ABI and the clinical presentation of an ASC are clearly foundational to the clinician’s assumptions about illness, but a focus on the positivistic discourse of these presentations risk subjugating both the personal biography of illness and the value of narrative work as evidence for practice. Reflecting Heidegger’s philosophy, Inwood (1997, p. 48) asserts that *‘someone who accepts and passes on the current chatter, even if the chatter happens to be in some sense correct, sheds no light of his own’.* Accepting the medical discourse of an ASC secondary to ABI without challenge or debate risks perpetuating the ‘*current chatter’.* Consequently, practitioners will continue to hold assumptions as to how illness is defined and constructed, not as a personal narrative which is rendered meaningful, but *‘in a technical and highly epistemological way’* where the context of illness will ‘*be notably absent and gaps or breaches in inter-subjectivity ensue’* (McManus Holroyd, 2007, p. 5).

The empirical and theoretical evidence to date offers insight into the functional and cognitive limitations of an ABI which affect one’s self-construct, identity, and relational dynamics. However, as a corollary to the ABI presentation, an ASC is viewed as a symptom amongst others, the experience of which is rarely considered or reflected upon once consciousness is regained. Whilst existing studies yield highly descriptive accounts of the lived reality of immersion in the perceptually disordered landscape of delirium and other pathologies, none have endeavoured to explore the interpretation and construction of meaning of the phenomenon of an ASC secondary to ABI.

## 2.8 Research Aim and Questions

This inquiry addresses the methodological gap in the empirical evidence by giving voice to the individual *in-ASC*, to recount their story, the memories explicated by their journey, and subsequently how they ‘returned’ to an orientated identity of ‘self’. Similarly, the perspective of the layperson witness and their phenomenological bound narrative will be important to explore within the distinctive, social setting of the hospital setting. Examination of the content and context of these ‘*communal narratives’* (Seaton, 2008), has the potential to draw attention to the collective and discrete meaning of the first-person experience of the phenomenon of an ASC secondary to ABI.

### 2.8.1 Aim of the Research

To explore the construction and interpretation of meaning of a transitory period of an altered state of consciousness (ASC) in the immediacy of the acute phase of the acquired brain injury (ABI) trajectory in the inpatient, hospital setting from the perspective of the patient and the layperson witness.

### 2.8.2 Research Questions

- What is the meaning of a transitory period of an altered state of consciousness (ASC) in the immediacy of the acute phase of the acquired brain injury (ABI) trajectory for the patient *in-ASC*, and the layperson witness *of-ASC?*

- What factors influence the interpretation and construction of meaning of a transitory period of an altered state of consciousness (ASC) in the immediacy of the acute phase of the acquired brain injury (ABI) trajectory for the patient *in-ASC*, and the layperson witness *of-ASC?*

# CHAPTER THREE: RESEARCH METHODOLOGY

## 3.1 Introduction

The following chapter offers a personal account of my epistemological and ontological position and presents a critical overview of several philosophical foundations which informed the adoption of hermeneutic phenomenology as the methodology for this inquiry. Debate follows as to the role of 'bracketing' in hermeneutic inquiry with a personal reflection of how I positioned myself both as a researcher and practitioner in the field of clinical neurosciences.

## 3.2 Epistemological and Ontological Positioning

> ***'Phenomenology is an ontology, the study of being and of real and possible things, since it focuses exclusively on the ways things appear and the relation between appearance and reality'.***
>
> **(Tarozzi and Mortari, 2010, p. 16)**

Epistemology has been defined as '*the philosophy and theory of knowledge, which seeks to define it, distinguish its principled varieties, identify its sources, and establish its limits*' (Bullock and Trombley, 2000, p. 279), or in brief, concerned with '*how we know what we know'* (Kafle, 2011, p. 194). Ontology relates to the nature or study of the reality of being (Crotty, 1998) which can be external to the individual or derived from one's subjective conscious experience (Cohen, 1987; Cohen, Manion and Morrison, 2000).

Ratcliffe (2009, p. 330) acknowledges that empirical, scientific knowledge '*does not comprise our most fundamental understanding of the world'.* From the biomedical perspective, an understanding of ASC has evolved over time and although objective assessments of ASC exist, there is little empirical evidence which recounts the meaning of ASC from the unique position of the patient and the layperson witness. Evidence-based decisions about the assessment of ASC and the pragmatics of care in the clinical setting have arisen from positivist discourse which privileges the quantitative reduction of ASC as a set of measurable behaviours, but this offers limited scope for full understanding of the phenomena. On reflection, and from personal experience of working with individuals following cerebral trauma or neurosurgical intervention who present with ASC, care is directed to the patient in a manner which aims to reduce the risk of deterioration, confirm diagnosis, and manage presenting behaviour change to maximise prognostic, clinical outcomes.

Epistemological knowledge arises from questions about 'what it is to know' and from the perspective of ASC within the scientific community, much is known in the clinical neurosciences about its aetiology, presentation, and management. However, what constitutes our 'knowing' or ontological position, needs to reflect a commitment to uncover the phenomena from an insider perspective otherwise one's subjective reality of ASC becomes lost amidst a biomedical orientated discourse. My view is that certain aspects of knowledge can only be derived through an understanding of what constitutes human nature and the motivations for action. As individuals, we are always embodied in the world and '*that is why visions of reality are so meaningful and revealing of social reality' (*Tarozzi and Mortari, 2010, p. 19).

Whilst the qualitative research paradigm has been influenced by different disciplines, the fundamental aim of phenomenology is to grasp the meaning of social action and interaction within the life-world of the individual and attempt at '*understanding, at making the individual case significant in the context of theory'* (Vasilachis de Gialdino, 2009, p. 5). Hermeneutic phenomenology, introduced initially as a philosophy but evolved over time as a qualitative research methodology, is clearly relevant for my work. It is Ray's (1994, p. 99) definition which captures the true essence of phenomenology's utility as a methodology for this research because it '*turns toward phenomena which have been blocked from sight by the theoretical patterns in front of them'.* I believe that the '*theoretical patterns*' of the clinical setting have overshadowed an interpretive, subjective understanding of the meaning of ASC. If one adopts Kuhn's (1962, p. 75) definition of paradigm as *'the entire constellation of beliefs, values, techniques shared by members of a given scientific community',* then understanding the meaningful reality of ASC as a lived experience for those who uniquely experience it, will contribute to the collective epistemology, or body of knowledge of ASC. Understanding how the participant's experience of ASC is influenced by their enculturation within the hospital environment and their relational engagement with others over time, will undoubtedly contribute to a more nuanced, holistic understanding of the phenomenon.

One's understanding of existence or situatedness in time and space is captured by Heidegger's concept of '*thrownness*' (Heidegger, 1962). If we are to truly capture one's being in the world of '*Dasein*' (Heidegger, 1962) and how the life-world of ASC is lived through as a state of primordial way-of-being in world, then hermeneutic phenomenology is clearly relevant. The relationship between the appearance of the phenomenon and its reality, '*rests on the fact that man is an interpretive creature'* (Armour, Rivaux and Bell, 2009, p. 106). Hermeneutic phenomenology is the means through which one is able '*to reach a meaningful comprehension',* an understanding which prioritises lived experience (Tarozzi and Mortari, 2010) from the first-person perspective. As Heidegger (1962, p. 60) aptly reminds us '*only as phenomenology is ontology possible'.*

## 3.3 Philosophical Framework and Grounding

The aim of this hermeneutic, phenomenological inquiry was to understand how a transitory period of an altered state of consciousness (ASC) is constructed and interpreted in the immediacy of the acute phase of the acquired brain injury (ABI) trajectory in the inpatient, hospital setting, from the perspective of the patient and the layperson witness. The study of the patient's and layperson witness' narrative, at a time when the previously orientated patient is immersed in a personal journey of perceptual disorientation and viewed by others as disengaged from reality, revealed the meaningfulness of ASC from a context-sensitive and ontological perspective, and contributed to the epistemology of the acute phase of the ABI trajectory.

The following discussion offers a focused summary of key philosophical foundations and how they informed the methodological decisions which grounded this inquiry.

Phenomenology '*discloses the manner in which the individual actively constitutes meaning of his experience*' (Toombs, 1987, p. 220) and as Merleau-Ponty (1962, p. vii) describes, is the '*study of essences'.* Founded by the German philosopher, Edmund Husserl, phenomenology challenged the traditional scientific and cartesian description of the world and turned attention to questions of human experience. Through the careful attention to, and the description and reflective analysis of phenomena, which Husserl called '*phenomenological reduction'* or *'epoche',* he believed that new knowledge and understanding would emerge. Husserl's philosophy focused fundamentally on the function of human consciousness as a means of knowing. For Husserl, the fixed 'essence' of human experience could be objectively sensed and described. His scholar, Martin Heidegger (1889-1976) however, moved phenomenology in a different direction, turning his attention to the study of hermeneutics, a philosophical position which values an interpretive narration of description. He believed in a philosophy which strived to uncover the meaning of experience, human situatedness and 'being-in-the-world', rather than adopting a reductionist approach to define the experience by a set of characteristics. Heidegger (1962) was particularly concerned not with epistemology but rather with problems of ontology and the nature of being and knowing, believing that traditional science limits and imposes constraints on understanding human agency. To understand human action and behaviour in the phenomenological sense requires attention to the person and his 'Being-in the World', or as Heidegger posits '*Dasein'* and for things which have significance.

Hermeneutics has been described both as a philosophy of interpretation (Grondin, 1994) and a methodology, whereby '*insights about the world and the human condition are generated, interpreted and communicated'* (Koch, 1996, p. 174). Indeed, for Heidegger, the focus of inquiry was not simply to extract an 'essence' or 'truth' of the phenomenon, but rather to understand individuals within and through their 'life-world'. Heidegger (1962) espoused that interpretation of the world and its significance, is generated against a background of cultural, linguistic, and historical traditions. The personal 'life-world' for Heidegger, can only be revealed through considered attention of our orientation to and involvement with the world. Any meaning which is revealed is therefore relative, authentic, and infinitely personal.

Plager (1994, p. 71) details several assumptions that can be identified from Heidegger's philosophy. Human beings are '*social, dialogical beings'* and there is always a shared understanding because of the way individuals experience the *'human community',* through which *'intersubjective and common meanings'* are revealed. The most profound assumption is that we are '*always already in a hermeneutic cycle of understanding'.*

In developing Heidegger's philosophy of hermeneutics, Gadamer's distinctive contribution focused on the interpretation of dialogue to better understand the complexities of the human condition. Whilst he did not dismiss the contribution of traditional, positivist approaches to knowledge, he believed that the '*scientific method must not be the sole recourse to answer questions arising from human life'* (Moules *et al.*, 2015, p. 36). His concern with the totality of understanding and meaning is evident when he writes, '*founded on modern medicine, we must repeatedly ask if something has been omitted*' (Gadamer, 1996, p. 153). The very nature and essence of what is 'omitted' is at the heart of any hermeneutic inquiry. Hermeneutic phenomenology focuses uniquely on the lived experience and the interpretation of this experience from an etic viewpoint, *'an engagement with and a commitment to, describing experiences in all its richness and layers'* (Finlay, 2011, p. 15). Whilst philosophers have proposed different emphases on the foundational principles of phenomenological inquiry, the central and founding premise is that through narration (Wiklund, Lindhom and Lindström, 2002) one's embodied lived experience is interpreted and made explicit (Packer, 1985).

## 3.4 The Philosophical Life-World Approach

***'Reflective life-world research seeks to know how the implicit and tacit becomes explicit and can be heard, and how the assumed becomes problematized and reflected upon'.***

**(Dahlberg, Dahlberg and Nyströ̀m, 2008, p. 37)**

The utility of phenomenology as a methodology is that it privileges "*the individual as a conscious agent, whose experience must be studied from the first-person' perspective'* (Ashworth, 2003a, p. 13). Understanding the meaningfulness of disease becomes accessible through interpretive work, because it positions the ontology of experience central to the inquiry and away from the '*natural confines of its traditional epistemological understanding'* (Jay, 2009, p. 94).

One's existence in the life-world, conceptualised as pre-reflexive, was initially introduced by Husserl (1970) who believed that experience is always in context, informed by history and culture. Husserl's commitment was to isolate the structure and invariant features of phenomena, the utility being that the distinctness of experience would be realised and meaning derivable (Zelic, 2008). In developing this life-world perspective, Merleau-Ponty (2002, p. 475) believed mind and body to be inseparable:

*'…my existence as subjectivity is merely one with my existence as a body and with the existence of the world, because the subject that I am, is inseparable from this body and this world'.*

Van Manen (1990, p. 19) advocates that the purpose of any phenomenological work is to *'construct an animating, evocative description (text) of human actions, behaviours, intentions'.* Indeed, his philosophical position presupposes that there is an inevitable structure to life-world research and that a '*universal or essence'* will emerge during analysis of the lived experience as encountered by individuals. He identifies four '*existentials*' to which all human experience belongs (Van Manen, 1990). Firstly, he suggests that an individual's experience is always within a '*lived space'* (spatiality) which affects how individuals contextualise their situated experiences. It is the cultural and social conventions and qualities with one's lived space which inform understanding. Secondly, we have a bodily presence in the world, defined as corporeality, which is felt subjectively but also observed by others. Finlay (2011, p. 30) describes the lived body as an *'embodied consciousness which engages with its surrounding world*', the experience of which is potentially altered throughout the illness trajectory and by the interpersonal relations that are encountered during this journey. Van Manen (1990, p. 103) suggests that when we encounter another, we inevitably reveal something about ourselves '*first of all through his or her body'.* At any moment, the corporeal body is sensed within, and assessed against the subjectivity of time or temporality. Finally, experiences are always with respect to others, in their reciprocal, interpersonal engagement, defined as '*lived relations'* or '*communiality*' (Van Manen, 1990).

It was the philosophical school of hermeneutic phenomenology[1] and the historical

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[1] In Greek mythology, Hermes was the Greek god of commerce, the son of Zeus and Maia. He was able to transcend different worlds, moving freely between boundaries and served as a guide developing powers of observation and prediction through, and within different life worlds. In bringing messages to the gods, Hermes characterised creativity, complication and invention, and in doing so was able to see things anew. The Latin word, 'hermeneutica' evolved from the theological and biblical traditions, influencing philosophical thought henceforth.

positions and legacies of Heidegger, Gadamer and Van Manen which influenced the methodological decisions of the study. Hermeneutic rather than descriptive phenomenology offered the potential for a more revealing, richer, and deeper view of ASC secondary to ABI. The interpretive nature of my inquiry acknowledged that whilst all participants experienced ASC in the hospital setting, it was the uniqueness of the situation, the context of the experience and the personal meaning for each participant which was revealing. In support, Ehrich (2005, p. 5) states that hermeneutic phenomenology should, '*explicate the meaning of human phenomena and help to understand the lived structures of meaning',* which inevitably construct the life-world.

A phenomenological approach illuminated ASC as a lived reality but also focused on the relationship between the phenomena of ASC and those who experienced it (Marton 1986; Marton and Booth, 1997). The primacy of the participant's voice and an understanding as to how ASC was constructed and shifted by experiences, was then revealed. I questioned whether different frames of reference existed, whether there was a collective understanding of ASC by the participants and how social and professional expectations, health care culture and personal representations influenced meaning.

## 3.5 Methodological Considerations in Hermeneutic Inquiry

### 3.5.1 Researcher Positioning and Hermeneutic Phenomenology[2]

> ***'The interviewer is not a neutral bystander and their direct contributions to shaping the narrative, as well as their representation of a broader social world in which the narrative is orientated, cannot be minimised or ignored'.***
>
> **(Stephens, 2011, p. 67)**

The interpretive position of the researcher and one's influence in the pragmatics of conducting a phenomenological inquiry have been debated at length (Crotty, 1996; Dowling 2004; Dowling and Cooney, 2012; Kahn, 2000; Wilkinson and Kitzinger, 2013; Van Manen, 1990). The following discussion presents an analysis of my positioning both as a researcher and a practitioner with experience in the field of clinical neurosciences. Whilst the empirical 'view' of ASC was formative in shaping my initial research interests, I had to consider how I situated myself within the research trajectory, cognisant that my personal constructs and assumptions as a nurse had the potential to influence both the

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[2] Aspects of text within 3.5.1 and 3.5.2 reproduced with kind permission of The Licensor through PLSclear (Licence granted 22.9.21). Buckley, A.R. (2016) cited in Nixon, J., Buckley, A.R., Cheng, A., Dymoke, S., Spiro, J. and Vincent, J. (2016) 'The Questionableness of Things'. Cited in McNiff, J. (2016) (ed) *Values and Virtues in Higher Education.* London, Routledge, Taylor and Francis Group, pp. 118-120.

researcher–participant relationship and the emerging analysis (Buckley, 2016).

Proponents of descriptive phenomenology require the researcher to engage in *'epoche'* or the bracketing or suspension of potentially prejudicial priori assumptions and pre-understandings of the phenomenon under study (Husserl, 1970). Adopting a position of detachment in which one '*sets aside all previous habits of thought,* enables one '*to see what stands before our eyes'* (Husserl 1931, p. 43) and allows the true meaning of experience and reality as described by the participants to remain central and accessible.

This conscious 'bracketing' of experience is purportedly achieved primarily by a process of reflexivity, whereby the researcher makes conscious and explicit the intention to acknowledge '*preconceptions and habits of the mind'* (Beech, 1999, p.36), referred to as the *'natural attitude'* (Paley, 1997). In contrast, hermeneutic philosophers from Heidegger onwards, have challenged such interpretive positions arguing that whilst one should make explicit personal assumptions, these are not set aside or bracketed. Pre-understandings and historicity are understood to contribute to familiarity with the phenomenon under study and exist as starting positions for interpretation: *'we cannot stand neutral, as though outside our current understandings'* (Finlay, 2011, p. 52). For Gadamer, the position of the researcher is paramount, as he is always located in a *situation.* As we are inevitably influenced by a historical position, then the interpreter must adopt as Nixon (2014) states, a '*historical horizon'* whereby there is a conscious intention and acknowledgement of bias which may influence the interpretation. Gadamer (2004, p. 336) refers to this as '*consciousness of being affected by history'*.

The researcher's task is to consciously examine their fore-meanings and decide with a degree of appropriation which are the relevant and important intuitive links to the experience being investigated. Gadamer argues for deliberation and that this '*importing of ourselves into the process of understanding is a necessary component of that understanding'* (Nixon, 2014, p. 4). In a sense, the researcher needs to adopt a position of intellectual humility so that the authenticity of the participants' voice emerges clearly and with transparency. An acknowledgement of one's assumptions is necessary so that '*the text, as another's meaning, can be isolated and valued on its own'* (Austgard, 2012, p. 830). Indeed, it could be argued that the prejudices of the researcher are a 'view', which inevitably bestows meaning and is the very source of our repertoire of knowledge. I believe the negative attribution of researcher's 'prejudice', should be redefined and seen as a positive influence on the explication of meaning derived in the interpretive paradigm (Buckley, 2016). As Gadamer (2004, p. 392) posits, we already belong to the *'tradition'*, it '*becomes part of our own world*' and we have a relationship with the case. My 'situatedness' and relationship not only with patients but with the culture and tradition to which I belong needs to be viewed as important assets to the research and a valuable guide to inquiry, rather than a distraction or encumbrance (Buckley, 2016). The iterative process within hermeneutic inquiry acknowledges the centrality of the researcher as an interpreter and their '*historical horizon'* and familiarity with the phenomenon being studied, because as a starting position, we inevitably '*understand the world in and through our experience of the world* (Nixon, 2014, p. 4).

Drawing on the idiographic and philosophical traditions of hermeneutics, Interpretive Phenomenological Analysis (IPA) has been widely adopted across health and social psychology and cognate disciplines (Larkin, Shaw and Flowers, 2018; Pietkiewicz and Smith, 2014; Reid *et al.*, 2005; Smith, 1996; Smith, Jarman and Osborn, 1999; Smith, Flowers and Larkin, 2009; Smith, 2011; Smith, 2017; Sousa, 2014). IPA was initially considered as the methodology for this inquiry, however it was rejected for several reasons. IPA is suffused with hermeneutic philosophical traditions which situate the person's sense-making as central to inquiry because it sees *'the world as it is experienced by the respondent'* (Flowers *et al.*, 1998, p. 412). However, there is a tacit acceptance that the researcher's a-priori knowledge of the field is suspended or bracketed (Smith *et al.,* 1999). Secondly, whilst the degree of flexibility afforded by IPA's lack of prescriptive methodology (Giorgi, 2011; Smith *et al.,* 1999; Reid, Flowers and Larkin, 2005; Tuffour, 2017) has popularised it adoption within humanistic sciences, debate continues as to whether the philosophy of IPA is rigorously carried through in the methods (Giorgio, 2011; Pringle *et al.*, 2011; Sousa, 2008; Sullivan, 2014; Tracy, 2010). Thirdly, Paley (1997, 2005) offers caution in the adoption of phenomenologically influenced methodologies which are deemed hybrids or collectives of philosophical positions. Without a critical acceptance or challenge of IPA's philosophical and methodological origins, its adoption risks the misappropriation and misinterpretation of the founding principles of hermeneutic phenomenology. Despite IPA's appeal to the hermeneutic tradition and its increasing popularity, returning to the primary, historical hermeneutic text for an account of the foundational philosophical positions, confirmed hermeneutic phenomenology and not IPA, as the methodology for this inquiry.

### 3.5.2 Reflexivity

Reflexivity involves the realisation of the need for an honest examination of the values and interests of the researcher that may impinge upon research work (Primeau, 2003). Fischer (2009, p. 584) challenges the notion of objectivity by recognising that '*it is not possible to view without viewing from somewhere'.* Crotty (1998, p. 17) rightly acknowledges that throughout the research journey, there is an inevitability that the assumption and 'situatedness' of the researcher will shape *'for us the meaning of research questions and the purposiveness of research methodologies'.* Van Manen (1990, p. 20) explicates an interesting perspective on the objectivity-subjectivity debate. He suggests that they are not mutually exclusive either in their definitions nor within the hermeneutic research process. The researcher is viewed as the *'guardian and a defender of the true nature of the object'.* Subjectivity is achieved when the researcher remains actively engaged and attentive to the object of study. Gadamer's philosophy supports such reflexivity and an honest evaluation of my position and 'view' of ASC, because it gave a '*real thrust'* (Gadamer, 2004, p. 272) to the hermeneutic inquiry.

By establishing my own temporal positioning and pre-suppositions, I was able to view the participant's narrative text with a more nuanced understanding. I reflected at length on my professional experience whilst supporting patients and their significant others within the clinical environment. My fore-groundings and historical horizons of ASC have inevitably evolved over many years of clinical experience and through involvement in different clinical scenarios. The nursing *'tradition and culture to which I belong*' (Austgard, 2012, p. 830) are fundamental tenets of who I am as a practitioner and the knowledge I brought to bear to this inquiry.

I have assessed patients diagnosed with different pathologies who have subsequently presented with an ASC and observed their varied behaviours and clinical presentations. The Glasgow Coma Scale (GCS) (Teasdale and Jennett, 1974) defines levels of consciousness through the assessment of an individual's eye opening, verbal and motor responses. The improvement or deterioration in a patient's GCS, along with other clinically informed assessments guide therapeutic interventions and decision making. However, whilst the GCS is universally recognised as a clinically valid and reliable indicator of wakefulness and awareness, the reductionist nature of the tool limits the practitioner's engagement with, and the assessment of, the nuanced behaviours, actions, and responses of the patient *in-ASC.*

I had become increasingly familiar and comfortable with the clinical and medically informed discourse present within the neuroscience care setting. On reflection (and with some trepidation in such a disclosure), my personal construction of professional knowledge and competence have been informed by this biomedical discourse. Despite this, my personal philosophy of care has always been to 'see the person within the illness'. As an academic involved in the delivery of undergraduate nursing programmes, I am an advocate of the value of the illness narrative in pedagogy, but on reflection, whilst nursing patients who experienced time *in-ASC*, it had never occurred to me to enquire as to the nature of their experiences of ASC or consider how memories of this time may influence their recovery henceforth. I am unsure why these questions lay dormant at the time. Perhaps I had concern that encouraging a patient to reflect on their experiences of ASC on recovery would be potentially distressing, or there would be little motivation for patients to share their stories.

During my time in clinical practice, I always believed that the support of families and their significant others was important, particularly within the neuroscience setting where the nature of clinical diagnosis and prognosis is difficult and at times, traumatic and unpredictable. I felt confident in my skills in providing support during their journey and have been empathic as they bore witness to the uncharacteristic behaviours and actions of their loved one *in-ASC*, the personality changes frequently seen post-ABI and uncertainty in prognostic outcomes. Yet, deep reflection has made me question whether I have always focused, to the extent I perhaps should have done, on the meaning that ASC had for those who bear witness. Understanding their perceptions and experiences *of-ASC* in the context of the hospital environment and the consequences for them and their relationship with their 'loved one' had perhaps not been part of my support.

### 3.5.3 Reflections of Researcher Positionality and Hermeneutic Phenomenology

In recognising that one's fusion of horizon comprises '*the range of vision that includes everything that can be seen from a particular vantage point'* (Gadamer, 2004, p. 336), I had to acknowledge that my vantage point shifted as I developed my understanding of the influence of the extant literature, during the interviews and engagement with the participants, through to interpretation and beyond. Similarly, whilst I had reflected on my prejudices at the beginning of the study and considered how these positioned my thinking and motivations both as a nurse and researcher, this had to be a dynamic and ever evolving process. As Heidegger (1992, p. 369) reminds us, '*we truly incline toward something only when it in turn inclines towards us'*.

An initial meeting at one of the support meetings where relatives began to share their narratives was revealing and profoundly humbling. I began to understand how formative their experiences had been, the hours they had spent at the bedside and the challenges they had faced. The members shared their stories so freely and with such transparency that I began to understand how personally transformative and on occasions, deeply distressing their illness trajectory had been and the continuing challenges they faced on discharge from the inpatient services. As a practitioner, I had failed to appreciate the extent and longevity of their difficulties. There appeared such an unmet need. They had truly suffered and, and in some instances continued to do so. I felt that services had somehow let them down, and yet despite this, they remained resilient. Their stories left me questioning the depth of my empathy, along with my professional priorities and motivations during my time in practice. Using a journal to record my experiences and reflections was important (see diary extract: Appendix 4), I was able to see how from my initial introductions with potential participants through to data analysis, the influence of my *horizon* and *prejudices*. Although already immersed in the tradition of nursing, I recognised the limits to my understanding of ASC whilst acknowledging that my *'prejudices'* positioned my horizon of thinking as I engaged with the participants. I could see how their narratives tested my '*prejudices*' and how my '*foregroundings'* as a nurse informed the '*horizon of the present*' (Gadamer, 2004, p. 340).

I have been privileged to meet participants who welcomed me into their space, who narrated their stories unconditionally and with such honesty and authenticity, following a time when ABI had been an untimely and unwelcome disruption in their life trajectory. I was humbled by their experiences and felt privileged they had shared their autobiographies, personal stories which belonged '*not to the physician nor to the literary scholar'* (Shapiro, 2011, p. 71). On reflection I feel justified that I acknowledged I was a nurse with a clinical background and research interests in neurosciences. Gadamer (2004, p. 330) states that hermeneutics *'must start from the position that a person seeking to understand something has a bond to the subject matter'.* To hide my *historical position* as a practitioner would have been disingenuous and misguided. My clinical background afforded me a common language with the participants. As Moules *et al*., (2015, p. 121) acknowledge, my foregrounding and prejudices as a practitioner served to '*mobilise the space of understanding between the researcher and the topic*'. It was in the '*hermeneutic space*' that I felt able to clarify, delve deeper and gain more than an appreciation of the content and context of their narratives. I could visualise the spatiality of the hospital, recognise the context of their relationships and communication with clinical staff, and as a result became the '*empathic witness'* (Kleinman, 1989) to their narratives. Whilst Moules *et al*., (2015, p. 98) acknowledge that neither the participant nor the researcher *'depart from the interview unchanged',* I perhaps failed to appreciate the emotional and demanding nature of hermeneutic work ((McCaffrey, Raffin-Bouchals and Moules, 2012).

In summary, the discussion has presented my epistemological and ontological stance and justified the adoption of hermeneutic phenomenology as the methodology for this inquiry. The life-world approach to hermeneutic inquiry has been introduced along with a critical, reflexive discourse of my positioning as a nurse and a researcher in the context of my 'historical position'. The following chapter will detail the study design and methods which grounded this inquiry.

# CHAPTER FOUR: STUDY DESIGN AND METHOD: A HERMENEUTIC PHENOMENOLOGICAL INQUIRY

> ***'The great deceit of Western physico-materialistic medicine is that diseases are separate from who we are and what we experience, separate from our stories. This is not so. The primary goal then is to show that the meaning- fullness of disease does make sense, that it is something to be taken seriously, and if we do so we create potential for healing and clinical practice'.***
>
> **(Broom, 2007, p. 4)**

## 4.1 Introduction

The concept of '*intentionality'*, initially proposed by Gadamer (2004, p. 198) as an essential quality of consciousness, purports that in the immediacy of one's life-world, '*consciousness is consciousness of something*', and always directed to an object. Objects which are empirically sensed are defined as *real,* and those which are not within the physical realm of experience, but nevertheless present in one's consciousness i.e., hallucinations and delusions, are *irreal* (Giorgi, 2014). However, independent of the nature of phenomenon, the fact that they are given to us as a subjective experience suggest that they are meaningful (Kohák, 1978; Wiggins and Schwartz, 2007). Giorgi (2014, p. 247) contends that in the field of psychology, by moving away from empiricism and attending to *'irreal phenomena and the irreal dimensions of real phenomena*', one can be '*faithful to human presentive acts and consciousness's modes of presencing'.* The adoption of hermeneutic phenomenology as discussed in chapter three, was therefore an appropriate methodology to explore the testimonies of the patient's *irreal* experiences *in-ASC* secondary to ABI, and the *real* experiences of the witness who resides by the bedside, within the acute hospital, inpatient setting.

## 4.2 Sampling

In hermeneutic phenomenology, participants are chosen because they have requisite experience of the phenomenon (Cresswell and Plano Clark, 2011; Denzin and Lincoln, 2013; Merriam, 2009). In this inquiry, the 'patient' is defined as an individual who has sustained an ABI and self-reported a transitory period *in-ASC* during the acute phase of the hospital admission.

Recovery from an ASC is recognised as variable and unpredictable, with individuals categorised as the '*normal to recovery'* group who wake from coma within six months post-injury but with varied functional and cognitive limitations (Ansell and Keenan, 1989). It was this group of patients who had been discharged from healthcare services but were able to reflect upon and articulate their lived experiences of ASC who were eligible for the study. The layperson witness (henceforth defined as the ‘witness’) was a spouse, partner or significant other, who spent time at the bedside of an individual *in-ASC,* within the acute, inpatient setting.

For both participant groups, time since the ABI, recovery from ASC or discharge from inpatient services were not prescribed, but such that there was a significant time duration, so they were able *‘to gain a reflective grasp of their own life’* (Frank, 1995, p. 98).

Purposive sampling, or defined by Polit and Beck (2004, p. 306) as ‘*nominated sampling’* was employed. There is an ongoing, conceptual debate particularly with phenomenological inquiries about whether theoretical saturation is sought (Whitehead, 2004) and how data saturation, or as defined by Sandelowski (2008, p. 875), ‘*informational redundancy’* is achieved (Lincoln and Guba, 1985; Creswell, 1998; Morse, 2000; Baker and Edwards, 2012; Rubin and Rubin, 2012; Sandelowski, 1995). Vasileiou *et al.,* (2018) advocate decisions should be informed by methodology and study design, and the pragmatics of access to participants and resources. No decision was made in advance of the commencement of the study to define the sample size, as it was difficult to predict at onset how many patients would be able to recall memories during ASC, and for those who could, whether they would be in a position to be involved. The iterative relationship between sampling, the inductive and exploratory approach to data analysis (Tuckett, 2004), and the depth and richness of the textual data was such that a pragmatic decision was made to conclude data collection when ten patients and eight witnesses had been interviewed (Lincoln and Guba, 1985; Morse, 1991; Morse, 1995).

## 4.3 Participant Inclusion and Exclusion Criteria

### 4.3.1The Patient *in-ASC*

| **Table 1** |
|---|
| **Inclusion criteria** |
| A patient who self-referred and was able to recall a time *in-ASC,* secondary to a self-defined ABI during the acute phase of the inpatient hospital setting |
| Adults 18 years and over |
| Able to provide informed consent |
| Recruitment at any length of time following ABI and discharge from NHS inpatient and community services |
| **Exclusion criteria** |

| |
|---|
| A patient who experienced a period *in-ASC* but was either unable to remember this time, had limited memory or did not feel it was appropriate to participate in the study. |
| Minors, under the age of 18 years |
| A patient who was unable to provide informed consent due to a lack of mental capacity and /or significant limitations in cognitive and executive functioning. Determined through discussion with regional Chairs / support coordinators in consultation with individual members of the charitable network group |
| A patient with a self-reported mental health diagnosis / illness prior to the ABI |

### 4.3.2 The Witness *of-ASC*

| **Table 2** |
|---|
| **Inclusion criteria** |
| Spouse, relative or significant other who was witness to an individual *in-ASC* during the acute phase of the ABI trajectory in the inpatient, hospital setting |
| Adult, 18 years and over |
| Able to provide informed consent |
| Recruitment at any length of time following the patient's presentation of ABI and discharge from NHS inpatient and community services |
| **Exclusion Criteria** |
| Minors, under the age of 18 |
| Unable to provide informed consent |
| The patient, as a spouse, relative or significant other, who did not give consent to the witness to participate in the study |

### 4.4 Recruitment Phase

All participants were recruited purposively through a UK national charity which provides a supportive network for those who have sustained an ABI, and to family, friends, and significant others, during the recovery phase of ABI and beyond. I made an initial approach to the National Research Director of the UK charity who subsequently referred me to the Facilitators or Chairs of the regional support groups. With their consent, I attended several local support groups where I introduced myself and explained the remit of, and rationale for my research. I was able to discuss the voluntary nature of consent, right to withdraw interest or involvement, and the participant's control over what was disclosed during the interview. Copies of a flyer (Appendix 5), the  Patient Participation Information Sheet

(Appendix 6) and the Witness Participation Information Sheet, which included my personal contact details should members wish to have a further conversation with me and /or consider involvement, were left for perusal. Following these initial introductions, potential participants expressed their interest, and during further contact (either at a further pre-arranged meeting or through telephone contact), I provided them with more detailed information about the study (Appendix 7).

A '*snowballing*' (Goodman, 1961) effect to recruitment was seen when I was contacted by other potential participants who had not attended these meetings but were members of the charitable organisation or had close association with existing members. One member expressed an interest to be involved but their case had been referred for consideration of medical negligence. Following consultation with their litigation team, the member was advised not to engage. Other members of the group also expressed interest in my work and whilst they were aware they had experienced a period of altered consciousness post-ABI injury, they either had limited or no memory of this time, or for those who did have some recall, felt on reflection, participation would not be in their interests. As I was not privy to the medical history of members who came forward, I valued guidance from the Chair and Facilitators of the local network groups about the suitability of potential participants. The nature of an ABI is such that individuals may present with vulnerabilities which may include cognitive impairments, limits to mental capacity, and personality change, which are not always evident during initial introductions. Along with the Chair or network Facilitators, discussion took place with the participants and I, as to their eligibility and suitability to participate in the study**.** Whilst the meetings also support relatives and significant others, several potential witnesses did not feel it appropriate to participate in the absence of the individual who had sustained an ABI.

For the patients and witnesses who agreed to participate in shared, collaborative interviews, the likelihood that experiences would be heard from the first time, was discussed in advance. The charity offered me private space, either during the weekly planned meetings or at an alternative time to conduct the interviews. For the participants who expressed preferences to be interviewed elsewhere, I visited their home or negotiated alternative accommodation. On these occasions, I adhered to the University of Cumbria (2015/2020), '*Lone Worker Procedures for Researchers'* policy.

## 4.5 Ethical Considerations

***'One of the most difficult duties as human beings is to listen to the voices of those who suffer. Listening is hard but it is also a fundamental moral act'***

**(Frank 1995, p. 25)**

Frank (2000) asserts that ethics is a primary concern in any engagement with illness narratives in so far as matters of methodology. Following minor amendments, ethical approval for the study was granted by the University of Cumbria, Ethics Committee, in June 2015 (see Appendix 8). I provided assurance that the principle-based ethical framework proposed by Beauchamp and Childress (1994), namely attention to the promotion of autonomy, beneficence, non-maleficence, and justice, grounded the tenure of the study. However, adherence to an ethical code of practice should only be part of the moral protection afforded to potentially vulnerable participants.

Throughout the study, I was cognisant of the evolving moral landscape of hermeneutic work and mindful of my accountability as a moral agent. I developed an ongoing attunement and responsiveness to the methodological challenges which presented themselves throughout the study. Relational ethics is defined '*as an action ethic that is placed within the interpersonal relationship'* (Upasen, 2017, p. 2) and requires the researcher to be morally attentive to the developing interpersonal and dialogical conditions which inform the relationship with the participants. However, there must be recognition of the wider reach and relevance of 'relational'. It is about a moral sensibility to one's relationship with the philosophy of hermeneutic work, to its guiding characteristics, to my positioning of self and acknowledgement of my historicity as a practitioner. Every stage of the research process requires one to be alert to the evolving and at times unforeseen, context-driven ethical challenges. As Posel and Ross (2014, p. 3) remind us, research and ethics is *'often unruly and abidingly ambiguous, their complexities resistant to simple and neat formal assurances'.*

Listening to illness narratives by those who have perhaps never shared such personal accounts requires the researcher to attend to the conduct of the interview and consider the moral consequences of narrative telling. I hoped that my initial introductions at the charitable support meetings would be formative in raising interest. However, I was morally obligated to ensure that I was clear in articulating to prospective participants, the ethical nuances of participating in the research. There was a potential risk that the recall of memories of ASC may be distressing, memories which may not have been remembered to such an extent since their discharge from hospital. Whilst the effect of their recall was difficult to gauge, possible consequences were explored when patients initially expressed interest to be involved in the study. Participants were assured that if at any time during the interview they wished to terminate the interview and / or withdraw their involvement in the study, their decision would be wholly respected. A 'Debriefing Letter' was given to the participants following the interview which provided my contact details and that of the Charitable Trust should they require further support (see Appendix 9).

There is broad agreement that qualitative research is not simply about the gaining of consent for the story to be told, but rather as Frank (2002, p. 115) asserts:

'*The researcher who solicits people's stories does not simply collect data but assents to enter into a relationship with the respondent and becomes part of that person's on-going struggle*'.

The moral responsibility of the researcher, particularly in studies which combine description and interpretation is complex. Following my initial introductory meetings at the support groups, I reflected on several, potentially ethical and personal considerations. Whilst there was variation in the willingness of members to be formally interviewed, several individuals approached me to informally recount their stories of illness and the challenges they had faced during protracted periods of hospitalisation and rehabilitation. Some were keen to explain that whilst they could not remember being *in-ASC*, they nevertheless had a valid personal story to recount and felt empowered by the opportunity I had offered them. The development of a relationship with individuals at these introductions and my presentation as someone who has knowledge and understanding of their clinical experiences appeared to influence the group's acceptance of me. In this way there was not only collective support and empowerment but a sense of safety in disclosure.

Schultz and Flasher (2011, p. 395) acknowledge that illness narratives have the '*ability to benefit patients as well as the potential to cause harm or iatrogenic effects*', but these consequences are also contingent upon '*how the story is told and understood'.* Invariably, because there is a degree of ambiguity and uncertainty in storytelling, it was somewhat difficult to predict the degree of beneficence and maleficence that results, both during and after the interview. The researcher enters a privileged relationship with the narrator of storied accounts of illness. It was important that the group members viewed me, not as a transitory imposter with the intention to 'take' and reduce their stories to 'data' for academic gain, but someone who had a genuine interest in their narratives. At an introductory meeting at one of the support meetings, a member had been left disillusioned and suspicious of the motivations of an academic from another Higher Education Institution who had previously visited the group:

*'We get a lot of people from universities wanting to do research on us'.*

'*Research fatigue'* (Clark, 2008), embodied in the group member's comment, is seen when participants of a study tire of repeated invitations simply because they belong to a homogenous group, whose characteristics are deemed to be of interest to the academic community (Emmel *et al*., 2007; Clark, 2008). It was the *'on us'* that was particularly poignant. To the group, I represented academia and unless I shifted their perceptions, participants risked perceiving they were objects of academic curiosity. It was important that I was authentic in my engagement with the group members and transparent as to my motivations.

Whilst the deductive application of a principlist framework affords a degree of ethical protection for all parties employed in narrative work, I feel it fails to completely address the ethical nuances and emerging considerations for both the participants and the researcher who are immersed in narrative work (Campbell, 2003). Attention needs to be paid to the moral character and the emotions of context. I frequently reflected on the emotionality of the research narratives, the potential vulnerability of the participants and how I was ultimately perceived by those who had been so generous with their time and honesty in their disclosures. As a nurse I was 'present' in their narratives and ultimately became part of the meta-narrative that evolved during the interviews. However, the researcher needs to facilitate a space whereby participants maintain their narrative agency. I was conscious not to identify myself as the 'nurse' in their stories or comment on the management of care to avoid re-framing their accounts.

In summary, negotiating the moral maze of hermeneutic research cannot rely on being in possession of a set of guiding ethical principles alone. The hermeneutic path is too undulating and unpredictable. I had to develop a moral sensibility and responsiveness to the ethical particularities of the study as they presented themselves and appreciate that studies which seek to capture the lived experience present a web of moral uncertainty, which must be negotiated through with sensitivity and compassion.

### 4.6 Returning to the Participants

Whilst authors support returning to the participants for member-checking (Colaizzi, 1978; Hycner, 1985; Van Manen, 1990) others believe it to be incongruent with the philosophy of hermeneutic phenomenology (Crowther *et al.*, 2017; Giorgi, 2006; Webb and Kevern, 2001; Webb, 2003) asserting that because there is never certainty in interpretation, the pursuit of interpretive finality or 'truth' is futile. McConnell-Henry, Chapman and Francis (2011, p. 5) lend support to this view, arguing that '*the interpretation of data can differ each time texts are revisited and questioned, depending on the disposition, time and space of the researcher',* to the extent that follow-up interviews are invalid. However, the offer of a return interview was discussed with the participants as it provided an opportunity for what Frank (2002) believes is a *'dialogical recognition'* and affirmation that for the participants, their account holds inherent value (Zambas, 2016). Van Manen (1990, p. 99) suggests that following the identification of tentative themes, a return to the participants allows for the question: *'is this what the experience is really like'* to be answered and provides the opportunity for both the researcher and the participant to '*self- reflectively orient* *themselves to the interpersonal and collective ground that brings the significance of the phenomenological question into view'* (Van Manen, 1990, p. 99).

As I anticipated there would be a temporal constraint before the completion of transcription and data analysis, I applied for ethical approval for amendments to the initial approval (see Appendix 10) and to the Participant Patient and Witness Consent Forms (see Appendix 11 and 12 respectively). The revised forms provided documentary evidence that during the initial interview I had discussed whether the participants had requested a copy of the transcript and / or consented to a further discussion. With their expressed consent, returning to three participants, one patient and two witnesses, was consistent with the perpetual movement of the hermeneutic cycle between the text and one's interpretation and served to deepen mutual understanding. During the return interview, I used their interview transcript as an informal template to demonstrate how the '*meaning structures*' emerged from their narrative accounts and this served as a platform for further discussion. Any new and relevant data which transpired from these interviews was included in the analysis (Colaizzi, 1978). My interpretative findings resonated with the participants, and they were able to relate to the existential life-world discussions which had emerged from the analysis. Aside from the methodological rationale, several participants requested a copy of the transcript and expressed an interest in my analysis during the initial interview.

### 4.7 Data Storage and Protection

Only I, as the lead researcher, members of my supervisory team and participants of the study had access to personal biographical and research data during the tenure of the study. Assurance was given that as a member of staff at the University of Cumbria, I would act as custodian and ensure that data collected was managed and stored accordingly. All research data was treated in accordance with the Data Protection Act 1998 / 2018 and associated General Data Protection Regulations (2018), common law duty of confidentiality, UK Policy Framework for Health and Social Care Research (NHS Health Research Authority, 2020) and University of Cumbria Data Storage Guidelines (University of Cumbria, 2015/2020). The primary data (audio recording files, consent forms and hard copy transcripts arising from the audio recordings) was stored in a lockable cupboard, the key to which was held securely and only I, the lead researcher, had access. Portable media devices used to store or transfer data were encrypted and data stored on University of Cumbria computers was password protected.

The participants were assured that any identifying personal and biographical data was anonymised at the point of transcription, and confidentiality assured throughout the duration of the research process. Participants were given a pseudonym, and this was adopted when presenting findings of the study to contextualise the voice of the participants. One participant requested to choose their pseudonym, and this was respected. The participants were informed that their transcript may be directly quoted in any research output. I explained that particularities of their experiences shared during the interview had the potential to identify them and therefore risked breaching their confidentiality. Consent was gained either to present the data in its entirety or refrain from publishing particular aspects. Any digital recordings, files and manual records compiled during the tenure of the study will be destroyed using the confidential waste disposal service at the University of Cumbria, two years post-publication and completion of the thesis. This will allow for further review and analysis of the data and aid any future queries about the conduct of the research and intellectual property rights.

### 4.8 Data Collection: The Interview

Kinsella (2006, p. 3) invites the reader to consider the characteristics of a hermeneutic approach to data collection, the aim being to seek an understanding of the phenomenon, rather than to provide a formal, conceptual, and authoritarian explanation. Recognising that any interpretation is contextually situated within a socio-cultural and historical life-world, the inquiry should be conducted in such a manner that meaning of ASC emerges as an authentic description of the experience. The willingness to narrate experiences should not be suppressed nor constrained by either the format of the interview or the conduct and presence of the interviewer. Rather than a structured dialogue with participants, the researcher is required to enter a conversation where ambiguity is expected (Mishler, 1986).

Gadamer's philosophy was an important guide as to how I positioned myself as the researcher and managed the dialectic of questions and answers throughout the interview. For Gadamer, a subject is understood through genuine open conversation and the to-and-fro of dialogue. It was this '*fusion of horizons*' (Gadamer, 1976, p. 95) which occurred during the interview that allowed for a more revealing, shared understanding and meaning to evolve. Gadamer (2004, p. 391) emphasised that a genuine conversation is achieved when both parties '*adopt a fundamental sort of openness'* and consideration is given to *'the essence of the question'*. The researcher is required to adopt a degree of humility where one begins from a position of not knowing to one which *'breaks open the being of the object, as it were'* (Gadamer, 2004, p. 391). In this way, there is a sense of indeterminacy and unpredictability as to the meaning of the participant's experience. For Moules *et al*., (2015, p. 41) the characteristic of a genuine conversation is '*that both participants find themselves subordinated to the flow of the conversation itself, so that it is the subject matter that leads'.* The adoption of a conversational style revealed a richer and more nuanced narrative account. As Van Manen (1990, p. 98) states, the conversation needs to have a ‘*hermeneutic thrust’* and it is the responsibility of the researcher to maintain orientation to the phenomenon. In narrative interviewing, the quality of the narrative is dependent on the nature of the alliance created by the interviewer. I disclosed that I had worked in the field of neuroscience nursing, and therefore held a degree of familiarity with the context of the study. I referred to myself as nurse with a particular research interest in understanding the lived and personal experiences of illness. As a nurse with expertise within the field of neuroscience nursing, I was confident I had the emotional intelligence to engender a safe space for the participants. Whilst remaining respectful of the ‘*primacy and immediacy of the participant’s narrative*’ and ‘*acknowledging that participant-researcher dynamics’* existed, the ‘*utterances, descriptions and dialogue of the participants emerged as the dominant and authentic voice’* (Buckley, 2016, p. 118).

Heidegger (1927/1969, p. 269) states that in any hermeneutic endeavour *‘the very fact of posing a question is disclosure, for to question is to sketch in advance the context of meaning in which a particular inquiry will move’.* The interview was an invitation for the participants to share their memories of ASC, and for some, their first opportunity. Meaning evolved and became ‘layered’ as the interview progressed. The participants were observed ‘moving’ through the hermeneutic circle where upon they described their experiences and sought clarification, validation, or mutual understanding of their experiences. Interpretation and sense-making became a shared endeavour, an example of participatory sense-making defined by Gallagher (2012, p. 120) as ‘*making sense of the world, a co-constitution of meaning’.* For Heidegger, interpretation takes place in all our encounters against the backdrop of our individual histories (Laverty, 2003) and so the interview became part of their ‘history’ of the ASC meta-narrative. For the participants, recounting experiences in the immediacy of the interview opened further opportunities for reflection and sense making. There were many occasions during the interview when the participants paused, were reflexive and engaged in active meaning-making.

### 4.9 The Interview Questions

In grounding the ontological orientation of the inquiry, the phenomenological question should comprise ‘*an element of wonder: discovering the extraordinary in the ordinary, the strange in the taken for granted’* (Van Manen, 2014, p. 298). It was important that I framed my research questions so that the participants’ lived-through, experiential narrative of an ASC was accessible and revealed in all its fullness. To this end, I avoided the adoption of a repertoire of pre-arranged questions which risked constraining and directing the interview but identified possible questions which were open and reflexive in nature and if required, would serve to gently guide the hermeneutic conversation.

Husserl (1970) identifies *'noema'* as the phenomena which is experienced and '*noesis*', the way it is experienced, and it was these positions which informed the development of guiding questions. Questions invited the participants to describe the phenomenon of ASC in the context of the ABI, the '*noema*', and encouraged the emergence and interpretation of ASC from the first-person perspective, the '*noesis'.*

### 4.9.1 The Patient *in-ASC*

The patient was invited to briefly describe what they could recall about the sequence of events immediately prior to their admission to hospital and their understanding of the ABI. Once the context of their experience was understood, whilst not exhaustive nor exclusive, the following questions guided the conversation:

- Can you describe the time when you were in an altered state of conscious (ASC)?
- What do you remember about being in an altered state of consciousness (ASC)?
- Can you remember being in the hospital?
- Could you describe what you remember about your experiences?
- Can you remember how you felt during the time you were *in-ASC* or coming out *of- ASC?*
- What did it mean to you?
- How do you think you looked to others?
- What do you think your behaviour meant to others?
- How do you think your behaviour affected others?
- Do you remember anything particularly which you have thought about since?

### 4.9.2 The Witness *of-ASC*

The witness was asked to briefly describe the sequence of events immediately prior to and following the patient's admission to the acute inpatient setting and provide an account of their role and involvement in supporting the patient. Once the context of their experience was understood, then the following questions guided the conversation:

- Can you tell what it was like for you when you sat by his/her bedside in the hospital?
- What was he / she doing, saying?
- How was he / she behaving? What did it feel like to watch him/her behaving in this way?
- How did you respond?
- How did his / her behaviour affect you?
- What did the nursing or medical staff do?
- What did his/her behaviour mean to you?

## 4.10 Reflection: From Description to Meaning – The Hermeneutic Interview

If the aim of the hermeneutic interview is to reveal the meanings embedded in one's life-world rather than seek mere descriptions of a phenomenon (Lopez and Willis, 2004), then the interview questions need to be framed such that the ensuing dialogic conversation facilitates free and untethered co-constructed sense-making. Whilst directive questions open the conversation and orientate the participants to the phenomenon, the interview should seek to '*anticipate without expectation, expose what is not known, thus creating the space for truth, or what is, to manifest* (Vandermause, 2008, p. 70). Following the first interview, I recognised that my questioning was too directive, a style antithetical to the hermeneutic endeavour. I was also keen to ensure that my use of paraphrasing, an important skill during the interview to establish assent and clarify meaning did not direct the interview nor focus on what I deemed to be salient aspects of the narrative. If I was to reflect the ontological orientation of the study and allow the interview to be truly hermeneutical, then I had to observe the silences and for example, avoid offering justifications or explanations for the decisions made by the clinical teams. During subsequent interviews, I recognised how instrumental I could be in enabling a *'skilled facilitation'* (Vandermause and Fleming, 2011, p. 373) of understanding and that by cultivating a hermeneutic space, the phenomenon of ASC had the potential to be recalled in all its fullness.

## 4.11 Data Transcription

In view of time restraints and the wealth of the empirical data, a pragmatic decision was made to employ a transcriber. The transcriber was bound by the confidentiality requirements of the study. Whilst I appreciate Finlay's (2011, p. 229) position that transcribing interviews as the researcher allows one to '*dwell with the data'*, outsourcing did not distract nor inhibit the depth of my engagement with the data and subsequent analysis. I requested that the transcriber annotated the pauses, utterances, length of the silences and noted omitted text if unsure of the medical terminology. I subsequently reviewed the completed transcripts with the associated audio recordings for accuracy.

## 4.12 Data Analysis: Hermeneutic Interpretation and the Construction of Meaning

> ***'All knowledge emanates from persons who are already in the world,***
> ***seeking to understand persons who are already in the world'***
>
> **(Leonard, 1994, p. 55)**

The aim of phenomenological data analysis is to '*transform lived experience into a textual* *expression of its essence, a reflective appropriation of something meaningful*' (Van Manen, 1997, p. 36). Analysis should highlight the particularities or essences of a phenomenon rather than seek generalisations such that new knowledge informs and contributes to a more nuanced and transformative understanding of the phenomenon under study. It would have been potentially easier to adopt a broad thematic approach to analyse the data but if I was to lay claim to phenomenology and associate with the merits of hermeneutic philosophy, I had to attend to the distinctness of its methodological traditions.

Strauss (1987) acknowledges that if we are to be true to the evolving phenomena under study, then data analysis requires a commitment to, and an acknowledgement that analysis is a complex process. To maintain the hermeneutic and phenomenological groundings of the inquiry, data analysis required, on my part, authentic and committed action so that I remained focused and '*true to the text*' (Leonard, 1994, p. 57). In accordance with Gadamerian philosophy, I made no formal presuppositions or theoretical assumptions in advance but rather attempted, through analysis, to engage empathetically in an *'interpretive relationship'* (Smith, 1995, p. 18) with the data. Interpretive work should aim to deconstruct and reconstruct text so that rich descriptions of the phenomenon are exposed, new insights emerge, and meanings and counter-meanings are made explicit.

Rather than a method or a methodological approach to the uncovering of meaning, the *'hermeneutic circle'* identified by Heidegger (1962), is a scholarly metaphor for the conceptualisation of understanding, an analytical tool which facilitates a dynamic and evolving immersion in the data in the search for meaning (Moules, 2002; Packer and Addison, 1989). Analysis of the dialogue between the narrator and the interpreter pays attention to the entirety of the '*object of comprehension'*, its 'whole', and the integration of parts of which '*the object of comprehension is composed*' (Bontekoe, 1996, p. 3). The particularities and nuances of the phenomenon emerge as one acknowledges both the '*alien that we strive to understand and the familiar world that we already understand* (Linge, 1976, p. xii). The 'hermeneutic circle' was clearly 'at work' during the interview, in that the participants 'entered' the circle and engaged in a cycle of iterative and interpretative dialogue, a movement whereupon one arrives at a place of '*sensible meaning, free of inner contradictions'* (Heidegger, 1962, p. 9). This does not suggest that understanding is finite but on-going, and so the interview served as the forum for the reflective, collaborative, and emerging construction and re-construction of the participants' experiences *in-* and *of-ASC.*

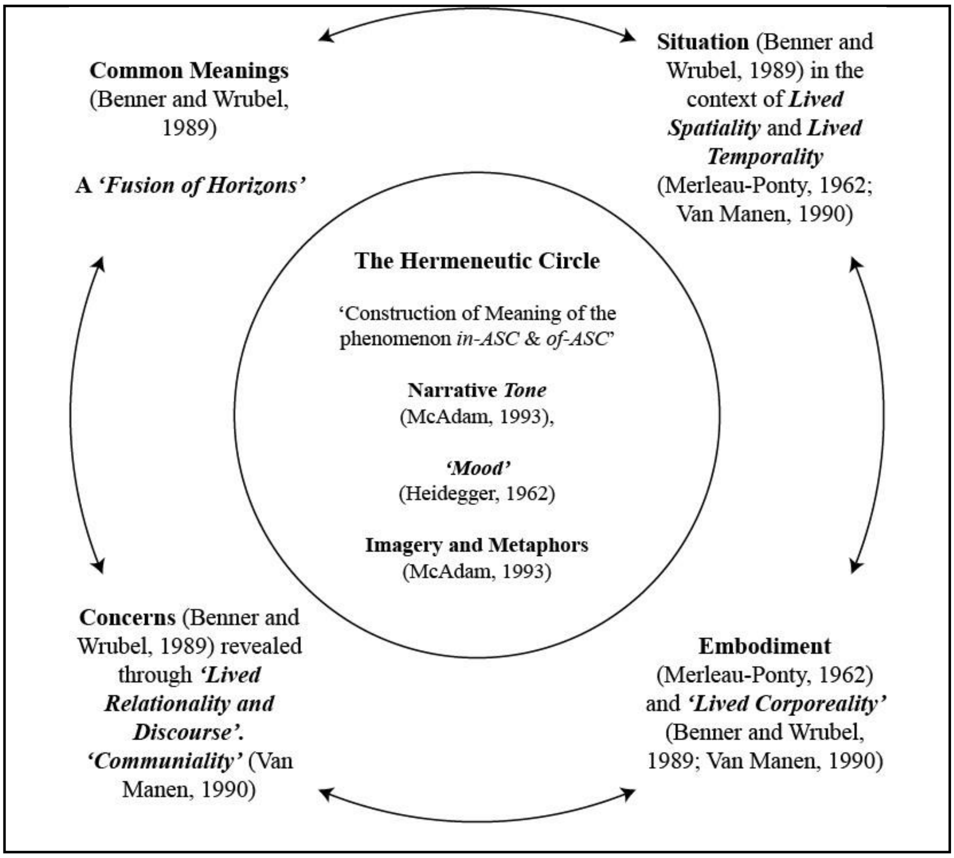
Engaging in participatory sense making enabled what Gadamer refers to as a *'fusion of horizons'*, which facilitates a *'bridging of personal or historical distance between minds'* (Gadamer, 1976, p. 95), the outcome of which is an inevitable and indeterminate change for those involved in the phenomenological inquiry. Understanding then becomes a mutual endeavour, but this trajectory of understanding cannot be undertaken lightly or tentatively. Although this '*fusion*' primarily occurs during the interviewer's engagement with the data during analysis, when one's interpretation of the data 'fuses' with the historical perspective or position of the Other (Taylor, 1994), it was evident in the immediacy of the interview. Through the sharing of experiences, new understandings and perspectives emerged. The very process of narrating and recounting of experiences*, 'a meaning-creating activity',* facilitates an *'understanding of one's self and others, our relations, and our world'* (Schuster, 2013, p. 200). Whilst the hermeneutic interview afforded the participants an opportunity to share their lived experiences of ASC, it also became a medium through which the reality of the patient's experiences *in-ASC* was validated and meaning further constituted. My 'historical position' and pre-understandings as a nurse became a '*window on the world, or base for recognition and comparison'* (Arnold and Fischer 1994, p, 57). As the *'conduit'* or '*instrument of inquiry'* (Arnold and Fischer, 1994, p. 57), I was uniquely positioned to facilitate understanding. My familiarity with, and pre-understandings of the phenomenon of ASC, were brought to bear as I too, 'entered' the cycle and began to engage with data interpretation. Phenomenological understanding and meaning emerged as I located my '*horizon*' as the interpreter and acknowledged that there was a new and emerging hermeneutical horizon to be understood.

Whilst authors (Moules, 2002; Moules *et al.*, 2015; Van Manen, 1990) lend caution in the adoption of a formulaic framework for data analysis believing it to be antithetical to the practice of hermeneutic works, it is nevertheless incumbent on the researcher to adopt '*meticulous scholaticism'* (Moules, 2002, p. 26) during the interpretive phase of hermeneutic works. Van Manen (1984a, 1984b) suggests the text can be organised either thematically, analytically, exemplicatively, exegetically, or existentially, acknowledging that these approaches are not mutually exclusive nor exhaustive. However, the emergence of 'themes' are not viewed as broad categorical formulations or conceptual abstractions but rather seen hermeneutically as '*structures of experience'* (Van Manen, 1990, p. 79), *fractions*', '*contingencies*' *(*Ashworth, 2003b*)* or '*meaning structures'* (Dahlberg, 2009), *'without which the phenomenon could not be what it is'* (Van Manen, 1990, p. 107).

Whilst Ashworth (2003b, p.156) advocates caution in adopting '*meaning structures'* which risk subjugating the '*phenomenological attitude by presupposing a framework of investigation in advance of the things themselves'*, the life-world constructs, body, time and space, anchored in the tenets of phenomenology (Dahlberg, Dahlberg and Nyström, 2008; Ehrich, 2005; Finlay, 2011; Merleau Ponty, 1962, 2002; Van Manen, 1990) are nevertheless symbolic of the collective of the phenomenological field of one's '*being-in-*

*the-world*'. Integrating Merleau-Ponty's philosophy of the life-world, Van Manen's exposition of life-world essences introduced in chapter three, with Benner and Wrubel's (1989, pp. 51-69), five '*sources of commonality*': *situation, embodiment, temporality, concerns and common meanings'*, I have produced a visual representation (Figure 1) which demonstrates how the '*meaning structures'* informed the dialectic and cyclical movement of the 'hermeneutic circle' and how, individually and collectively, these served to operationalise the data analysis.

**Figure 1: The 'Meaning Structures' and The Hermeneutic Circle – Data Analysis**



### 4.12.1 Hermeneutic Interpretation: Procedural Steps and Audit Trail

Data analysis of the hermeneutic conversation allows for the systematic and rigorous recovery of the experiential '*structures of meaning'* that are '*embodied and dramatized in human experience represented in a text'* (Van Manen, 2014, p. 319). Commensurate with the philosophical tenets of Gadamerian philosophy, the procedural steps proposed by Alsaigh and Coyne (2021) aligned with the stages of '*Phenomenological Reflection'* advocated by Van Manen (1984b, p. 42; 2014), informed the pragmatics of data interpretation and synthesis (Table 3).

**Table 3: Procedural Steps in Hermeneutic Data Analysis**

| Alsaigh and Coyne (2021) | Van Manen (1984b, p. 42) |
|---|---|
| Stage 1: Immersion | Existential Investigation<br>- Exploring the Phenomenon: Generating "Data"<br>Obtaining Experiential Descriptions from Others |
| Stage 2: Understanding – identification of first order 'participant constructs' | 'Conducting Thematic Analysis'<br>- Uncovering Thematic Aspects in Lifeworld Descriptions<br>- Isolating Thematic Statements |
| Stage 3: Abstraction – second order 'researcher constructs' identified | Composing Linguistic Transformations |
| Stage 4: Synthesis and theme development | Determining Essential Themes |
| Stage 5: Illumination and Illustration of the Phenomena | Phenomenological Writing<br>- Attending to the Speaking of Language<br>- Varying the Examples |
| Stage 6: Integration and Critique | Writing<br>- Thematically<br>- Analytically<br>- Exemplicatively.<br>- Existentially<br>- Exegetically |

The following discussion details the audit trail which prefaced the emergence of the construction of meaning of the phenomenon of ASC from the perspectives of patient *in-ASC* and the witness *of-ASC.*

The initial stage began with the transcription of the interview dialogue into text. The individual interview transcripts were formatted in a word document file, a pseudonym was assigned to the participant(s), personal and biographical information included, and the primary cause of the ABI documented. When offered by the participants, a verbatim summary of their understanding of the events leading to the ABI and admission to the inpatient setting were included. The transcripts were annotated line by line which allowed for identification of the source text as exemplifiers to support the presentation of findings. Margins were added to the transcriptions so that the diary field entries, researcher's thoughts, emotions of context and reflective memos made following the interviews could be included **(**Gadamer, Weinsheimer and Marshall, 2004).

Stage one required 'immersion' in the data corpus, the raw data (Alsaigh and Coyne, 2021). Textual analysis and interpretation began by the successive and systematic reading of the individual verbatim interview transcripts in a sequential manner, reviewing the associated field and reflective diary entries, and listening to the interview audio recordings alongside the transcripts (Crowther *et al*., 2017). This highly iterative, recursive, and systematic process of reading and revisiting the verbatim text alongside the interview recordings, began the process of understanding the text as a 'whole' and metaphorically 'entering' the hermeneutic circle.

The transcribed texts were then systematically read line by line which began the initial process of selecting 'parts' of the text, the anecdotes, phrases, singular statements and sentences, expressions, single words, and metaphors felt to be significant; '*rhetorical gems*' which were '*particularly evocative or possessed a sense of punctum'* (Van Manen, 2014, p. 320). These data extracts viewed as '*thematic statements*' (Van Manen, 2014b, p. 42), were highlighted manually on the transcript and considerable annotations added which reflected my initial thoughts. This '*superficial grasp*' (Geanellos, 2000, p. 115) of the construction of meaning of ASC, began the process of exposing naïve or initial interpretations which were particularly revealing (Linseth and Norberg, 2004; Van Manen, 1984b; Van Manen, 2014). Annotations in the margins also captured the '*tone'*, a pervasive feature of the personal narrative (McAdam, 1993) or the '*mood*' (Heidegger, 1962, p. 176) reflected by the subtext, inferences, and aspects of the narrative recognised as those which '*assail us',* that arise '*neither from 'outside' nor from 'inside'* but out of *'Being-in-the-World'*. The participants' primary '*concerns*' were revealed through their storytelling and conveyed not solely by their narrative but through their use of imagery, metaphors and as powerfully, through their silences. Grondin (1995, p. x) advocates that analysis should acknowledge not solely '*what is said, what is uttered, but at the same time what is silenced'.* The silences *'may speak more than words'* (Sorrell and Redmond, 1995, p. 1122) and contribute to one's understanding of the aesthetics and the emotionality of the experiential constructs of the phenomenon under study (Van Manen, 1990; Schuster, 2013).

Reviewing the 'whole' narrative along with attention to the 'parts', was not a linear process but rather a 'back and forth', recursive and reflexive activity (Braun and Clarke, 2006; Patton, 1990, Van Manen, 2014). During this stage, pertinent questions came to mind: 'Why is the statement significant? What is the participant saying about their experiences? How are they describing their lived experiences? What do their experiences say about the lived experience of ASC? The posing of questions and reflexive approach to the data served to open up, '*possibilities of meaning*' (Bleicher, 1980, p. 144). Deep engagement with the data allowed me to '*ek-sist* [exist] *in the language of the participants* and in doing so, *'preserve the various manifestations of beings, veiled behind the spoken message'* (Ho, Chiang, and Leung, 2017, p. 1759).

Stage two allowed for the identification of first order '*participant constructs*' (Alsaigh and Coyne (2021) or '*isolated thematic statements'* (Van Manen, 1984b, p.42). The emergence of these tentative constructs of the phenomenon of ASC from the participant's horizon were captured as subordinate *'meaning essences'*. This was followed by '*abstraction*', stage three, (Alsaigh and Coyne 2021) in which second order '*researcher constructs'* were identified which became increasingly re-framed and formalised as superordinate '*meaning* *essences'*, defined as '*linguistic transformations*' (Van Manen, 1984b, p. 42), until the emergent findings captured the participant's perceptual life-world of the phenomenon of ASC. For each of the interpretive constructs which emerged from the data analysis, a matrix table was compiled which drew together the data extracts deemed to be appropriate phrases or singular statements which captured the '*main thrust of meaning*' (Van Manen, 1984b, p. 61) under the emerging superordinate '*meaning essences'*.

An illustration of an extract of a participant's interview transcript and analysis can be found in Appendix 13.

Whilst it was important to view each interview as a new and 'opening' dialogue, challenges with the pragmatics of participant recruitment resulted in interviews being conducted whilst simultaneously undertaking the analysis of others (Ramsook, 2018). I was cognisant that as the life-world '*meaning essences'* began to emerge during analysis, I did not direct subsequent interviews or the participant's narrative for further evidence or validation of their influence. However, whilst initially considered as a limitation, I recognised that this dualistic and iterative approach to interpretation and data collection located me within the hermeneutic circle of understanding, a position which enabled me to remain faithful to the cyclical and reflexive methodological characteristics of hermeneutic inquiry.

Following the analysis of the interviews across the entire data corpus, stage four (Alsaigh and Coyne, 2021) involved the synthesis and collation of data extracts into summary matrices, which captured similar and comparable subordinate and superordinate *'meaning essences'*. This involved copying data extracts from across the entire data set, and collating these under the emerging *'meaning structures'*: *lived corporeality*, *lived spatiality*, *lived temporality, lived relationality* and *discourse*. This constant challenging and recursive process considered whether the subordinate and superordinate '*meaning essences'* were truly representative of the construction of the interpretation and meaning of the phenomenon of ASC for both participant groups. Re-reading the entire corpus of data confirmed whether the emerging interpretations 'worked' and identified additional data which may have been omitted during the initial analysis (Braun and Clarke, 2006).

A matrix of the data analysis of the '*meaning structure'*, '*lived corporeality' in-ASC* and *of-ASC* as an illustration, can be found in Appendix 14.

## 4.13 Interpretation and Infinite Possibilities

> ***'The ongoing dialogue permits no final conclusion. It would be a poor hermeneuticist who thought he could have, or had to have, the last word'.***

**(Gadamer, 2004, p. 616)**

As I 'entered' and 're-entered' the hermeneutic circle during the interpretative phases of the study, my historical horizon and interpretive lens shifted. Interpretation became layered and not surprisingly complex. Whilst I could see the utility of the hermeneutic circle of understanding in play and the relationship between the parts and the whole of the text (Inwood, 2000), I felt overwhelmed by the interpretative possibilities and could not envisage a time when I would be satisfied that I had truly captured the life-world of ASC. I was reassured however by Van Manen's (1990, p. 31) position that in phenomenological inquiry, '*no single interpretation of human experience will ever exhaust the possibility of yet another complementary or even potentially richer or deeper description'.* For the hermeneutic researcher, it is important to acknowledge that one's interpretive position or horizon of understanding is temporal and forever evolving (Gadamer, 2004). Indeed, as Frank (1997, p.85) asserts '*categories are not an end in themselves*'. Interpretation then, is never finite nor beyond challenge, but '*one closes the hermeneutic circle, if only for now'* (Debesay, Nǎden and Slettebø 2008, p. 65).

## 4.14 Rigour and Integrity

***'It is important to acknowledge at the outset that particular philosophical underpinnings or theoretical orientations for qualitative inquiry will generate different criteria for judging quality and credibility'***

**(Patton, 2002, p. 543)**

In positivistic inquiry, concepts of methodological rigour and integrity are evaluated against a set of recognised criteria, which involve the consideration of validity, reliability, and generalisability. Whilst there is a degree of consensus that external assessments of rigour should be conceptualised very differently within the qualitative paradigm (Bochner, 2000; Gergen and Gergen, 2000; Guba and Lincoln, 1994; Heron, 1996; Koch and Harrington, 1998; Lincoln and Guba, 1985; Sandelowski, 1993), debate continues to be polarised as to whether the same pre-determined criteria can be universally applied within the diverse landscape of naturalistic inquiry (Armour, Rivaux and Bell, 2009; Denzin and Lincoln, 1994; Morse, 2015; Sandelowski, 1986; Smith and Deemer, 2000).

Those who belong to the hermeneutic tradition have proposed methodologically appropriate criteria which capture the context and philosophical foundations of interpretive works synonymous with the inductive resonance of qualitative studies (De Witt and Ploeg, 2006; Munhall, 1994) (see Summary Table: Appendix 15). Whilst there is criticism that hermeneutic-relevant criteria remain somewhat '*over-schematic'* (McCaffrey, Raffin-

Bouchel and Moules, 2012), I have considered those developed by Van Manen (1990, 2014) and integrated these with the work of Finlay and Evans (2009) as criteria to confirm rigour and integrity. Van Manen (2014) asks that the emerging interpretation and discussion should, for the reader, induce a '*sense of contemplative wonder'* or '*aesthetic quality'.* There should be an '*interpretive depth'* (Van Manen, 1990, 2014) to the inquiry evidenced through the emergence of meaning structures of the phenomenon under study such that the text and emergent findings has '*resonance*' and an '*addressive meaning*' (Van Manen 2014, p. 356). Depth is what gives the *'phenomenon or lived experience to which we orient ourselves its meaning and its resistance to our fuller understanding'* (Van Manen, 2014, p. 152). Secondly, there should a '*strength'* to the text which holds a '*convincing capacity'* (Van Manen, 1990, 2014) with interpretations emerging which are '*faithful, recognisable, and 'true' descriptions of experience…. that ring true'* (Moules, 2002, p. 17). Hermeneutic works should address what Finlay and Evans (2009) cite as '*relevance*' and what I have included as the 'reach' whereby one appraises the contribution and value of the research, questioning whether the research enhances and enriches one's understanding of the phenomenon under study (Finlay and Evans, 2009). The emerging reflexive insights (Finlay and Evans, 2009) should move beyond the '*taken-for-granted understandings of everyday life'* (Van Manen, 2014, p. 356). Finally, Van Manen's (2014, p. 356) questioning of the study's '*inceptual epiphany'* captures the overarching thrust of hermeneutic phenomenology by asking whether the study offers *'the possibility of a deeper and original insight'.*

In the thesis, I have referred to these criteria, demonstrating how throughout the application of methodology, and in the presentation of findings and discussion chapters, my commitment in asserting my integrity as researcher to re-present a rich and authentic exposition of the phenomenon of ASC.

Prior to commencing the inquiry, I had little engagement with the philosophical traditions and ancestry which ground hermeneutic work and admitted feeling somewhat overwhelmed and challenged by the myriad positions of eminent philosophers. Whilst hermeneutic phenomenology seemed relevant, I had to develop a familiarity with the language of philosophy to the extent I was able to appreciate the different philosophical legacies and could articulate with a degree of authority the rationale for the methodological decisions which ultimately shaped and informed the research process. I have grappled with the textual challenge of writing phenomenologically and communicating the hermeneutic, experiential qualities of the participants' narratives. Through sustained engagement with the data and a commitment with the philosophy, scholacism and language of hermeneutics, I have learnt to '*dwell comfortably in the space of hesitation'* (Saevi, 2013, p. 5). I recognise that phenomenology *'thrives on a certain irrevocable tension between what is unique and what is shared, between particular and transcendent meaning, and between the reflective and the pre-reflective spheres of the life-world'* (Van Manen, 1997, p. 345). I am confident that I have re-presented and captured the tone and persuasiveness of the participants' narratives, and in doing so, brought the reader in touch with the utility and transformative power of hermeneutic text (Van Leeuwen *et al*., 2017; Van Manen, 1997).

The following chapters have been written with the intention and commitment to faithfully convey the participants' stories and capture the meaning of the phenomenon of ASC with dignity and reverence. Caputo's (1987, p. 267) poignant metaphor resonated with me as I realised the transformative, yet unsettling path of hermeneutic work:

> *'In the end, hermeneutics does not lead us back to safe shores and terra firm: it leaves us twisting slowly in the wind. It leaves us exposed and without grounds, exposed to the groundlessness of the mystery, this intractable mystery is the final difficulty that hermeneutics is bent on restoring'.*

# CHAPTER FIVE: RESEARCH FINDINGS

## 5.1 Introduction to the Participants

The following chapter introduces the 18 participants of the study and presents the findings of this inquiry.

Pseudonyms have been given to each of the participants. One participant requested their own pseudonym. A biography, brief history, reason for admission and cause of the ABI is documented. The accompanying verbatim description was given by the participants of the study and reflects their understanding of the diagnosis and cause of the ASC. Clinical history or presentations which were unusual or included identifying features which, through '*deductive disclosure*' (Boruch, Dennis and Cecil, 1996, p. 161) were sufficient to breach the participant's confidentiality and anonymity are excluded.

Where both the patient and their witness were interviewed jointly, this is acknowledged in the participant's biography. As discussed in section 4.6, where participants gave their expressed consent to participate in a further interview once data analysis has been undertaken, this is also detailed in the biography.

### 5.1.1 The Patient: Single Interview

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**Salar**

Salar was initially admitted with an ABI secondary to a pedal cycle accident to the ICU but later transferred to the neurosurgical unit *in-ASC,* where he remained for several weeks prior to transfer to the rehabilitation unit. The interview took place twelve months following his injury.

*'Severe, brain injury yeah, level eight coma score. I was in critical care unit, and I was rushed into hospital by a helicopter, and I was in the critical care unit for over three and a half weeks'* (Salar: P4-5).

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**Andrew**

Andrew sustained an ABI following an assault. He was sedated and ventilated in the ICU and later transferred to a neurosurgical unit where he remained *in- ASC* for several weeks. The interview was the first opportunity for Andrew to describe his experiences four years since the injury. Andrew was supported during the interview by a family member, who requested not to be formally cited in the study.

*'Yeah, I was assaulted in town, didn't have a clue what had happened'* (Andrew:P2).

**John**

John sustained an ABI secondary to an assault seven years prior to the interview. He was transferred to the neurosurgical ward following an admission to the ICU.

*'I remember just being really confused and quite angry because the last thing I can remember is getting assaulted'* (John:P7-8)

**June**

June was admitted to the ICU following a diagnosis of a large intracerebral haemorrhage. She was later transferred to the neurosurgical ward and remained *in-ASC* for, what she reports to be approximately eight days. The interview took place 15 years post-injury.

*'Yeah, I had a haemorrhagic stroke, and took about an hour to go unconscious'* (June:P3).

**Donna**

Donna was admitted with cerebral hypoxia secondary to airway occlusion. On admission, she deteriorated which further complicated her ABI. She was initially admitted to the ICU and later transferred to the neurological ward for continued support. Over a protracted period, she presented with *in-ASC.*

*'It then caused the oxygen supply to be cut off from my brain, so from there I had lots of weird dreams'* (Donna:P2).

### 5.1.2 The Witness: Single Interview

**Patricia**

Patricia's husband, David, was diagnosed with a malignant brain tumour and underwent extensive neurosurgery to remove the tumour. Following surgery, he was intubated and ventilated initially in the ICU but was transferred to the neurosurgical ward, one day post-operatively. During the post-operative period he was diagnosed with ASC. Patricia spent significant time on the ward during this post-operative period and gave an account of her experiences as a witness to David's ASC presentation. The interview took place two years following his admission. Patricia participated in two interviews, the second following data analysis and interpretation of the initial interview.

*'When they diagnosed the brain tumour they thought that it was a meningioma at the time and for some reason they didn't do a biopsy which, I don't know why, they just thought it would be, they said it was about satsuma size, so quite large, but they thought it would be just really straightforward to remove, and on the run up to it he'd been experiencing fatigue, weight loss, clumsiness and a lot of vomiting episodes that came and went, and just the general fuzziness, we didn't*

*you know, we couldn't pinpoint what was wrong with him. So, he had the operation'* (Patricia:W1-6)

**Sarah**

Sarah's brother, Amir was diagnosed with a hypoxic brain injury secondary to a sudden cardiac event. He was initially admitted to an ICU facility and then transferred to a neurological unit. During the time *in-ASC* he had profound neurological impairments including difficulty with communication, significant physical limitations, and was verbally aggressive and disorientated. Sarah spent significant time on the ward during this period and gave an account of her experiences as a witness to Amir's ASC. Amir gave consent for his sister to participate in the research study. The interview took place two years post-admission.

*'He initially started having a cardiac arrest. Amir suffered the brain injury 'cos it took 45 minutes for the ambulance to get to him. We were told he was in a coma, we were told he was critical but stable'* (Sarah:W11-12)

**Mary**

Mary's daughter, Donna presented with hypoxia secondary to airway occlusion. Following admission to hospital, she deteriorated with further complicated her ABI. She was initially admitted to the ICU and later transferred to the neurological ward. Mary spent significant time with Donna during this period of hospitalisation and gave her account of witnessing Donna's presentation of ASC

*'The actual coma side of it began with when we were told that it was only four to five days till the swelling of the epiglottis went down and then she'd go straight to the medical ward'* (Mary:W3).

### 5.1.3 The Patient and the Witness: Shared Interview

**Nina (Patient) and Jane (Witness: Daughter)**

Nina was admitted to the ICU with pneumonia but developed secondary cerebral hypoxia resulting in ASC. She was subsequently transferred to an acute neurological ward. Nina's daughter, Jane was present during the interview to support her mother and was invited to participate as a witness. The interview took place 18 months post-admission.

*'I had a bad chest infection and it caused me to go unconscious'* (Nina:P3)

**Simon (Patient) and Kathy (Witness: Wife)**

Simon was admitted to the ICU following a cardiac arrest and presented to the Emergency Department where he developed significant cardiac complications. He was initially admitted to the ICU, intubated and ventilated, and when stabilised, transferred to the neurological ward where he continued to experience intermittent ASC secondary to cerebral hypoxia. Kathy, his wife, participated in the interview. The interview took place 18 months post-admission

*'I'm in hospital and I've had some sort of bloody stroke' and she went, 'no, you've had a heart attack'. I went, 'right anyway same thing'* (Simon:P7-8).

**Alice (Patient) and Paul (Witness: Husband)**

Alice was admitted to the ICU, following a significant cerebellar ischaemic event which resulted in a left hemiparesis, dysphasia, ataxia, visual difficulties, and ASC. She was later transferred to the neurosurgical unit. Paul, her husband, participated in the interview. The interview took place approximately two years post-admission.

Alice and Paul participated in two interviews, the second following data analysis and interpretation of the initial interview.

*'And the doctor was like, she's definitely had a stroke'* (Paul:W316).

**Barry (Patient) and Heather (Witness: Wife)**

Barry was admitted to the ICU with pneumonia which resulted in secondary cerebral hypoxia. Whilst in the ICU he was intubated and ventilated. On transfer to the neurological ward, he presented with ASC. Barry was interviewed in the presence of his wife, Heather who participated in the interview. The interview took place 18 months post-discharge.

*'So I think all the time through my coma on the ward and in ICU and a bit after that, I were just all over t'place'* (Barry:P96-97).

**James (Patient) and Carol (Witness: Wife)**

James sustained a traumatic brain injury approximately eight years previously. Initially he was admitted to ICU where he was sedated and ventilated. He was transferred to the acute neurological unit where he presented with ASC, confusion, and disorientation. By his own admission, he was, on occasions aggressive, inappropriate, and lacked ability to rationalise, frequently using profanities. His behaviour was chaotic and unpredictable. His wife, Carol, participated in the interview.

*'You know, you get a phone call to say your husband's had an accident, well just slipped on the ice and banged his head, and he goes in for brain surgery'* (Carol:W15-16).

*'I ended up with a head injury in the first place, slipping on the snow'* (James:P4).

## 5.2 Explanation of post-script when citing verbatim text to support the presentation of findings

In the presentation of findings that follows, the superscript states the participant's pseudonym followed by the letter 'P' to denote 'patient' or 'W', the 'witness'. If the verbatim text is cited from the second interview transcript, then '2' will be included, otherwise the absence of a number signifies that the participant engaged with one interview only. This is followed by the line number(s) of the verbatim, interview transcript.

## 5.3 Introduction to the *'Structures of Meaning'* of the Phenomenological Life-World of an ASC secondary to ABI

For the participants of this inquiry who were unexpectedly '*thrown*' (Heidegger, 1962) into a transitory experience of ASC, secondary to ABI, the meaning of the phenomenon of ASC, was interpreted and constructed through the existential, '*meaning structures'*: *lived spatiality, lived corporeality, lived temporality, and lived relationality and discourse,* which independently and collectively emerged as higher-order constructs.

*Lived spatiality* has conceptualised how the participants were situated in place and space both physically and existentially. For the patient, their transitory residency in the perceptually disordered landscape of ASC, through to emergence as they became increasingly lucid and orientated is described. For the witness, their situatedness within the spatial characteristics, properties, and physicality of the hospital environment, along with the cultural and social conventions and qualities which defined space became their inhabited place at the bedside. The '*meaning structure': lived corporeality,* describes how the participant's embodiment of 'self', identity and personhood were perceived and constructed throughout the trajectory of ASC. Understanding how time was experienced both chronologically but also existentially was significant and is conceptualised throughout the presentation of findings as *lived temporality,* Whilst Van Manen (1990, p.102) identifies lived human relations as '*communiality*', for the participants of this inquiry, it was not solely their engagement and interactions with others but the dialogue, subtext, inferences, and the narrative tone which collectively served to construct meaning of *in-ASC* and *of-ASC*. The '*meaning structure'*: *lived relationality* and *discourse,* was therefore felt to better conceptualise the content, context and dynamics of the interpersonal relationships and associated discourse.

The following discussion will present each of the life-world superordinate '*meaning structures*' in turn, identified as: *lived spatiality, lived corporeality, lived temporality,* and *lived relationality* and *discourse*, from the perspective of the patient, *in-ASC,* and the witness *of-ASC.* The superordinate and subordinate '*meaning essences'* which informed the emergence of the higher order '*meaning structures'* are also presented and supported by the empirical data from the interviews (Dahlberg and Dahlberg, 2020). This is commensurate with the criteria for rigour, that the interpretive findings should have *'resonance'* (Finlay and Evans, 2009) or a *'convincing capacity'* (Van Manen, 2014, p. 356). Data analysis did not reveal a hierarchy to the emergence of the *'meaning structures'* and therefore no inference should be made of the order in which each is presented. It is also important to acknowledge that the essential *structures* which serve to construct the meaning of the life-world '*intrinsically affect the meaning of the other'* (Ashworth 2003b, p. 156). To this end, if the analysis of the empirical data, highlighted the emergence of more than one '*meaning structure'* or '*meaning essence'*, the same verbatim citation may be presented across the presentation of findings.

It was difficult to establish whether, unlike in single-respondent interviews, certain aspects of the participant's narratives were modified, privileged, or hidden because of the presence of the 'other' during the shared interview. A group approach to data collection risks the '*contamination*' (Webb and Kevern, 2001, p. 800) of data, deemed antithetical to the phenomenological method. However, whilst it is acknowledged that the '*lived experience belongs to a single person*' (Giorgi, 1997, p. 236), the shared interview became one of co-facilitation whereby the participants' stories each served as a platform for further discourse, reflection, and clarification. Across the presentation of findings, independent as to whether the participant engaged in a single-respondent or shared interview, a pragmatic decision was made to present isolated excerpts from the datasets, from the perspective of the patient *in-ASC* and the witness *of-ASC*.

The identification of 'disconfirming cases' (Booth *et al.,* 2013) or discrepant 'negative cases' defined as descriptions of experience which do not align to the emergent patterns of meaning during the data analysis is deemed a hallmark of qualitative inquiry (Lincoln and Guba, 1985; Patton, 1990). However, in hermeneutic analysis, whilst '*every single description is going to be different from the other*' (Giorgi, 2009, p. 132), the phenomenological meaning can be identical. To offer an example, whilst several patients described distressing experiences of the perceptually disordered and disorientated landscape *in-ASC*, one participant was less perturbed by their experience. The shared and communal interpretations of the participant's residency *in-ASC* were collectively captured by the *'meaning structure': lived spatiality*.

I was also cognisant that the narratives of individual participants were neither over- nor under-represented in the presentation of findings. Commensurate with Van Manen's (1984b) '*exemplicative*' approach to phenomenological writing, I have therefore paid particular attention to the inclusion of exemplary quotes from the data set (Sandelowski, 1994), which I believe portray, render visible and *'transform the lived experience into a textual expression of its essence'* (Van Manen, 1990, p. 36). However, it was difficult to honour the narratives of all the participants and balance representation with the wealth and richness of the data. As many quotations were included as word limitation allowed.

It is hoped that the following phenomenological account therefore captures the '*ambiguity, ambivalences, and paradoxes*' (Finlay, 2011, p. 232) of the collective lived experience of an ASC secondary to ABI, within the acute inpatient, hospital setting, from the perspective of the patient *in-ASC* and the witness *of-ASC*.

## 5.4 'Legacy Self'

Whilst there is immutable variance in neurological, functional and cognitive outcomes post-ABI (Corrigan *et al.,* 2015; Katz and Alexander, 1994; Ponsford, 2013), there is a wealth of evidence that one's post-injury construct of 'self', identity, and personhood are frequently compared against their pre-injury 'self' (Gracey *et al*., 2008; Gracey and Ownsworth, 2012; Levack, Kayes and Fadyl, 2010; Tyerman and Humphrey, 1984; Whiffin *et al*., 2019), with effects ranging from feelings of '*differentness or estrangement, to a total disconnection from the person's past identity*' (Pollack, 1994, pp. 673).

For the participants of this inquiry, whilst formal referents to identity were limited, negative self-evaluations relating to the neurological burden of ABI reflected the findings of Myles (2004). Throughout the narratives, both participant groups evaluated the patient's presentation *in-ASC*, as compared with their character traits, identify signifiers, behaviours, and presentation of 'self', prior to the ABI. These observations served as a baseline for post-injury comparison of the functional status and neuro-behavioural prognostic outcomes assessed in the immediacy of the acute phase of the ABI with the aim of preserving the premorbid self (Oddy, 1995; Snyder and Mitchell, 2006; Stewart, 2013) and establish a degree of self-continuity for both participant groups.

In the context of traumatic brain injury, Cantor *et al.,* (2005) defined the aspect of self that risks being discrepant from one's actual self as the person's '*pre-injury self*', and this has been widely adopted throughout the ABI community. However, in the context of the findings of this inquiry, the term '*pre-injury self'* fails to capture a mode of '*being-in-the-world*' in which the patient's construct of self was frequently recognised and searched for during the post-ABI phase. Dahlstrom's (2008, p. 228) philosophical view of one's legacy is a state of being in the present, '*itself a moving target*' to '*a past that is untouchable*'. Whilst it could be argued that the etymology of '*legacy*' has historical roots related to bequeaths following death, a more contemporary view and one that is adopted for this inquiry, is that an individual's 'legacy self' reflects one's pre-reflective '*being-in-the-world.*' It is only when injury disrupts one's pre-reflective self can '*we have the experience of ourselves, of that consciousness which we are aware*' (Merleau-Ponty 1964, p. xv). The term 'legacy self' has therefore been adopted to conceptualise an individual's 'taken-for granted' pre-injury construal of self which comprises the '*corporeal skills, habits and styles of expressions which set us apart from who we are'* (Leder, 1984, p. 32).

## 5.5 LIVED SPATIALITY: Superordinate '*Meaning Structure*'

***'Every figure stands out against the double horizon of external and bodily space'.***

**(Merleau-Ponty, 1962, p. 101)**

### 5.5.1 Introduction

The patient *in-ASC* resided in a distinct and pervasive spatial reality, a landscape of hallucinations, delusions, illusions and altered perceptions. As they began to develop increasing situational and personal awareness, they found themselves situated in another alternate but equally formative, transitional space.

The witness too, resided in a distinct reality at the bedside, a '*new world and you're having to make sense of it'* (Paul W:240). The different 'lived spaces' of the hospital, namely the clinical areas and those deemed to be public spaces, afforded qualities as they observed the patient's behaviour, actions and interactions. The witness' observations contributed to their collective understanding of the phenomena of ASC. Certain areas within the hospital appeared to normalise the presentations and behaviours of the patient *in-ASC,* whereas in other areas, the phenomena emerged with greater drama and significance. The lived spaces conferred varying qualities which 'tested' for the presence or absence of signifiers of the patient's pre-injury, 'legacy self'. Spaces were also deemed to possess varying degrees of therapeutic-ness.

### 5.5.2 Lived Spatiality *in-ASC*: The Patient

Table 4 presents the superordinate '*meaning essence'*: '*The Territory of the Lived Spatiality in-ASC*, and the associated subordinate '*meaning essences': 'The Transition'*, '*The Landscape Described'* and '*Sense-making'*. The '*Boundaries of the Lived Spaces'* is also presented as a further superordinate '*meaning essence'*. These collectively served to construct the meaning of lived spatiality for the patient *in-ASC.*

**Table 4**
**Superordinate *Meaning Structure*: Lived Spatiality *in-ASC*: The Patient**

| **Superordinate *'Meaning Essences'*** | **Subordinate '*Meaning Essences'*** |
|---|---|
| **5.5.2.1** The Territory of the Lived Spatiality *in-ASC* | The Transition |
| | The Landscape Described |
| | Sense Making |
| **5.5.2.2** Boundaries of the Lived Spaces | |

### 5.5.2.1 The Territory of the Lived Spatiality *in-ASC*

The 'lived space' of ASC was unique and tangible for the patients. Patients found themselves immersed in an unfamiliar and unpredictable landscape where they experienced an array of vivid perceptual disturbances which included hallucinations, delusions, and illusions. This 'lived space' presented them with an exclusive and previously unexplored arena, as they became embroiled as a central character and witness to a personal narrative of ASC.

#### The Transition

Participants described the moment of transition as they 'left' consciousness and 'moved' or 'entered' the lived space of ASC. On 'arrival' they were presented with an unfamiliar and chaotic space which became their temporary life-world thereafter:

*'And then from the beginning it was really weird, the only way I can describe it is like desolate land, almost like space in a way and it's like very medieval and I was trekking through the land'* (Donna:P7-9).

June recalled the moment when she appeared to entered ASC, as though it possessed a distinct boundary that had to be navigated:

*'I remember taking about an hour to go unconscious and then in my mind I have this long feeling of blankness'* (June:P12-13).

She proceeded to describe how these transitory periods of 'blankness' punctuated her confusion:

*'Whereas from being completely lucid to going unconscious, you know, I've got memories about being very sort of confused but still being able to remember that feeling of being confused even though the confusedness became more and more and then there's this complete blankness of nothing, then this vivid memory of that and then again this feeling of*

*blankness'* (June:P21-25).

Entry into this lived space was described by Donna as:

'*darkness*', '*all dark'*, *'a scenario in my head of darkness'* (Donna: P4-7).

As entry into ASC was remembered, so too was emergence with patients recalling a sense of movement or 'travel' from a subliminal, dark, and dense space as they gained increasing personal and situational awareness. As Donna reflects on this time, she was pensive:

*'This was coming towards the end of the ASC, like it seemed to be more, it seemed to get more like things, almost like towards the surface in a way'* (Donna:P126-128).

### The Landscape Described

From the onset of ASC, patients found themselves embroiled in the unfamiliar and unpredictable inner landscape of ASC, a unique and profoundly personal space which was perceptually disordered.

Whilst for some of the participants, the hallucinations, delusions, and illusions experienced *in-ASC* were recounted as pleasurable and on occasions, inspirational, for others they were remembered as enduring, threatening and powerfully pervasive. Some were manifestly unpleasant, experienced as a confusing constellation of images and scenarios. There was a sense of inescapability as familiar and unfamiliar characters presented themselves indiscriminately.

On occasions they found themselves complicit in the hallucinogenic narratives whilst at other times, marginalised as the passive observer. On the threshold of increasing situational awareness, participants found themselves in an equally intriguing and at times disturbing, liminal landscape, unsure of where the boundary of ASC and the common reality was situated. They questioned the content of their experiences, finding solace when their memories *in-ASC* were validated in the context of the landscape of the hospital.

For some participants, their immersion in this landscape was frightening, sinister and all consuming, where *'mad things happen'* (Andrew:P31), they *'seem to last forever'* (Andrew:P64) and '*they're very vivid. I remember being haunted by the motion of the coma dreams'* (Donna:P335). On recovery they recounted characters and plots with a surprising sense of detail. Whilst individual experiences were unique they shared some common themes which involved travel: '*oh, loads of travel, I travelled the world',* the presence of characters fictional or familiar, bizarre mythical creatures, animistic hallucinations: *'flying monkey things which were all over the spot'* (Andrew:P76), '*little round Japanese robots, crawling around on little wheels'* (Nina:P243) and delusional scenes. They became central characters complicit in conspiracies, embroiled in disarticulated and unrelated plots which were compelling but remained frequently unresolved. Whilst some memories were recalled with cynicism and disbelief, the content of which was questioned or challenged on recovery, other encounters were welcomed. Characters presented with bizarre incongruities, plots were elaborate and imagery fanciful. The vividness of their experiences and the ability to recall this imagery with considerable detail on emergence from ASC and over time, was distinct from the experience of dreams.

For Barry (P192-193), the hallucinations were consuming which '*took over what in real life was happening'*. His memory of the '*white panther in t'corner of t'room with a cat's face and a panther's body'* (Barry:P10) persisted for months after recovery and there were many occasions when his ASC experiences were 'triggered' and the panther came to the fore as an unwelcome visitor: '*the panther were there again but then they were there*'(Barry:P20).

Other participants were so affected by the unrelenting and distressing nature of their experiences that they were reluctant to sleep for fear of the hallucinations returning:

*'I didn't want to sleep because I'd have things like bombing at the tube station and all sorts really, you know there was never a good dream, it was bad dreams, like bad things happening to you'* (Alice:P542-544).

For Donna, unlike a fleeting dream which is quickly forgotten, the 'space' was experienced authentically as she became embroiled in the stories and scenarios presented to her:

*'Like you were there, like you were living it, like it wasn't like it was a dream, it was like my life at the time'* (Donna:P31-32).

Some participants experienced this life-world passively, unable to effect or influence the content and trajectory of ASC or the plots of the stories encountered:

'*It was horrendous and these bits of coming out of ASC, I didn't have any control'* (June:P330).

For June (P35-44), the scenes she described were largely sinister, persecutory, and remembered as emotionally distressing. Sensing she was in hospital, she believed staff were colluding with each other to remove her oxygen supply and manipulating her breathing tube to intentionally inflict harm:

*'I was aware of having a breathing tube, and I knew the nurse was saying to me, 'this other person is my friend and she needs a breathing tube as well and I've only got one so I'm going to give the breathing tube to her, and so she would do that and then I really had that horrible feeling of like gagging and nothing coming out and then a doctor would come past or something so then the nurse had to pretend to be nice and friendly and gave it back to me again so then I could breathe again and get a few gulps in and then the same thing would happen and it was just horrible. I remember she used to come really close to me when the doctor wasn't about and say, 'you're gonna die, die, die' because she wanted to give the breathing tube to her friend'.*

Nina’s descriptions were equally distressing as she described a family fishing trip and the death of her friend’s husband. Following his death, members of the party appeared unaffected:

‘*They didn’t seem to be at all bothered and got on with drinking cocktails and things’* (Nina:P39).

Donna’s narrative experiences during ASC were full of detail and her descriptions vivid. She recounted periods of ‘*darkness’* interspersed with a series of dramatic scenarios involving rich, powerful imagery. On occasions she recognised places that she had previously visited and family members, friends, and acquaintances she had known prior to her injury. She acknowledged that her delusions were random, disordered and largely illogical, describing the context and landscape as ‘*bizarre*’, ‘*weird’, ‘like lots of strange dreams happened’* (Donna:P7). At times, the ‘drama’ of her life events prior to her injury appeared to be ‘played out’ within ASC, but on other occasions her experiences were unorthodox and unfamiliar in the context of her life history. She acknowledged that some of her memories were fabrications reflecting little of reality. At times, they were so random and indiscriminate that she questioned their origins:

*‘I thought that my GP was my best friend’s Mum, and he was like running round naked with some other man that she was having an affair with which was really weird. Then they ended up pumping poo through my veins’* (Donna:P131-135).

Andrew described his experiences in ASC as he moved frenetically through different locations:

‘*Mad things happening, and I was like in different rooms, one of them was like a big scary open hall sort of thing... a house somewhere one time .... and other times it was like you were up on a storey or summit’* (Andrew:P31, 37-39).

Nina witnessed different terrains and unexplainable storylines which involved being in a plane with Angelina Jolie and her husband delivering wolves to Nova Scotia:

‘*It was like a warehouse, the building, there was a lake next to it and trees and things like that and a road’* (Nina:P51-52).

John (P22-23) had no sense as to where he was but described a ‘*severe hallucination’* involving Nazi Germany and the belief that ‘*we’d lost the war to the Germans, and we were being controlled by the Nazis’*. He recalled addressing a doctor as a Nazi but was quick to defend his actions: ‘*not normally my character’*. He returned to this memory later in the interview describing the emotions evoked by this delusion and attempted to justify his persistence in his attempts to leave the ward:

*‘I was petrified. I think that’s why I tried to get out of hospital’* (John:P127-128).

A sense of entrapment and containment were recurring themes. Barry's experiences were so disturbing and recurrent that on recovery he was reluctant to sleep fearful that the hallucinations would return:

'*The one coming back the most is, I think, and this is how absurd they are, and one of them a Chinese Mafia were coming to kill me and I always remember they were threatening me and it were like a video call and in the background there were like this white panther in t'corner of the room, but it was like a cat's face but a panther's body, and every now and then I used to, even now I'd wake up screaming like shaking, like I can see it in the room they were full of vivid colour, feeling trapped like feeling trapped in the ward and in my body'* (Barry:P8-11, 24-26).

The need to 'escape' from the confines of the lived space of ASC was described by participants. Whilst Nina was not aware of being in hospital, she felt contained and imprisoned within her experiences of ASC and 'searched' for a safer 'lived space': *'I could have been trying to escape because seemingly in my delusions I was trying to escape'* (Nina:P22). However, her attempts were futile and upon recovery she sought to provide a reasonable justification for her behaviour:

*'But I think I was trying to find the toilet…' cos that seems more logical to me, that I was trying to find the toilet'* (Nina: P27&P29).

Andrew recalled feeling '*stuck there'* and restrained, to the extent: '*they wouldn't let us go'* (Andrew:P56). He felt '*boredom*' and planned his escape to *'get out of here'* (Andrew:P124). He recalled people berating him as he made frequent attempts to climb out of bed:

'*Stay a bit longer and I don't know what they were doing 'cos they were just - take them pills, take them pills, take them pills, do this and this'* (Andrew:P124-126).

Similarly, although James had no sense as to where he was, he described frequent occasions when he planned an escape strategy:

*'I don't really remember where I was. I just really, really just wanted to get out and go home*' (James:P33-34).

Independent of the content of the perceptually disordered landscape, stories were narrated with conviction. The patients' experiences held a profound sense of realism and were remembered with impassioned detail, months and years later. On recovery, some patients found it difficult to acknowledge they were delusional and continued to question relatives about the validity of the storyline. In ASC, Donna had seven babies, one who she named Annabella. She questioned her mother:

*'Where's my baby? Bella, Annabella that's what I called her, Annabella, yeah*' (Donna:P460).

James and Carol discussed an occasion when, *in-ASC*, he reported there had been a fire outside the ward. His conviction was so strong at the time that despite attempts by Carol to explain that there had not been a fire and it was likely he had misinterpreted a fire for the sunset, he remained resolute in his belief:

'*James said to me one day, Oh last night there was a massive fire out there, massive ... out of the window ... burst into flames'* (James:P253)*.... I might have been dreaming, but I was definitely sure there was a fire out of that window'* (James:P254).

The landscape of ASC was experienced with such intensity that participants found it difficult, on reflection, to challenge their authenticity and reality:

*'Yeah, yeah really busy, like you were there, like you were living it, like it wasn't like it was .a dream, it was like my life at the time'* (Donna:P31)*.... 'Like you know you can have dreams that you wake up from and you go, 'what's the idea, I don't really remember that', but that was vivid, as vivid as anything'* *(Donna:P52)*.

*'I think a lot of the weird dreams were that intense they felt that real, you know.. full of vivid colour'* (Barry: P21,24).

From the moment he 'entered' the lived space of ASC, Salar believed he was in a field and this memory remained with him to the extent that:

'*The memory of me being in a field was so overpowering that every day I woke up for months I thought I was there'* (Salar:P20).

**Sense Making**

During the interview, participants recalled trying to make sense of their experiences whilst *in-ASC* and during recovery. Sense making was a means of reconciling the random presence of characters and offering a degree of restitution to the distressing and chaotic delusions experienced. Nina described a boat scene involving a lady who she later found out had been a cleaner on the ward. She had been told that the cleaner had tried to communicate with Nina daily and realising this, Nina felt reconciled that there had some element of truth to her delusion:

'S*o there's again another dream taken care of*' (Nina:P231).

She also recalled visualising a '*red glow in the room'* (Nina:P37) which along with the *'curtains between the beds'* (Nina:P39) she had likened at the time to a brothel. Other delusions involved frequent travel, complicated plots and characters previously known to participants. Although Nina felt somewhat reassured that she recognised places and family members she encountered, she could not, however, reconcile the chaotic scenes and the uncharacteristic behaviours and actions of those embroiled in the stories:

*'They'd bought this big boat so while the girls were on the desk sunning themselves with cocktails, which is my sister and her friends, the husbands went off fishing in the little boat and it sank 'cos there was a storm. And I remember saying to my sister, 'you're gonna have to get under cover because there's a storm coming. This was all in the hallucination, you know, 'you've got to get yourself and the kids'. And the kids were small although they're grown up now and that was, that was odd. And for some weird reason* [cites the name of a road] *came into it. So, off their men went; one of them drowned; the other one ended up turning up in France, he was saved, that was my sister's husband'* (Nina:P139-150).

When narratives were elaborate and chaotic, participants questioned the 'storyline' but persisted in their attempts to make sense in the context of their previous experiences prior to the injury. *In-ASC*, Nina recalled reading a book which involved her '*riding a raft in a little car with this cat in this top hat in a nice little Lakes village and my cousin was there'.* She justified the location by saying:

*'We often go up to the* [cites locality] *for a day out, but I did find that one very weird because why am in a car?'* (Nina:P85-88).

For Donna, she remembered her ex-boyfriend and his parents visiting her but the reality was they '*never came to see me whilst I was in hospital but they were always there in my dreams, weirdly enough*' (Donna:P70-73). For her, the relationship she had previously had with her boyfriend 'continued' whilst in ASC, although on recovery she had realised this had not been the case:

*'He'd phoned me in my ASC as well as split up with me. He's been straight with me in my coma but he didn't actually in real life he didn't' (Donna:P96-97)*.

Simon recalls waiting with members of his family for his cousin to arrive to join him in a hotel room in Calgary so they could all go and watch the parade. On recovery, Kathy, his wife had recounted an occasion when, sat at Simon's bedside, his cousin who lives in [cites the name of a country] had phoned her. Simon was able to rationalise this memory:

'*They were always on the phone.. so maybe it was just a case of they'd been talking about it while I was out'* (Simon:P74).

During the interviews, there was evidence of mutual validation between the patient and their witness, and agreement that events had happened as remembered, but also self-validation when the patient justified their experiences with respect to their pre-injury personality or knowledge:

*'I think a lot of it was that most of the way through the ASC the hallucinations took over what in real life was happening'* (Barry:P192-193).

Simon justified the enduring central theme of always '*missing somewhere to go'* in his hallucinations, by the fact he was formerly a good timekeeper:

*'I like to be on time, I do like to be on time. I hate being late, I think it's very, very rude, I do'* (Simon:P138-139).

Barry related his hallucinations to his love of cars and where he lived, and John to his fascination with history:

*'So even though they are weird and absurd, they link back to me in some way'.* (Barry:P524) *'So like me and my dad's love for cars or lives places in* [cites a town]*'* (Barry:P526-527).

*'I had a severe hallucination that I perceived we had lost the war to the Germans, and we were being controlled by the Nazis'.* (John:P21-22). *Yeah, and that's probably why I called the doctor a Nazi 'cos obviously prior to the brain injury I did history as GCSE, so I know quite a bit what the Nazis did'* (John:P122-125).

Nina reflected on the presence of the Cornish Pixie, but felt reconciled, when during the interview her daughter informed her that there had been a nurse in the ICU with purple hair and tattoos:

*'I was convinced she was a pixie, a Cornish Pixie'* (Nina:P57). *'She had purple hair, tattoos and an earring, oh and her head was shaved, half her head'* *(Nina:P54-55)*. *'I don't remember seeing her in person, so whether she was real or not, I don't know. But I saw her, I did see her a few times in this hallucination'.* (Nina:P63-65)…… '*So there again, that's another dream that's taken care of'* (Nina:P230).

The plots were at times complex and disordered which left the patient, on recovery, seeking to rationalise and seek justification for their experiences. Alice's memories of being a beggar in the Huguenot region in the time of the French Revolution, a place, by her own admission she knew little about, but was justified because '*It's like living in Les Mis and I've seen that on the stage'* (Alice:P19).

James, a former lorry driver, questioned his memory of wandering around the hospital car park looking for his lorry and felt reassured when this was verified by Carol, his wife:

'*But I have this one where I was, I don't know, I was in my slippers and pyjamas but I was wandering round the car park* (James:P68-72) *'I had gone off looking for my lorry and they found me in* [shop name] *and I was stood in the car park'* (James:P143-145).

Reflection continued throughout the recovery period as patients ruminated and searched for a rational and coherent explanations to account for their experiences:

*'I don't sit and dwell on them, but I have thought about why, why those dreams'* (Simon:P149).

*'I mean it tormented, well it didn't torment, it drove me nuts thinking about it, because I*

*still had these, it was still going round in my head'* (Nina:P154-156).

For other participants their memories *in-ASC* were experienced with such authenticity, they found it difficult on reflection to believe otherwise:

*'Because as far as I'm concerned everything was real, but I couldn't understand why I was there. Now that made me a bit anxious trying to put it together, you know'* (Simon: P182-186).

Whilst some of the patients had shared their experiences with family and friends, none had been afforded the same opportunity with staff during their hospital admission. Simon and Barry had purposefully refrained from verbalising their memories *in-ASC*, fearful that their experiences would add weight to concerns already expressed about the prognosis or result in further undue distress to the family:

*'I never thought to tell them especially as Kathy said that 'they said you were going to be brain damaged, I thought I'll just keep that to myself... mad as a hatter'* (Simon:P193-197).

*I just felt like I'd sort of deal with them myself on my own, you know'* (Barry:P180).

When sense-making was not achieved, the risk was that the person struggled to reconcile their experiences and ended up in a continuous and ruminating cycle. This rumination was illustrated by June (P:307) when she said:

'*It's a horrible feeling to have bits of memory that are just like floating about in your mind'.*

For others, the content and context of their hallucinations were so bizarre that they struggled to comprehend meaning and yet their experiences held significance. They sought to understand why they had 'travelled' to certain places, met characters fictional or familiar, their role and the actions of others, as they became embroiled in complicated and inexplicable plots:

*'There was confusion because at times when you were going, like I kept missing the ferry and instead of going 'where am I?', it was 'why do I keep missing the ferry, or 'why is it snowing in Australia? You know, that sort of thing. That's what the confusion was.. you were just struggling to sometimes understand why you were here'* (Simon:P79-83).

On recovery, Barry continued to reminisce about his hallucinations and reflect on their vividness:

*'You see even like on Friday I were sat watching telly with my mum and dad and I said "oh, that's the car I were dreaming about, you know, so I can pick it up on t'telly, if they were like an American hot rod car, that's the car I were driving, you know, and I'd drive through* (cites local town) *, that's where the Chinese Mafia lived that rang me'* (Barry:P518-520).

Through shared sense-making, the interview served to provide June(P306-310) with an opportunity for resolution:

*'I'm a person who likes to be sorted in my life and have things in order and so, it's horrible feeling to have bits of memory that are just like floating about in your mind and so it's just been a fantastic position in the fact that I've been able to analyse a lot of stuff and put things in order. And even things like the horrible bits, the confusion and the choking ones and the gagging ones and all that business, well because I know now it wasn't'.*

Barry found sharing his memories and reflecting on his experiences *in-ASC* cathartic, and with the support of a psychologist on discharge from hospital, Donna was able to begin to make sense of her hallucinations:

*'I mean as weird as it sounds it does help talking about it, a way for therapy* (Barry:P571). '*It's hard to explain to someone who hasn't been there'* (Barry:P579).

*'Yeah, I mean my psychologist helped me a lot trying to decipher the dreams in a way. I spoke a lot with my psychologist about the dreams 'cos I could vividly remember them but never with anyone else but my psychologist, no one asked, no one seemed interested'* (Donna: P473-475)*... 'It almost made them not real in a way, that they weren't real. So, it helped me rationalise that it didn't actually happen*' (Donna:P490-491).

### 5.5.2.2 Boundaries of the Lived Space

On occasions, the boundary between the participant's lived spatiality of ASC and that of the external world was distinct and impenetrable. On recovery, there was a realisation that 'distance' had been too great and there could be no shared understanding of the life-world of ASC at the time. As they failed to make themselves heard to those 'outside', for some, the inner world of ASC became increasingly lonely and frustrating. The space imposed a sense of alienation and dissociation:

'*I felt frustrated, very frustrated, really yeah I was, I was extremely frustrated, why is it happening to me, why me? You know, at the time, I felt alienated'* (Salar:P352-353).

*'It feels like you're outside looking in, like looking through a window on someone else's life'* (Barry:P490).

As the patient began to emerge from ASC and gain a degree of situational and personal awareness, they found themselves in yet another unfamiliar landscape, a transitional territory where they were neither situated in the familiar hallucinogenic landscape of ASC, nor able to fully engage with the communal reality of those present within the hospital. It became increasingly difficult for them to discern the boundaries of these different spaces and determine whether their experiences were fact and universally experienced, or remained delusionary and exclusive:

*'I weren't sure what was dreams or wasn't dreams'* (Donna:P356).

‘*It’s like I had images in me head of the ward and then I don’t know if it’s real or not, you know, it’s just really confusing’* (Barry:P104-105).

This juxtaposed space was equally perplexing and for some, more so, as they strived to meaningfully engage with this ‘external life-world’. The patient appeared to reside in two realities simultaneously, the first the reality of ASC and the second, that which was interspersed and punctuated with a sense there was an alternate reality of the hospital. They were increasingly sentient and whilst able to recall a sense of being moved, re-positioned, and engaged within this liminal space, continued to find it difficult to make sense of their experiences. Donna (P162-163) recalls:

*‘So I could hear the machines and I knew what hospital beds, you know felt like and smelt like.. I knew where I was, you know’.*

Patients tried to make sense of their behaviours in the lived space of the ward and to establish a degree of coherence and understanding as to whether their memories of events in ASC were legitimate or simply fictional:

*‘I don’t know what it was all about.. the confusion bits, when you don’t know what you are doing and you think to yourself ‘why am I here?, how have I got here?’. Because as far as I was concerned, everything was real, it was all real, but I couldn’t understand why I was there. Now that made me a bit anxious trying to put it together you know’* (Simon:S182-185).

Whilst *in-ASC*, participants reported that they experienced momentary periods of awareness, both regarding their illness and the reality of the lived spaces of the hospital. Although Donna believed she was at her grandmother’s house, she did sense she was unwell:

*‘Yeah, I knew I was ill ‘cos I was in bed, and everyone was coming to visit me as I was ill’.* (Donna:P11-13)*…I wasn’t sure what was wrong with me but I knew I was ill’* (Donna:P52-55).

For Donna, her injury had resulted in significant visual loss. This appeared not to affect her *in-ASC* as she was able to ‘see’ but as she began to recover, the impact of her visual loss became apparent. A formative moment in her emergence from ASC was when she was able to ‘sense’ the lived space as being a hospital, she discerned the presence of furniture in the room and remembered her interactions:

*‘It kind of came clearer that I was actually in a hospital, like in a hospital setting, like I knew I was in hospital. When I woke up though I thought I was in hospital. I could tell I had a hoist and a bed, and I could tell that I was moving round the room on a hoist. By that point I did know I was in hospital, towards the end of it, you know’* (Donna:P141-145).

### 5.5.3 Lived Spatiality *of-ASC*: The Witness

Table 5 presents the superordinate '*meaning essence'*: '*Cultural Norms and ASC Behaviours'*, '*The Lived Space Tests the Absence or Presence of Signifiers of the Pre-Injury*, '*Legacy Self*' and '*The 'Therapeutic-ness' of the Lived Space'*. These collectively served to construct the meaning of lived spatiality for the witness *of-ASC*.

**Table 5**
**Superordinate *Meaning Structure*: Lived Spatiality *of-ASC*: The Witness**

| **Superordinate *'Meaning Essences'*** |
|---|
| **5.5.3.1** Cultural Norms and ASC Behaviours |
| **5.5.3.2** The Lived Space Tests the Absence or Presence of Signifiers of the Pre-Injury, 'Legacy Self' |
| **5.5.3.3** The 'Therapeutic-ness' of the Lived Space |

### 5.5.3.1 Cultural Norms and ASC Behaviours

The 'lived spaces' of the inpatient, hospital setting contributed to the construction of meaning of ASC for the witness. The cultural norms of the clinical areas and public spaces imposed different spatial qualities and characteristics.

Staff appeared to impose different orders within the various clinical settings in the hospital and provided conflicting justifications to Mary and her family. These settings enforced very different cultural norms and expectations. For example, in the ward area, silence was imposed by the restriction of visitors and the formal request not to play music. These noise reduction strategies were justified by staff in order to '*rest the brain'* (Mary:W61). However, no such restrictions were imposed in the ICU. On the contrary, visitors were encouraged at a time when Mary perceived Donna to be more critically ill and unstable. Whilst Mary initially conformed to these orders, she was unable to reconcile the conflicting information between the lived spaces within the same hospital and sought to challenge these disparities:

*'She wasn't allowed visitors for quite a while because of the noise level and stuff and eventually we did, I actually put my foot down and said 'look people need to see her – you're saying we don't know how long she's got or if she's going to pull through all this'* (Mary:W65-68).

'*We did put a few friends in when we shouldn't have done'* (Mary:W72).

For Mary, the 'lived space' and the mandates imposed by staff as to how she and her family should behave became important measures of her understanding of ASC, and the role she played in influencing her daughter's recovery. The lack of consistent advice and the inability of staff to provide a sound and reasonable rationale were distinct sources of irritation and only served to confuse her understanding of how ASC was influenced by the presence of others within the different lived spaces.

The lived spaces of the hospital were imbued with exclusive cultural conventions which were believed to govern institutional practices on the ward. Paul felt that he was expected not simply to have knowledge of ASC presentation as a sequela of his wife's brain injury but arrive with a degree of familiarity with the physicality of the space and be prepared to conform to the daily regimens of the ward:

*'I need to know my place and how I can operate in that system, not get in the way kind of thing, and there was none of that. I didn't know who I could talk to, I didn't know who was in charge, I didn't know anything, you know, I didn't know if I had to leave at mealtimes or anything, there was no information'* (Paul:W2:19).

Similarly, Paul felt that there was no acknowledgement by staff that entering the ward for the first time to visit his wife would be emotionally traumatic:

*'The most horrific thing for me was when I first went in the day after.....and I didn't have a clue what I was gonna get the other side of the door and walking through that door was one of the hardest things I have ever done you know.. not because I didn't want to do it 'cos, I didn't know what I was going to get'* (Paul:30-32).

Despite Paul's efforts to actively immerse himself in this unfamiliar space, he became increasingly isolated in his endeavours. He felt contained by the lived space of the hospital ward and frustrated by the restrictions imposed on him and his wife. He believed that the ward was not conducive to his wife's recovery and persisted in challenging decisions that he regarded not to be in her interests. He sensed resistance by staff when he offered to take her outside the ward in a wheelchair and felt berated when unknowingly used the wrong bathroom when showering his wife; '*oh, we don't use that bathroom, we use this one over here you know'* (Paul:W2:20). He persistently tried to find his 'place' in the culturally informed space of the ward, evidenced by the way he sought clarification about visiting times. He questioned the 'open' visiting times but when told there were no restrictions was then challenged for the timing of his visits:

*'When asked about visiting times, staff said 'any time'. Well obviously, if you were sat there at 11 o'clock I think they'd have something to say. So the answer any time is a lie, you know, give me the time, give me the parameters then I can work with them'* (Paul:W2:20).

A significant number of patients will present *in-ASC* on the ward and relatives will not only bear witness to their loved one, but others admitted during this time. Relatives very quickly gained a sense that ASC behaviours, however bizarre in their presentation, were commonplace following ABI and that clinicians and staff were not unduly perturbed by their observations. The presentations of ASC were normalised and became part of the social landscape and culture of the clinical settings. However, outside the ward, in the public spaces within the hospital, these behaviours were palpable and had heightened significance for the witness. The 'lived space' of the hospital ward somehow 'contained' the presentation of ASC. When witnesses observed their loved ones in these public spaces outside the ward, they appeared to use this as an opportunity  to search for and identify fundamental signifiers of the 'legacy self'.

Donna's incessant screaming, heard by her mother in the hospital corridor as she walked towards the ward was profoundly disturbing. Outside the spatial limits of the ward, Donna's behaviour had a heightened poignancy and served to reinforce her mother's fears that her daughter's behaviour in ASC was markedly estranged from self:

*'I don't know if you've been to* [cites hospital] *but they have quite long corridors and you could hear her from the minute you got into the nursing station, she was screaming'* (Mary:W33-36).

Patricia's experience of her husband's behaviours and interactions with others in the lived spaces of the ICU, the acute ward setting, day room and hospital cafe appeared to 'shift' her perceptions of the meaning and significance of his clinical presentation of ASC and recovery. David had a persistent delusion that he had died. Whilst his behaviour and actions within the ward were distressing for her, the ward setting appeared to facilitate 'normalisation' of his behaviour and within the unfamiliar lived space of the ICU, she offered a defence:

*'I mean we partly put it down to the fact that it is quite other worldly in intensive care, isn't it? You know it's very ethereal, isn't it and there are no windows anywhere for daylight'* (Patricia:W1:70- 71).

When David left the ward and entered the communal areas of the hospital, Patricia had the opportunity to assess his ability to engage with the public and in doing so recognised signifiers of his behaviour reflective of his 'legacy self'. On one occasion at the hospital cafe, a place where there was '*more normality'* (Patricia:W1:143), he initially engaged appropriately in a conversation with a gentleman who sat next to him. However, her relief was quickly dispelled, when on leaving:

'*David just threw in 'yeah, I used to think that when I was alive as well'* (Patrica:W1:150-151).

His insistence and continued belief that he was 'dead' was experienced more profoundly within the public 'lived spaces' of the hospital.

### 5.5.3.2 The Lived Space Tests the Presence or Absence of Signifiers of Pre-injury, 'Legacy Self'

The lived space of the different hospital settings was formative in revealing hidden signifiers of the patient's 'legacy self'. When relatives observed the patient within these different lived spaces, they had an opportunity to assess whether the 'legacy self' remained and the extent to which recovery would be realised. The meaning *of-ASC* was revealed by observing a patient's behaviour in these different settings and the patient's interactions with members of the public. Whilst not their intention, relatives appeared to 'test' the patient's responses in these settings and made judgements about the significance of the ASC with respect to the likelihood of recovery.

For other witnesses, the 'lived space' altered their perceptions of the 'legacy self'. The technological and mechanistic lived space of the ICU environment was vividly remembered by Carol. She reflected on the environment:

'*You go in a room and there's the most unimaginable, whole barrage of machinery and beeping lights and everything'* (Carol:W22).

She described how 'space' appeared to dominate and consume her husband:

*'And then there's this tiny little person – I mean you couldn't describe James as a tiny little person - but he seemed to be like a tiny little person in a room full of machinery'* (Carol:W23-24).

Amir's behaviour within the spatiality of the hospital was revealing. On one occasion, Sarah accompanied her brother to the Faith Room and without prompting observed him perform rituals in preparation for prayer. He appeared comfortable and familiar in this 'lived space' which served to reassure her that he was able to function despite his ASC. His actions and behaviours were recognised as commensurate with his historical former self:

*'I remember taking him, there's a prayer room in the hospital so I remember taking him and he wanted to; I said, 'well you have to do your ablution first' and I remember standing there and there's step by step, you have to wash your hands first to your wrist and then your face, so it's all in sequence. And he remembered every single one from start to finish'* (Sarah:W83-86).

However, these 'signifiers' of 'legacy self' were short lived. On one occasion, Amir was found sitting in a conservatory at a local DIY store a few miles from the hospital. The police brought him back to the hospital in a distressed and disorientated state. His actions outside the hospital served to reinforce to relatives the true extent of his behaviour change *in-ASC*.

The bedside appeared to become a unique 'lived space' for Donna, with family and friends adorning the area with cards, photographs, and letters. These visual displays became important for Mary, as she found a practical and visual way of relaying messages to Donna from her family and friends. The bedside also appeared to become an individualised, personalised space, a biography of her daughter, and a reminder to staff of Donna's 'legacy self'.

### 5.5.3.3 The Therapeutic-ness of the Lived Space

The lived spaces within the hospital were viewed and assessed according to their therapeutic potential. These judgements were made in the context of the ASC and whether certain activities either positively or adversely influenced ASC recovery.

Mary observed that Donna's distress *in-ASC* was relieved when she accessed the gym as part of her physiotherapy. It is interesting to note that Mary was of the belief at this point that Donna had a degree of awareness of her environment and therefore the hectic ward environment was not conducive to recovery:

*'The staff used to go and lay her in there, probably because it was so peaceful 'cos she was up by the nurse's station she would hear everything constantly'* (Mary:W218).

Similarly, Carol also viewed the lived space of the hospital ward as frenetic and not conducive to James' recovery:

*'It were bedlam, it really was bedlam'* (Carol:W223).

She described the activities around another patient and how this escalated James' behaviour. He was irritated by the noise of equipment to the extent that she felt the need to reprimand him to prevent further escalation:

*'But this lad was very, very ill. He was an Asian lad and people were praying over him all the time and he were in a really bad way. He had this massive extra head. James were laid in bed going, 'I'm going to turn that f-ing thing off in a minute. I'm going, James you mustn't. But he would have done'* (Carol:W228-230).

Whilst patients were moved through the acute services within the hospital spending time in critical care, the ward or rehabilitation facilities, their journey also afforded them with access to the public spaces of the in-patient setting. The dependency of the patient and their clinical need informed decisions as to whether patients were transferred between these clinical facilities and the duration of stay, but decisions to transfer appeared to be influenced by resources and bed availability. Witnesses interpreted decisions about the location of care as an indication of recovery or deterioration of the ABI. However, on occasions, anticipated transfers were either not realised or believed to occur without sound clinical justification, which misled and confused the meaning of ASC for the witness.

The lived spaces within the hospital environment became important in Mary's understanding of Donna's recovery of ASC. Staff within the ICU associated the length of time Donna would remain in the ICU with the reduction in the swelling of the epiglottis (cause of the hypoxia and ASC). Once the swelling had resolved then Donna would be transferred to the ward, and this would be an indication of improvement. However, despite the transfer taking place as planned, there was no measurable improvement in her ASC. For Mary, this only served to engender further concern that Donna was not making the progress as predicted:

*‘We were told that it was only four to five days till the swelling of the epiglottis went down and then she’d go straight to the medical ward and just 24 hours to check that she was eating and drinking, but it got the fifth day, and she was still comatose at this stage* (Mary:W2-5) *.. I realised something was wrong when it got into the second week’* (Mary:W7-9).

Patricia remembered the physicality of the ICU as significant. She described the space as *‘quite other wordly, ethereal’* (Patricia:W82). A lack of natural light and its location in the basement of the hospital, was claustrophobic and stifling. Whilst she understood the need for critical care, this ‘felt-space’ also had a disturbing and detrimental influence on David’s delusion that he was deceased. She envisaged the move to the brighter, less technologically driven ward environment would promote orientation and be conducive to recovery:

‘*But then he was moved back to the ward, so I thought that might help him knowing he was alive and things’* (Patricia:W82).

Carol’s memory of the coffee machine in the ICU waiting room: *‘you are sat in this awful room with fluid coming out, that’s supposed to be tea or coffee’* (Carol:W17-18), appeared to reflect the all-consuming emotionality of her experience as she anxiously waited for news of her husband. For Paul, the lived space of the hospital ward also projected an affective quality. The interminable routines and ritualistic practices which characterised the ward were equally oppressive, perceived to constrain his wife’s recovery from ASC and more profoundly her sense of self. He described the starkness of the ward bay, how equipment dominated space, the way she was objectified by staff and how cultures and routine served to dehumanise his wife:

*‘On the ward you were just on a list of things to do. It was like, it’s time to do that end, we’ll start here and we’ll work our way around’* (Paul:W383-384)*. Yeah, it was almost like farm animals, you know, what it was like we’ve got all these people with a stroke to deal with, we’ve got this amount of time to do it and this is the order we’re gonna do it in, and that’s what they did’* (Paul:W395-397).

Against medical advice, he took her to the hospital cafe and on one occasion, outside the ward to *‘sit outside for a little bit in the rain because you can feel the rain, where there was like birds, there was squirrels’* (Paul:W2:18). He believed that these spaces were conducive to her recovery, as though she sensed freedom and emancipation from the confines of the ward.

The presence of machinery and technology were remembered by the witness as oppressive and appeared to dominate both space and person. Carol describes how the physicality of her husband, a well built and formidable frame, was transformed. He appeared '*tiny'* in the context of the unfamiliar and physically consuming space of ICU, and amongst the '*whole barrage of machinery'* (Carol:W23-24). Once transferred to the ward she described how behaviours reminiscent of his 'legacy self' were somehow given permission to reveal themselves. Absolved from the confines of the technologically-driven and mechanistic space of the ICU, he appeared to regain a sense of agency, and *'a bit more of James'* (Carol:W34) was revealed.

On the ward, the physicality of the patient's lived body *in-ASC* was revealed through the nuanced way it responded to care activities and engaged with staff and visitors. For the witness, the meaning of ASC was shaped and continuously re-evaluated by the body's interaction and responsiveness within this space. Space was revealing and seen as a medium for the testing of the presence or absence of the familiar signifiers of the 'legacy self'. However, functional, and cognitive limitations of ASC and dependency on life-sustaining equipment, imposed restrictions on the body's ability to interact and respond within the different lived spaces of the hospital.

For the witness, the public and communal spaces within the hospital were sanctuaries amongst the homogenised spaces of the hospital. They opened opportunities for emergence of the patient's presentation of self and provided reassurance that 'legacy self' remained. However, for others, they served as a prophetic reminder that ASC may affect restitution and one's return to self. Whilst these lived spaces constituted the meaning of ASC, they also served to affect the agency of the witness. Paul felt he had limited control within the ward area: *'the ward was such, so surreal and different that you just had to have that control*' (Paul:W512), but in the transgressive, public arenas of the hospital he felt more able to effect improvements in his wife's condition.

## 5.6 LIVED CORPOREALITY: Superordinate '*Meaning Structure'*

**'*The body is the vehicle of being in the world, and having a body is, for a living creature, to be intervolved in a definite environment, to identify oneself with certain projects, and to be continually committed to them'*.**

**(Merleau-Ponty, 1962, p. 82)**

### 5.6.1 Introduction

Lived Corporeality or Lived Body emerged as significant for those *in-ASC* and those who were witness *of-ASC*.

*In-ASC*, ‘lived corporeality’ was understood and held significance, as the patient recalled the functionality and sentience of their body. The physicality of body presentation, the way the lived body *in-ASC* engaged with and was perceived by others contributed to a collective understanding of the phenomenon of ASC. Experiences were recalled in the context of pre- injury, ‘legacy self’, and the extent to which, on recovery, their lived body returned to previous functional ability or remained estranged.

For the witness, the ‘lived corporeality’ of the patient *in-ASC* was understood and held significance through body presentation, the recognition or otherwise of signifiers of the patient’s ‘legacy self’ and the extent to which the body was dependent or independent on supportive systems. For the witness, there were many contradictions and uncertainties which collectively challenged the construction of meaning along the ASC trajectory.

### 5.6.2 Lived Corporeality *in-ASC*: The Patient

Table 6 presents the superordinate ‘*meaning essence’*: ‘*Functionality and Sentience of Lived Corporeality in-ASC’* and the associated subordinate ‘*meaning essences’*: ‘*Lived Body functions as the Pre-Injury, ‘Legacy Self’’* and ‘*Functional Limitations Realised’*. The *‘Intentionality of Lived Corporeality in-ASC’* also emerged as a superordinate ‘meaning essence’. These collectively served to construct the meaning of lived corporeality *in-ASC* from the perspective of the patient.

**Table 6**
**Superordinate *Meaning Structure*: Lived Corporeality *in-ASC*: The Patient**

| **Superordinate *‘Meaning Essences’*** | **Subordinate *‘Meaning Essences’*** |
|---|---|
| **5.6.2.1** Functionality and Sentience of Lived Corporeality *in-ASC* | Lived Body functions as the Pre-Injury, ‘Legacy Self’ ’ |
| | Functional Limitations Realised |
| **5.6.2.2** Intentionality of Lived Corporeality *in-ASC* | |

#### 5.6.2.1 Functionality and Sentience of Lived Corporeality *in-ASC*

The findings revealed how the individual subjectively experienced their physical body *in-ASC*. Patients reflected on how their body responded and interacted with the environment and others, both within the landscape of hallucinations and delusions and on recovery. For some, the lived body ‘performed’ as a fully functional being within this new space. There was limited awareness of the neurological complications associated with the brain injury and so they functioned *in ASC* as a former, intact ‘legacy self’. However, as they became increasingly more lucid and aware of the lived body’s functional and cognitive limitations, there was a sense of bewilderment and despondency. This was particularly felt with the increasing dependency on others and equipment to move and perform fundamental human functions. The functionality and limitations of the lived body became re-situated throughout the trajectory of ASC.

### Lived Body Functions as Pre-Injury, 'Legacy Self'.

Even though the lived body existed in the exclusive and landscape of ASC, the body remained appropriately sentient. Patients recalled how their body responded physically to others and the 'external' environment but also how it functioned as a corporeal being within the hallucinations and delusions of ASC. The body initially performed as an intact, 'legacy self' and whilst for some patients this perception remained throughout the trajectory of ASC, for others, the physical and cognitive limitations of brain injury were increasingly realised as they gained awareness.

June was perceptive and physically responsive *in-ASC*. She was able to describe her position in bed '*more upright, not lying flat'* (June:P108), sensing her '*legs being in a spa'* (June:P104). She recalled hearing the sound of bubbling water and whilst the feeling was initially comforting, it went on for '*hours and hours and hours and I started to get very agitated'* (June:P109). She also remembered the illusion of a yellow snake coming out of her genital area, '*going way into the distance, you know, I can remember this'* and tried to pull it out. She described the discomfort of the artificial feeding tube in her nose, it being '*very, very uncomfortable at the end'.* The emotionality of her physical experiences *in-ASC* was profound. She felt '*agitated', 'very agitated'* (June:P109). and her distress was heightened because she '*didn't have the words'* (June:P109) or the means to articulate her 'lived body' experiences.

Donna also remembered the physicality of her body. She sensed pain and discomfort, lying in a bed and being hoisted: *'I was in a bed, I was in a bed, and I was moving round on a hoist'* (Donna:P152-153), having her hair washed and being fed. She remembered feeling the need to go to the toilet but frustrated that her requests were ignored:

'*I remember thinking, I need the toilet, why is no one listening to me? I need the toilet. I was catheterised at the time, but I remember thinking, I need the toilet, I need the loo. I needed to pee. You just take me to the toilet right here right now*' (Donna:P174-176).

On reflection, Donna believed her hallucinations and delusions had relevance to what was happening in the 'lived spaces' of the hospital at the time**.** Donna remembered her physical 'legacy self' and was perceptive to bodily changes following the onset of ASC. She had dental braces fixed before the injury which had been removed following her admission to hospital to aid ventilation:

*'I didn't know I had my brace taken off because I had braces before my brain injury, but the people had to come and take them off because of the ventilating tube, so the*

*orthodontist had to come and take them off. So, I was going like this with my teeth, what’s different about my mouth? I could sense something was different and no one had told me that I’d had my braces taken off. I was like this, what’s different, what’s different with my mouth’* (Donna:P196-201).

## Functional Limitations Realised

Whilst *in-ASC*, Salar had no perception of the extent of his injuries and functional limitations. He recalls:

*‘The mind thinks there’s nothing wrong’* (Salar:P29).

‘*Yeah, I thought I was perfect. I could do everything but obviously I couldn’t’* (Salar:P122).

However, as he began to emerge from ASC, he realised the gravity of his injuries believing himself to be *‘more useless’* (Salar:P129). A formative moment was remembered:

*‘Later that night somehow, I was on the way to sleep, thinking about sleeping and I touched my head because of a little prick or something. So, I felt it and then I found out that I’d lost half of my head. There was a big gap and then I was absolutely lost. I was in tears. I was thinking what’s happened to me? I was fine before and then I woke up and I was like this’* (Salar:P15-19).

He recalled feeling increasingly distressed and isolated in his recovery, to the extent he retreated:

‘*under the covers in the hospital bed and it was night anyway so there were not many nurses around, so I tried to be quiet, but I was in tears’* (Salar:P155-156).

It wasn’t until later in his recovery, that Salar realised the full extent of his limitations:

*‘Like I thought in my head I could get back up and it weren’t till I literally tried to get out of bed or I’d try to move and I think, I can’t do this, you know* (Salar:P145).

‘*Like I couldn’t even pick myself up out of t’chair’* (Salar:P152).

The belief that ‘legacy self’ remained was reported by several participants. James recalls, ‘*I thought I was normal’* (James:P126) and Nina was frustrated when she realised she could not independently change her position in bed:

‘*That was very annoying, very frustrating, you can’t, you want to sort of sit up, but you can’t because you haven’t got the strength to pull yourself up, things like that’* (Nina:P519).

Prior to her injury, she experienced restless leg syndrome which was resolved if she lay at the opposite end of her bed and ‘walked’ her legs up the bedroom wall. On recovery, Nina’s cousin told her that she had persistently tried to lie upside down in bed whilst in hospital. Staff had become frustrated as they frequently had to re-position her. For Nina, her behaviour was easily explained with respect to her ‘legacy self’:

'*Yeah, I mean for me it was, that was just natural so I couldn't understand why they were, you know why you were all so bothered* [laughs]*, I walk walls'* (Nina:P546-547).

June came to understand that some of her behaviours and actions in ASC had been inappropriate. She had sworn persistently, refused to comply with directions from staff and had behaved in a childish manner. She recalled having some awareness of her behaviour, albeit limited, but did not feel unduly embarrassed even though family members had subsequently told her that they had berated her at the time:

'*I thought, oh I like this, just like a teenager really, I definitely remember that feeling, but I was thinking that's quite cool'* (June:P297, 299).

On another occasion, she recalled her indifference when, despite her mother's alarm, an intravenous cannula sited in her arm had leaked. Blood '*had gone off the bed and was going down the floor, I was just watching the blood'* (June:P162-163). She remembered being given a plate of pureed food but did not know how to use the cutlery and because her right hand was paralysed, she '*picked it up with my left hand ... and put it straight into my mouth like a baby and it missed and went on top of my head and everything'* (June:P151-152). She recalled being asked to sign a consent form for a clinical procedure:

'*I sat looking at my hands and absolutely nothing would work. I just had no idea what to do. I didn't know how to pick up my hands. I had no knowledge of what to do with your fingers to hold a pen'* (June:P280-282).

Following ABI, there were some changes to the functionality of the body which were not observable or known to the witnesses and clinical staff but experienced by the patient whilst *in-ASC*. This had a profound impact on patients, particularly so, as they gained awareness. Nina's vision had been affected by her injury. She would require a new prescription for her glasses. Unaware of this, her family gave her the glasses she had previously worn. Unable to see properly, Nina repeatedly complained: *'they're not my glasses',* but this was dismissed: '*well they are your glasses'* (Nina:P479-481). Whilst it was likely that family members could not know with any degree of certainty the extent of the limitations resulting from the brain injury, challenging Nina's account served to isolate and discredit her. Donna also felt dismissed when witnesses refuted her account of events. Donna recalled watching Bart Simpson on television and remembered saying:

'*Bart Simpson's on telly…..Marge, blue hair and yellow skin.. yeah that's the first thing I ever saw was Bart Simpson on telly'* (Donna:P419, 422).

However, her mother's response at the time challenged her account:

'*No, it's alright, she can't see it really, she's probably just imagining it'* (Donna:P426).

For Simon, seeing himself for the first time after he regained orientation and full awareness was formative. He recounts the moment:

*'And I looked in the mirror and just went, 'oh shit', and remember coming out to Kathy and going 'what is this? What is all this? There were a bit of a beard thing and hair sort of sticking up everywhere, 'cos that's not the way I wear my hair. Just not seeing myself for 3 or 4 weeks, I just went, 'what the bloody hell'. That was one of the biggest shocks'* (Simon:P267-271).

Whilst *in-ASC*, John had no sense as to how his behaviours and actions had impacted on those around him, but on gaining awareness realised how disruptive and impulsive he had been. He was able to recall isolated incidents when he tried to 'escape' from the ward, when his cognitive limitations and confusion affected his ability to make sense of the situation and being reprimanded for not being able to dress himself. He remembered having to '*learn to behave'* (John:P146). He recalled with frustration, the response of staff when he had been incontinent of urine. On recovery he had learnt that nursing staff had attributed his incontinence with the fact that prior to his injury he had been diagnosed with alcohol dependency. He understood that knowledge of his 'legacy self' had, on this occasion, been used to define him and his behaviours negatively and served to influence staff's perception of who he had been prior to the injury, and more importantly, who he would become on recovery.

### 5.6.2.2 Intentionality of Lived Corporeality *in-ASC*

*In-ASC*, patients recalled actions and behaviours as intentional and purposeful. Donna vividly remembered her hand clasping a necklace and was resolute in her belief that she had held onto it for safe keeping whilst *in-ASC* and on recovery:

'*So I had this heart – it was like a Tiffany necklace, like a heart, and I had it in my hand and when I woke up from my ASC, I would not release my hand and I was going, 'where's my necklace, where's the heart necklace' and everyone was trying to understand what I was saying but they didn't have a clue what I was taking about'* (Donna:P99-103). '*Cos, I thought it was in my hand therefore I wasn't going to open my hand up because I thought I had it in my hand and I was going, "where is it?", you know like 'cos I had it in my hand'* (Donna:P105-107).

It wasn't until much later in her recovery she reconciled with herself the fact that despite engaging family members in a lengthy search, the necklace had not existed.

Not only were actions and gestures remembered as intentional, but patients recalled attempting to effect recovery of the lived body whilst *in-ASC*. Salar was aware that his hand was paralysed but planned strategies:

*'What I did was, I made a plan. I thought with this finger and then moved it into my thumb, then at the same time I imagined moving my thumb on the other hand'* (Salar:P41-43).

### 5.6.3 Lived Corporeality *of-ASC*: The Witness

Table 7 presents the superordinate '*meaning essences': 'Physicality of Body Presentation', 'Signifiers of Pre-Injury 'Legacy Self'', 'Dependency of Lived Corporeality'* and '*Contradictions of Lived Corporeality'*, which served to collectively construct the meaning of lived corporeality from the perspective of the witness.

**Table 7**
**Superordinate '*Meaning Structure*': Lived Corporeality *of-ASC*: The Witness**

| **Superordinate '*Meaning Essences'*** |
|---|
| **5.6.3.1** Physicality of Body Presentation |
| **5.6.3.2** Signifiers of Pre-Injury 'Legacy Self' |
| **5.6.3.3** Dependency of Lived Corporeality |
| **5.6.3.4** Contradictions of Lived Corporeality |

#### 5.6.3.1 Physicality of Body Presentation

ASC presented itself as a range of observable behaviours and actions which were described in detail and emerged as significant in the narrative of the witness. It was the physicality of ASC as a lived, corporeal presentation which was recalled and described with clarity. The 'lived body' as it presented itself *in-ASC* influenced the witness' knowledge and understanding of what ASC meant in terms of prognosis, recovery, and the signifiers or restoration of 'legacy self'. Throughout the trajectory of ASC, the witness became the 'expert observer', as they became increasingly attuned to the physical changes and behavioural presentations *of-ASC.*

The witness was quick to discern that it was the physical presentation and behaviours demonstrated during the trajectory of ASC, which informed the judgements made by the clinicians as to whether recovery would be realised and to what extent. They became increasingly familiar with the medical narrative which focused on the corporeal presentation of ASC as the key prognostic indicator.

Mary assigned significant meaning to her daughter's physicality and bodily presence. She became particularly astute in her observations of Donna's bodily positioning and responses, noting abnormal posturing and limb function which despite her attempts, she was not able to remedy:

*'She was still unconscious. And then her arms and stuff went into one complete spasm, so I think it was her left arm, yes, it's her left side with the weakness. It went into like cerebral*

*palsy stage and every time we tried to straighten it, it couldn't do it*' (Mary:W13-16).

Donna's inability to maintain 'normal' physical function, respond appropriately and failure to physically engage in therapeutic activities were noted. These profound changes to her physical body were compounded by the fact that she was unable to communicate verbally apart from constant screaming:

*'She just slept and couldn't do any physio, any speech and language, she couldn't do anything* (Mary:W146)*….When she was distressed it was horrendous, absolutely horrendous. She would scream for 24 hours, just totally scream. She didn't respond to any of our voices at all'* (Mary:W45).

Despite Mary's belief that Donna was regaining consciousness, her physical presentation revealed the extent of her brain injury and served to compound concern about her daughter's prognosis:

*'We didn't know she was blind, we didn't know she couldn't speak, we didn't know she couldn't sit up, none'* (Mary:W35).

Mary felt isolated as she became increasingly vigilant of her physical and cognitive limitations, particularly as she began to appreciate the extent to which changes to Donna's physical body were estranged from her 'legacy self'.

Carol was reminiscent of her husband, James' physicality prior to his injury, so much so that she believed he was able to independently effect recovery:

'*I just knew with him being a big, strong bloke that eventually he would get this stuff out of his system and that he would come round'* (Carol:W11).

Sarah's understanding of ASC evolved as she witnessed her brother Amir's 'lived body'. She observed his actions, behaviours and physical presentation following the brain injury and associated his responses in ASC as representative of the depth of his ASC. She described his recovery from ASC when he initially opened his eyes, a formative moment in his illness trajectory. She was of the understanding that when he opened his eyes, recovery would be realised:

*'Amir came out of the coma after 72 hours* [pause six seconds], *that's three days, isn't it? Yeah, on the fourth day. I just remember I got a phone call saying he's opened his eyes'* (Sarah:W34-37).

However, despite his eye opening, recovery from ASC was not realised. She reflected on his continued inability to communicate and recognise family members, his limited physical movements and increasingly aggressive behaviour. She described him as a '*vegetable*' and '*not the same person'*:

*'All I remember him saying was he doesn't know who I am. He's opened his eyes, but he doesn't recognise anyone, and he couldn't speak. He's basically a vegetable'* (Sarah:W44). *'I could see* [pause ten seconds] *he's not the same person, if you know what I mean* [pause eight seconds]. *I think he was able to move one of his hands* [pause three seconds] *but nothing else really apart from moving his legs. He couldn't do anything else* [pause eleven seconds]*'* (Sarah:W57-62).

**5.6.3.2 Signifiers of Pre-Injury, 'Legacy Self'**

ASC manifested itself as a complex and dynamic physical and cognitive presentation which witnesses constantly observed and appraised. The extent to which the 'lived body' was aligned to, or estranged from, the 'legacy self' was revealed by the witness' continual assessment of communication, behaviours and actions throughout the hospital stay. Witnesses became 'expert observers' and vigilant in their search for behaviours *'in-ASC'* which represented 'normal' body presentation or recognised as reminiscent of the person and / or their relationship with the patient prior to the ABI. Whilst, on occasions, these were highly nuanced and subtle responses, they were upheld as important signifiers of the 'legacy self'. However, when behaviours were observed as bizarre and atypical of 'legacy self', witnesses endeavoured to justify these as anticipated consequences of the ABI:

'*He was being promiscuous to the nurses, so I was like, pack it in, I were like, this is not Barry. This is not Barry*' (Heather:W224).

*'All we were told was that she was so distressed because of the swelling of the brain. That was all we were told, that once the swelling started to go down she would start to calm down'* (Mary:W208).

When behaviours were recognised as familiar and characteristic, however subtle, the witness focused on these as evidence that 'legacy self' remained. The characteristic way in which Barry *'sniffed the air, twitched your finger or like roll his eyes a little bit'* (Heather:W256), '*he gave me eye contact*' (Heather:W230), were mannerisms which reassured the witness that the person was 'present' *in-ASC*. Despite Simon's inappropriateness and asking one of the physiotherapists to *'get her kit off'* and calling '*two of the nurses, lesbians'*, his wife, Kathy, defended his behaviour in the context of his pre-injury self: '*Simon does say inappropriate things quite often'* (Kathy:W253).

However, despite their 'search' for the 'legacy self', the witness was frequently disappointed and moved along a dynamic and ever-changing continuum of cautious optimism and despondency:

'*Because you just think, 'oh we're getting there, we're getting there' and then you weren't getting there'* (Mary:W150).

There was a distinct lack of transparency and discussion by staff of Donna's ASC. Mary became the experienced observer as she witnessed Donna's evolving manifestations of ASC. She frequently compared Donna's physical and behavioural presentations with her 'legacy self' and reminded staff that she, for example, was a *'very, very clever girl'* (Mary:W176) prior to the brain injury. However, there was a sense of ominous foreboding and melancholy as to whether these bodily changes would be permanent and that a return to 'legacy self' may not be realised.

Carol believed that James, her husband, was comforted by her presence as he held her hand at the bedside, a reciprocal and intimate gesture reminiscent of their relationship. When he was able to respond to the offer of a drink, this was reassuring. Although he remained disorientated, these small, yet significant responses were seen as important along the trajectory of ASC:

*'Well, he wasn't frightened of me, and I was holding his hand and he was holding my hand back. I think I just assumed that he knew who I was. I kept giving him a drink and he was like, 'OK'. It was like every day a little bit more of him came back. He had no idea where he was – no idea why he was in this place. When a little bit more of him came back'* (Carol:W45-48).

James' behaviour however, remained challenging throughout his admission and on one occasion he wandered out of the hospital and was subsequently found in a local supermarket. Carol defended this wandering behaviour and his like for the outdoors with reference to his 'legacy self':

*'If James stays in the house more than a couple of hours, he's climbing the walls. He's an outdoor person'* (Carol:W160).

David's physical and verbal presentations of self also became important measures of Patricia's experience of ASC. She recognised some of his behaviours as reminiscent of his former self and felt '*relieved*' and reassured that he was able to respond to her, albeit in a limited way:

*'I could see at times that he seemed to be, you know, if I spoke to him or anything, I felt there was some kind of understanding there from him, like that he would squeeze my hand a bit now and then'* (Patricia:W27-29). H*e quite seemed himself and I felt quite relieved that I felt like I could joke with him a bit and he seemed OK'* (Patricia:W37).

Paul's anxiety as he first met his wife was palpable, but he was somewhat reassured when:

'*Then she saw me, looked up and gives me a massive lopped-sided smile like and I just knew Alice was there and that was a massive relief. You know I could see there were issues but I though the main beast is still there, she's still in there, and she knew who I am'*

(Paul:W139-141).

However, whilst corporeal presentation is at times aligned to 'legacy self', on other occasions there appeared to be a significant distance between the reality of the patient's corporeal presentation and the witness' expectations. Patricia moved along a continuum of reassurance and despondency during her assessment of David's communication, behaviours and actions throughout his hospital stay:

*'I was having a bit of a joke with him with one of his Aunties and he seemed to laugh a bit with it'* (Patricia:W42) *….he'd asked for a drink and said he was thirsty'* (Patricia:W44).

However, these assurances were short lived. David had an enduring delusion that he was deceased. His conversations and behaviour became increasingly bizarre post-operatively and despite frequent attempts by Patricia to challenge his delusions, he persisted in his belief: *'..giving me death bed speeches and saying, 'We've been so happy and I wish I'd been able to be here longer'* (Patricia:W1:49). '*He just constantly referred to living as being in the past tense, so you know, 'I haven't got a heart anymore; I used to have one when I was alive', and saying to me, 'oh we've been so happy with the kids and I'm sorry that I've had to go'* (Patrcia:W1:64-67).

Unlike his former self, David failed to appreciate colloquialisms and took language literally:

*'Everything that I said completely literally, so, you know the way you speak in England that, I think he was taking some medicine and I said, 'Oh, knock it back', and he looked at me really confused. And anything you say, I can't think of another example, but he would literally take things as you said them, which was strange'* (Patricia:W75).

A meeting had been arranged for David to meet his three young children for the first time. This was a significant moment for Patricia, as she had previously refuted the suggestions by staff that this would help to re-orientate him and aid his recovery. Patricia eventually agreed despite expressing her reservations that her children would be distressed and that his persistent delusion he was dead would have a profound impact on his ability to engage both as a husband and father. The encounter was vividly remembered by Patricia. She observed him being assisted, '*shuffling*' down the corridor to the room where his family were anxiously waiting. Neither his gait, nor posture, belied that of a husband or father figure. The changes to his lived body presentation were profoundly realised at that moment:

*'It was really weird. Well, I'm not easily shocked 'cos literally every day was a different thing. Bear in mind we have three children, and I hadn't taken them in at this point, and I think around that time I thought I'd bring the children and that was really badly managed. They said they'd take us into a private room, and it was a little small room, and my sister*

*was with us, and the minute he saw the children they kind of shuffled him down the hall, he got really upset, but he was really sobbing and howling, so that was traumatising for everybody'* (Patrica:W130).

Carol viewed her husband's recovery and emergence from ASC as a staged process which, over time, revealed reassuring elements of his 'legacy self' or otherwise. Whilst Carol prepared herself for '*him not being the same'* she was increasingly relieved when behaviours were reminiscent of James' prior self. Carol predicted how he would respond in the Intensive Care Unit once the sedative drugs were discontinued and because her predictions were realised, she felt reassured that he remained 'present' in ASC:

*'I said, 'Look, he's going to come round, he's going to pull all his tubes out and if you give him any pants, he's going to be off'* (Carol:W12).

James' ability to discuss his hobbies and interests with authority served to reassure her further. James enjoyed fishing and asked her to buy some 'floats', naming the fishing shop. Initially she pacified him believing his request would be readily forgotten but was pleasantly surprised by his persistence the following day.

Sarah frequently reflected on her brother's, Amir's, personality traits, attributes and characteristics prior to the injury and compared these to his actions and behaviours whilst in ASC. Describing him as an independent, sociable person who had a close relationship with his mother, she was reassured that following the injury he expressed personal preferences reminiscent of his 'legacy self':

*'Apart from being fussy about his eating habits and* [pause 8 seconds] *he didn't like wearing pyjamas'* (Sarah:W216).

*'So those kind of things were still there'* (Sarah:W288).

She was also heartened that his injury had resulted in some unexpected consequences: '*He smiled more, which he never did before*'. Whilst she accepted that recovery was likely to be protracted and prognosis unpredictable, she encouraged his family to focus on what might be viewed as recognisable character traits and behaviours, reminders of his 'legacy self' amidst the chaos of the injury:

*'He's not the same but he's still our brother. He's not the same but he's still our brother'* (Sarah:W53).

Once Nina had been discharged from the ICU and transferred to the ward, her daughter, Jane, was under the impression that despite her inability to communicate, there was a sense she was '*compos mentis like*' (Jane:W263). Jane observed Nina '*miming for stuff like with her hands*' (Jane:W263). She recognised her mother's mischievousness as she repeatedly removed breathing equipment. The belief that her mother was acting intentionally was affirmed by the nurse: '*she's doing that on purpose*' (Jane:W264).

### 5.6.3.3 Dependency of Lived Corporeality

The patient's reliance on invasive clinical measures, for example, a tracheostomy tube, artificial ventilation to maintain life, and the body's dependency on equipment to enable physical movements, served to reaffirm the extent to which the 'lived body' was estranged from the previously independent and functional 'legacy self'. Donna was dependent on mechanical support to breathe, normally a passive, self-supporting human function. The increasing dependency of her 'lived body' on physical support, adversely influenced Mary's understanding of the prognostic trajectory of ASC:

*'And it got to about the third or fourth week and they said that the ventilator they couldn't switch it off because she just wasn't responding to anything really'* (Mary:W7).

Clinical decisions to withdraw supportive measures were viewed as reassuring indicators of the emergence from ASC and return of an independent, functioning self:

*'To see whether he could breathe on his own, so that was a big step that when he could without the breathing things'* (Patricia:W1:35-36).

Early in James' care, Carol believed that his ASC was therapeutically induced by drugs, anticipating that ASC was temporary and reversible, with recovery imminent:

*'They were actually keeping him asleep so his brain could rest, and he could deal with it'. He'd had a major brain operation and they kept him sedated for the first few days and it wasn't a natural coma*' (Carol:W8-9).

However, when the sedative drugs were withdrawn and his ASC persisted, she began to appreciate the potential extent of his injury:

*'They started to wean the sedation off and he was still out of it, he didn't seem to be coming round at all and they were saying to me that I had to prepare myself for him not being the same and not coming round'* (Carol: W7-11).

### 5.6.3.4 Contradictions of Lived Corporeality

The presentation of the 'lived body' informed the witness' understanding of the meaning of ASC, and their perception of the professional's formal clinical assessment of ASC. Witnesses were particularly eager to hear the professional's opinion, but the findings were often in conflict with their own conclusions. This resulted in tension, particularly when the professional was dismissive of the witness' report or failed to recognise its significance as a possible indication of recovery. Whilst the witness was astute to the outcome of the clinical assessments and information subsequently disclosed by staff, they balanced this against their own personal, subjective observations of the patient's 'lived body' presentation. Early in the post-operative phase, Patricia sensed that nursing staff were reassured by David’s progress:

‘*You know when the nurses came round and did the observations and whatever, you know, they were pleased with whatever they found’* (Patricia:W221).

These clinical findings were supported by Patricia’s observations:

*‘I mean when we went to see him his whole face and neck and everything was really swollen up and you could see the swelling going down during the night.. so you could actually see that he was looking a bit better as well’* (Patricia:W222-225).

However, there were occasions when the outcome of formal clinical assessments was not believed, particularly when the lived body’s responses were either not consistent over time or when the witness’ assessment was not aligned with those made by clinical staff. Sarah sensed that Amir was ‘present’ within ASC as confirmed by his behaviours, but staff repeatedly refuted her observations:

*‘The consultant kept saying he would never be the same, never walk, talk, and be like a vegetable’* (Sarah:W206-207).

## 5.7 LIVED TEMPORALITY: Superordinate ‘*Meaning Structure’*

**‘*Time arises from my relation to things*’**

**(Merleau-Ponty, 1962, p. 412)**

### 5.7.1 Introduction

The lived experience of time, defined as the ‘*meaning structure’*, ‘Lived Temporality’, was felt by both participant groups and became an important contribution to the understanding of the ASC trajectory.

For the patient, time *in-ASC* was experienced uniquely and existentially, whilst for the witness, time was understood to be a determinant of, and influenced the meaning of the ASC in the context of the diagnosis and prognosis of the ABI. For the witness, time emerged as an important influencer on the construction of meaning of ASC with respect to both diagnosis and prognosis. Time was a predictor of recovery or otherwise and informed the witness’ perception as to whether ‘legacy self’ was likely to emerge or be reconstructed because of the ABI.

### 5.7.2 Lived Temporality *in-ASC:* The Patient

Table 8 presents the superordinate ‘*meaning essences’*: ‘*Subjective Temporality in-ASC’* and *‘Objective Temporality in-ASC’*, which collectively served to construct the meaning of lived temporality from the perspective of the patient.

| **Table 8**<br>**Superordinate '*Meaning Structure'*: Lived Temporality *in-ASC*: The Patient** |
|---|
| **Superordinate '*Meaning Essences'*** |
| **5.7.2.1** Subjective Temporality *in-ASC* |
| **5.7.2.2** Objective Temporality *in-ASC* – Time Lost |

### 5.7.2.1 Subjective Temporality *in-ASC*

'Lived time' *in-ASC* was subjectively experienced. The duration of the ASC experience was not 'measured' or remembered as a distinct time frame but described as an abstract temporality. Experiences within ASC influenced and were influenced by the patient's perception and experience of time.

Patients described the persistence and duration of their hallucinations as seeming '*to last forever'* (Nina:P64-65), '*so in my head I'm thinking I've just been in there for a long sleep'* (Barry:P66). Patients had little sense of the duration of ASC: '*well I don't know how long it was*' (Andrew:P47); '*I didn't realise how long I had been in there*' (Barry:P80) or able to relate their experiences to specific time trajectories, stating, '*I didn't know one hour to the next'* (Andrew:P168).

The passage of time *in-ASC* was perceptually distorted. The patient resided in a 'temporal flux' and appeared to 'construct' their own temporality. On recovery, because 'normal' time trajectories had not been observed, they found it difficult to reconcile experiences *in-ASC*. Donna found it '*all very strange'* (Donna:P44), that she had imagined giving birth to seven children during her time *in-ASC* and that the encountered involved protracted and elaborate plots which defied conventional time:

*'Even how you get from being in a coma to having children'* (Donna:P44).

Time was relative to experiences *in-ASC,* in so far as there appeared to be temporal dimensions to the scenarios encountered in the 'lived space' of ASC. When experiences were disturbing and burdensome, time was protracted. June recalled hearing the sound of bubbling water and whilst she initially felt comforted, believing she was in a spa, '*it went on for such a long time'* (June:P123), *'this thing was going on and on all the time*' (June:P126). The temporality of ASC appeared to evoke an emotional response and for some of the participants, this dominated the narrative. For Andrew, whilst he had no sense of objective time *in-ASC* and '*didn't have a clue what was going on*', he had an acute sense of boredom, remembering it as, '*a lonely time'* (Andrew:P184).

Salar's experiences took him back to when he was nine years old, '*my mind went back as though it was yesterday*' (Salar:P72-73), and although on recovery, he remembered being frequently reminded he was 20 years of age, '*it felt distant like it's not me'* (Salar:P74). For him, reverting to childhood was therapeutic. By his own admission, he had experienced a difficult adolescence and so having the opportunity to return to a period of his life with '*a fresh mind was actually something that I'd pay twice for'* (Salar:P86). However, as he became increasingly aware, he remained resolute that he was now the youngest member of the family, and he held a very different chronological position in the family hierarchy. Family members berated him for his childish behaviours *in-ASC*, which served to affirm his beliefs:

'*It made me feel at the time like a baby because that's pretty much what I was, and I did childish things. I think at that point, my mind was resetting like I was one or two or three or something and later when I was aware, I was nine'* (Salar:P167-169).

Whilst John's awareness was sporadic and fleeting, he appeared able to discern night and day and this served to orientate him within the lived space of ASC:

*'Well, I don't know how long it was, but every time I was coming round and then,* [pause 2 seconds] *at just like random times during the night,* [pause 3 seconds] *and dead dark one time and light the next'* (John:P47-49).

Whilst for some participants the content of the scenarios and hallucinations were random and disorganised, lacking any sense of temporal organisation, for others, ASC presented itself as a succession of narratives relayed 'over time' with storylines progressing and evolving with a past, present, and future. This subjective experience of time was particularly disorientating as participants become increasingly aware. They found it difficult to transition from their now familiar temporality to that which was objectively and universally experienced by others. In contrast, Simon's awareness of reality was sudden, he was '*asleep and awake, it's as simple as that'* (Simon:P303).

#### 5.7.2.2 Objective Temporality *in-ASC* - Time Lost

For the patient, there was no knowledge of objectively measured time *in-ASC*:

'*I had no concept of time at all'* (Simon:P307). '*You don't even know what day it is, what time it is half of t'time. I thought at one point I were twelve hours being time-wise'* (Simon:P369-370).

It was only on recovery that the reality of the duration of ASC was fully appreciated. There was a profound sense of disbelief of 'time lost' and a stark realisation that for the patient, the temporal dimensions of the lived space of ASC was experienced in isolation:

*'It's like in a way I feel I've lost a part of my life with being in there* (Barry:P106). *It's like four or five weeks of that, you know, like you just think, well what happened, and in a way it's quite scary to not know. I've missed out on life'* (Barry:P111-115).

Witnesses held a privileged position. They were 'present', and as observers gave testimony to the patient's behaviours and responses *of-ASC*. However, as the 'absent' minority, patients could neither concede nor reject these accounts. Time *in-ASC* could only be retrieved if the witness was prepared to share what happened during this time. When the temporal experiences *in-ASC* reflected objective time then patients felt reassured. Donna believed she had received a Tiffany necklace from her boyfriend as a Valentine's gift whilst *in-ASC.* On recovery, whilst she realised that this had not happened, she was reconciled by the fact that her:

'*Calendar days from the months that I was in hospital did add up to my dream days, 'cos I remember having Valentine's Day'* (Donna:P59-60).

Certain lived spaces of the hospital served to orientate the patient to the reality of objective time. It was not until Donna was transferred to the neurological rehabilitation unit and a daily routine was imposed, that she able to differentiate circadian patterns '*by that point you kind of know when the day was and when the night was 'cos I had that routine'* (Donna:P349-350). This re- orientation in time and the daily alarm from her mobile phone, not only enabled her to discern '*what was dreams or wasn't dreams'* (Donna:P356), but also facilitated emergence from ASC:

*'That's really how I knew I was waking up a bit more 'cos the alarm went off every day at 7.20, 'cos it said that from my thing, and my Mum had left my phone in hospital, so it went off every time and that's the only, that's the only way that I knew like sense of time'* (Donna:P167-171).

### 5.7.3 Lived Temporality *of-ASC:* The Witness

Table 9 presents the superordinate '*meaning essences'*: '*Time as a Predictor'* and '*ASC and Circadian Rhythm: A Return to 'Legacy Self'* which served to construct the meaning of lived temporality *of-ASC* from the perspective of the witness.

**Table 9**
**Superordinate '*Meaning Structure*': Lived Temporality *of-ASC*: The Witness**

| **Superordinate '*Meaning Essences'*** |
|---|
| **5.7.3.1** Time as a Predictor |
| **5.7.3.2** ASC and Circadian Rhythm: A Return to 'Legacy Self' |

#### 5.7.3.1 Time as a Predictor

The meaning of the ASC trajectory was influenced by time. Time frames were frequently defined by clinical staff, and witnesses understood these to be predictive of recovery or deterioration. Witnesses accepted these time frames as the 'truth' and became despondent when recovery was not as anticipated. Time projections also influenced clinical decisions about transfer between clinical settings and became an important indicator of the illness-recovery trajectory of ABI. When there was improvement or otherwise in ASC, witnesses would define these in distinct time frames:

‘*The actual coma side of it to begin with we were told that it was only four to five days till the swelling of the epiglottis went down and then she’d go straight to a medical ward and just 24 hours to check that she was eating and drinking, but it got to the fifth day, and she was still coma at this stage’* (Mary:W2-6).

*‘I think I was, by his bedside we were only thinking, the only timespan we could think in at that point was minute by minute. Me and my mum and sister just kind of said, ‘we’ll take it minute by minute’* (Patricia:W214).

For Patricia, ‘lived time’ became an important factor in her attempts to make sense of her husband’s ASC. Immediately post-operatively, she reconciled his lack of responsiveness and depth of ASC as realistic consequences of the extensiveness of surgery and the anaesthetic drugs. On transfer to the ward, she appeared to measure his recovery in defined time parameters. The number of days post-surgery was remembered, as were specific days of the week and these seemed significant in her assessment of his recovery and of the meaning of ASC. At critical moments in his care, specific times of the day were recalled:

*‘So that was about nine o’clock at night, I think, or ten o’clock when we went and sat with him for the night’* (Patricia:W25).

T*his would be four or five days after the operation. You’d go in and he went like he was on drugs, like tripping, his pupils were big, and he’d say, ‘I’m looking down and everything’s wonderful and I can see fabulous things’, very much like he was flying above everything’* (Patricia:W119).

On one occasion, she specifically remembered the day of the week. She described visiting her husband on a Sunday, a day she traditionally associated with serenity and rest. It was on this occasion, that his delusional behaviour appeared more profound. This was compounded by the fact that staff could not relieve his distress and failed to provide any rationale as to the extent of his delusions:

‘*I think I’d rung up to see how he was in the morning. I could hear him screaming; it was a Sunday. So, I went in, and the nurses were just, it was quiet ‘cos it was a Sunday. I don’t think they knew what to do. They didn’t say anything to me about why he might be like that, and I just kept trying to distract him doing crosswords and anything’* (Patricia:W93).

Time trajectories were remembered with respect to Amir’s responsivity. Initially staff did not give an indication of prognosis or cite timelines for recovery. However, Sarah was able to recall that he opened his eyes four days following his admission to hospital:

*'Obviously, we were told he was in a coma. We had no idea if he was gonna come out of it'* (Sarah:W23-24).

*Amir came out of the coma after 72 hours* [pause six seconds], *that's three days, isn't it? Yeah, on the fourth day, I just remember I got a phone call saying he's opened his eyes'* (Sarah:W34-37).

The family understood that eye opening was an indication of recovery from ASC and were initially reassured by his progress. Unfortunately, over the proceeding weeks he continued to present with concerning behaviours. Sarah realised that the longer he remained *in-ASC,* the less likely recovery and return to his 'legacy self' would be. It would be four months before they saw any significant improvement, which was remembered as a formative moment in his recovery:

*'Anyway, miraculously after four months, obviously with the help of physio, etc, and I think people praying for him, he recovered, he was walking* (Sarah:W81-82).

#### 5.7.3.2 ASC and Circadian Rhythm: A Return to 'Legacy Self'

Routine was viewed as an important influence on ASC presentation. The ability of the patient to maintain a normal, sleep-wakeful circadian rhythm during a 24-hour period, was deemed to be a reassuring indication of recovery and emergence from the ASC. Witnesses recognised sleep and responses during natural circadian rhythms distinct from those seen in ASC:

*'So that was about nine o'clock at night, I think, or ten o'clock when we went and we'd sat with him for the night, and while he was asleep you could see at times that he seemed to be, you know, if I spoke to him or anything I felt there was some kind of understanding there from him, like that he would squeeze my hand a bit now and then.. and then there were times when it looked as though he was kind of coming up to consciousness a bit and then dip back down again'* (Patricia:W25).

A lack of daytime routine and failure by staff to maintain a distinction between day and night were perceived to adversely affect recovery and emergence from ASC. Mary felt that when a sense of order and routine was imposed in the neuro-rehabilitation unit, then Donna was able to respond appropriately. It wasn't until her transfer to neurorehabilitation that she perceived her daughter to be asleep, evidence of a normal circadian rhythm, rather than *in ASC*:

*'It was night time when she could sleep, the change in night and day and that routine really helped her as well, She wasn't in a routine before she went up to rehab because she was still not with us'* (Mary:W27).

## 5.8 LIVED RELATIONALITY AND DISCOURSE: Superordinate '*Meaning Structure'*

***'Language makes thought, as much as it is made by thought'.***

**(Merleau-Ponty, 1991, p. 102)**

### 5.8.1 Introduction

Both participant groups described their lived relations during the ASC trajectory. For the patient, in the immediacy of their perceptually disordered landscape through to emergence, and for the witness who was situated in the different locations within the hospital, the accompanying discourse, was revealing and directly informed their construction of the meaning of ASC.

The patient *in-ASC* described encounters and dialogue with characters within the immediacy of the hallucinogenic and delusional landscape and reflected on their memories of engagement with others in the liminal space as they became increasingly lucid through to recovery. The content of the patient's relationships with others was also reflected upon in the context of their pre-injury, 'legacy self'.

The 'lived relationships' the witnesses had with others significantly contributed to their understanding of ASC. Meaning was constructed through dialogue with healthcare staff, but also as they observed the staff's engagement with the patient *in-ASC*, and through the subtext, inferences, and narrative tone. At the bedside, the witness reflected on their role as advocate as they become increasingly isolated.

### 5.8.2 Lived Relationality and Discourse *in-ASC:* The Patient

Table 10 presents the superordinate '*meaning essences'*: '*Lived Intra-Relations in-ASC', 'Lived Inter- Relations in-ASC: The External Narrative'* and the '*Historicity of Relations'*, which served to construct the meaning of the lived relationality and discourse *in-ASC* from the perspective of the patient.

**Table 10**
**Superordinate '*Meaning Structure':* Lived Relationality and Discourse *in-ASC*: The Patient**

| **Superordinate '*Meaning Essences'*** |
|---|
| **5.8.2.1** Lived Intra-Relations *in-ASC* |
| **5.8.2.2** Lived Inter-Relations *in-ASC*: The External Narrative |
| **5.8.2.3** Historicity of Relations |

#### 5.8.2.1 Lived Intra-Relations *in-ASC*

Patients became embroiled in the plots of the hallucinations, delusions, and confusion of

ASC. They had a meaningful, internal dialogue with characters *in-ASC*. ASC presented them with stories of strife and struggle, through to stories where life narratives were recognised, re- experienced and on occasions, resolved.

The hallucinations and delusions sometimes involved characters previously known to the patients, but the context and stories portrayed were often embroiled in fiction. When patients described the content of these experiences, they frequently questioned the nature and context of their illusions and the presence of certain friends as the central characters. Donna vividly described a scene whereby she gave birth to seven babies, four of whom were removed by social services. The three babies left in her care were named after her cousins. Not only did Donna repeatedly attempt to make sense of the story but questioned the plot and sought resolution:

'*Yeah, and then end up with three 'cos social services took some way. How is that possible? I do not know. How is it possible be in a coma and have social services take babies away from you, I do not know but yeah… It's really strange, yeah. And like my ex was there and that and that was weird, yeah'* (Donna:P18-27).

On other occasions, Donna's experiences *in-ASC* involved scenarios with individuals who she subsequently found out had not visited her. On recovery, she questioned their presence:

*'Cos, I remember like being in hospital again and these people like relatives that didn't actually come and see me but I thought that they did come to visit me in hospital when I was in my coma… he's my ex-boyfriend, his Mum and Dad never came to see me whilst I was in hospital but they were always there in my dreams, weirdly enough. I don't know why'* (Donna:P70-72).

#### 5.8.2.2 Lived Inter-Relations *in-ASC*: The External Narrative

Participants appeared to be able to discern the presence of individuals at the bedside and, on occasions, recognised them as family members, friends, or staff. They tried to facilitate meaningful dialogue whilst *in-ASC*, believing they could be heard. However, attempts were often futile which caused distress and served to compound the patient's sense of isolation.

For a significant period, Donna acknowledged that, despite her persistence, she was unable to communicate verbally with others during ASC. She had an internal dialogue with herself and became increasingly frustrated when she could not make herself understood:

*'I remember being in hospital thinking my sister was next to me in the bed next to me. I remember thinking. I need the toilet. I needed the toilet, why is no one listening to me? I need the toilet'. I was catheterised at the time. I remember thinking, 'I need the toilet, I needed the loo, I needed to pee. Why is no one listening to me? I need the toilet. You just*

*take me to the toilet right here right now and that'* (Donna:P173-177).

Donna's attempts to communicate persisted and she became increasingly frustrated in the futility of conversation. She recalled the emotionality of the relationship she had previously experienced with her father and this remained with her *in-ASC*. Her distress was palpable as she recalled hearing her father saying:

*'Can you hear me Donna?', and, I'm going, like this, nodding, and he's crying 'cos he's like: 'Can you hear, understand what I'm saying?', and I'm going 'Yeah, I can understand what you're saying' and that and he's like, 'Can you hear me?' and I'm going, 'Yeah, yeah I can'* (Donna: P:79-81).

Donna's family attempted to communicate with her through musical games. On one occasion she remembered a music tune quiz where she had to guess the artist. She was able to hear the questions being asked and believed her answers were heard, but quickly realised her attempts were futile:

*'Like I remember my family being there and they're playing like, it was either they were playing guess the music tune, 'cos like they were switching the music and guessing who was singing it and guessing the song and the artist. Now I knew everything. I knew exactly who was singing it, exactly who it was and I was getting so frustrated 'cos I was shouting it out from what I thought I was saying it, saying the right words quicker than any of them were guessing them and I was getting really frustrated 'cos I was going, 'Why aren't you listening to me?', you know, 'Why aren't you hearing me?*' (Donna:P119-125).

For Donna, certain experiences remembered during the time she was *in-ASC*, or in the early stages when she was increasingly more aware, served to make her feel 'detached', not only from reality but also from others. She recalled numerous occasions when she was unsuccessful in her attempts to communicate and express herself, and this proved distressing. She recalled her family realising that her vision had been affected: '*my step-dad was jingling keys in front of me and going 'She can't see, she can't see these keys you know'* (Donna:P208-208). She remembered attempting to communicate by nodding her head and squeezing their hands in response to family members posing letters of the alphabet to form words, but her attempts were futile. She heard her stepfather again reiterating:

'*There is something wrong here, why are her eyes looking like this',* (Donna:P217) '*why is she not looking, why is she not flinching or anything'.* (Donna:P222-223). Donna had been convinced her requests were heard and understood by those at the bedside, but on recovery, was surprised to hear that she had simply made incomprehensible sounds and screamed incessantly:

*'I thought I was audibly talking like formed words, like 'I need the toilet' was in my head but*

*coming out was argh, you know, coming out to them was just moans and screams…….you know you're talking, yet not actually talking just like murmuring and screaming, yet you think you are talking'* (Donna:P260-264).

A formative moment for Donna occurred when a nurse gave her an ice cube and she recalled saying *'ice cubes'.* She believed that had this not happened, she would not have regained her speech:

*'But I guess if they had never given me an ice cube, I probably wouldn't have spoken you know'* (Donna:P308-309).

June's inability to speak as she began to emerge from ASC, meant that she could not articulate to others the extent of her hallucinations and how distressing her experiences had been:

'Y*ou know you don't have the language to explain the feelings that are whirling round in your mind'* (June:P73).

Salar recalled fleeting conversations with family members, but because he had no memory of his accident and the extent of his injuries, he found it difficult to engage and comply with the restrictions they imposed.

Following a fall out of her bed, Nina recalled hearing staff questioning her awareness *in-ASC*, but became increasingly frustrated and isolated when she was unable to communicate with them:

*'And I remember lying on the floor trying to get up, but I couldn't. I didn't have the strength. Then I heard two nurses came and I heard them say, 'How the hell did she do that?' and I'm assuming how did I get out of bed, and they had to get me up and into the bed. And they were asking me where I was going. Well, I couldn't answer them'* (Nina:P14-17).

June remembered overhearing members of staff communicating about her during a clinical procedure believing she was unconscious and unaware:

'*And I can remember them talking but I could tell that they knew that I wasn't, I knew that the way they were talking that, from their point of view, they thought I was unconscious. I definitely had a feeling of that'* (June:P261-263).

As Barry became increasingly aware, he continued to experience transitory periods of confusion, but because he was unable to communicate, continued to feel isolated:

'*I just felt like I'd sort of deal with them myself on my own, you know'* (Barry:P180).

In contrast, Salar remembered the positivity and presence of practitioners and the nuanced and respectful way in which they engaged with him whilst *in-ASC:*

'*Yeah, I remember good things that happened. I remember one of the nurses there, I still remember her face and how she was. She used to help me quite a lot'* (Salar:P110-112).

June described some of the practitioners she encountered as '*the other women'* (June:P210), one of whom was the Speech Therapist. Whilst she acknowledged her perception at the time was possibly misplaced, she nevertheless remembered feeling vulnerable and compromised as she was unable to complete the tasks requested of her. She vividly described the commanding presence of the practitioner who:

'*Looked all sort of strict in her uniform saying, right come on you to get out of bed and we're going to a room, we're going to do a bit of work to help you with your speech'* (June:P214-215).

As her abilities had been so affected by her injury, she was:

*'Embarrassed, because I couldn't speak, and I couldn't read and write or anything and I thought she was just like a teacher, and I can't do that. And so, if I used to see her coming down the ward I used to say 'Oh, she's coming back, pretend I'm asleep and she might think I'm so tired she will miss my session'* (June:P216-219).

Another '*other'* woman was later understood to be the Occupational Therapist. June remembers being taken into a *'little room'* to play what she believed to be '*children's games'* (June:P232), but without any explanation as to the purpose felt '*irritated by that and sort of being awkward'* (JuneP233-234).

'*I suppose in some ways because these games looked childish to me. I reacted to that, but because I couldn't do it and I wasn't in the mood for doing it I suppose I was a bit like sulking like children, do you know, I don't want to do this'* (June:P240-242).

On occasions, patients sensed staff as paternalistic and authoritarian in their approach. They recalled feeling rebuked and reprimanded for their behaviours *in-ASC*. James recalls referring to the physiotherapist as the '*psycho physio'* (James: P622) because he did not understand why he was required to '*perform'* exercises. He recalls her '*messing with my head'* (James: P640) and refused to comply with her instructions. Barry recalls feeling berated because he was unable to attend to his own hygiene after going to the toilet:

*'I had to go to the toilet on the ward and I as I say, it sounds crude, but I went for a poo and I said 'excuse me, could you wipe my bum? And she goes 'Can you not do it yourself?'* (Barry:P450-451).

Despite Andrew remembering having conversations with people and recognising familiar faces he could not recall detail and did not '*have a clue what they said* (Andrew:P206), except for one nurse who said to him:

‘*Oh, you had a 20% chance of living and eight out of ten people that’s had this head injury, they’re not here anymore’* (Andrew:P134-135).

At this stage in his recovery, he admitted having no understanding as to where he was and what had happened, ‘*I didn’t have a clue’, I had that going round in my head’* (Andrew:P136).

For John, the presence of family members at the bedside felt overwhelming because he was unable to communicate or function in any meaningful way. His response was:

*‘I just looked at them all and I just couldn’t cope so I fell back to sleep again’* (John:P69).

He described feeling paralysed by fatigue and his inability to make sense of communication and events happening around him:

‘*I can remember feeling really, really, really exhausted, but I could not process that all these people were here for me’* (John:P74).

As he began to gain more awareness, he sensed that family members and staff had expectations of him. However, his limited functional and cognitive abilities meant that he was unable to engage and function as he had done prior to the injury:

’*I couldn’t, so I get really, really wound up and bad tempered’* (John:P79-80).

Family members became instrumental in his recovery, and he recalled with gratitude the physical presence of his mother and auntie assisting him with washing and dressing. His memories of interactions with nursing staff were less favourable. On occasions he felt humiliated and belittled. Whilst he acknowledged that his memories might be misplaced, he recalls challenging a nurse who was laughing whilst giving him an enema:

*‘I remember them being a bit snotty and I said, ‘What are you laughing at?’* (John:P204).

Patients found it difficult to reject the validity of their experiences whilst *in-ASC*, to the extent they continued to believe in the reality of their narrative and were unable to discern fantasy from reality. Donna described a scene where she went with her father and boyfriend to an indoor laser tag game. Her father was ‘shot’ and died in the scene. Her delusion persisted to the extent that on recovery when her grandmother visited along with her father, she believed her grandmother had died also. Her distress was palpable:

*‘It was like my dad got shot and I thought he’d died then ‘cos he’d got shot and I thought he’d been like electrocuted by this laser thing and I thought he’d died. I thought he was dead by that point, so when I woke up, I thought my dad was dead’* (Donna:P62-65). *‘Oh, my days, my grandmother must be dead as well and I remember screaming, thinking, ‘they’re ghosts, they’re ghosts like get out, get out of my room’* (Donna:P183-186).

Following her recovery, Donna continued to feel isolated with her memories of ASC.

Whilst she had the opportunity to share her experiences with the psychologist, she sensed that family and friends were disinterested and dismissed the ‘reality’ of her experiences. During her research interview, Donna’s mother entered the room and began to challenge her recollection of events during ASC. Donna described hearing Andrew Lloyd Webber’s Greatest Hits album being played to her, but her mother was quick to denounce her recall of events: ‘*No, I never played that’.* A disagreement ensued resulting in her mother leaving the room.

On occasions, patients felt ‘tested’ by their witnesses. In attempts to re-orientate them *in-ASC*, witnesses would pose questions but when they answered incorrectly, the patient would feel further alienated and acutely aware of their emerging limitations:

*‘And my brothers, they came to me and said, ‘Who are we?, ‘cos my brother is a doctor and he knew the severity of this accident. Then he told me my whole family said, ‘Who are we? Do we know you?’, just to test me. They said, ‘Are you brothers, are you cousins, are you friends?’ then I said to them with a puzzled face, ‘Cousins?’ I didn’t know they were my brothers, and they all said to me, ‘How old are you?’ and I said, nine’* (Salar:P66-70).

As patients became increasingly aware, they overheard conversations which were pessimistic, sensing that staff had little faith in their recovery:

*‘Like I’m more useless a little bit, I’m not able’* (Salar:P129).

However, Salar was motivated to prove otherwise and felt empowered when his recovery was better than anticipated:

‘*They were really shocked at my recovery, like extremely shocked, even my doctor, he sat down with me and gave me a handshake... they said to me I’m a walking miracle’* (Salar:P137-139).

### 5.8.2.3 Historicity of Relations

June reflected on her ‘legacy self’ during the interview and compared her behaviours and character traits *in-ASC* with those pre-injury. She acknowledged that she was not particularly a demonstrative person but remembered how important the physical contact she had with one nurse [remembering her name] had been:

*‘Before I was ill, I was not particularly a demonstrative person so not always giving people hugs and holding hands and stuff all the time. I mean, I do with the family and stuff but not excessively. But when I came round there was a nurse, she was called, and I know she worked on Ward ... so it was just after coming round from the coma, and for whatever reason I just wanted to hold on to my hand the whole time’* (June:P164-172).

For all participants, recovery from ASC revealed functional, physical, and cognitive limitations that had not been anticipated by the clinician. On recovery, June related an incident when staff had expected her to feed herself following the removal of her artificial feeding tube, but her actions had been particularly distressing for her mother:

'*They probably must have given me some pureed food but I definitely remember it wasn't liquid it was definitely a plate and there's utensils and stuff but my mum was absolutely shocked but I've no history 'cos they gave me this food and I just picked up my left hand, 'cos obviously my right hand wouldn't work at the time and just put it straight into my mouth just like a baby and it missed and it went on top of my head and everything'* (June: P151-153).

Salar remembers his actions and behaviours in ASC being childish: '*I did childish things*' (Salar:P167), and this was reaffirmed when, on recovery, he was told by his family that he:

'*treated my younger brother, he's only five years younger than me, I treated him like he was much older than me'* (Salar:P172-173). *I was like a lost baby asking for help'* (Salar:P176).

For Nina, a formative moment was on the occasion she recalled '*waking up in the ward*' and recognising her daughter's voice, hearing her saying '*you're alright Mam, you're in hospital'* (Nina:P174). She reported seeing family members around the bedside but questioned the reality of the situation because her son, who was a recluse and rarely left the house was there:

*'I thought, 'what's he doing here? Why, why, why, where are we?* (Nina:P 174-175) '*and I thought, 'Well why would he be here?' 'cos you do, you know, he never went anywhere, he was practically a recluse apart from work'* (Nina:P177-178). *'It was just so odd and that was my first wake up'* (Nina:194-195).

### 5.8.3 Lived Relationality and Discourse *of-ASC:* The Witness

Table 11 presents the superordinate and subordinate '*meaning essences'*: '*Historicity of Relationships', 'Inter-Relations with the Healthcare Professional'* and '*The Inferred Narrative: Tension, Bargaining and Narrative Tone',* which served to construct the meaning of the lived relationality and discourse *of-ASC* from the perspective of the witness.

**Table 11**
**Superordinate '*Meaning Structure'*: Lived Relationality and Discourse *of-ASC*: The Witness**

| **Superordinate '*Meaning Essences'*** |
|---|
| **5.8.3.1** Historicity of Relationships |
| **5.8.3.2** Inter-Relations with the Healthcare Professional |
| **5.8.3.3** The Inferred Narrative: Tension, Bargaining and Narrative Tone |

### 5.8.3.1 Historicity of Relationships

The witness observed the patient's communication *in-ASC* as incoherent, confused, and delusional. This was compounded by the fact it was difficult to predict when lucidity and awareness would return and whether the quality and content of communication were such that there could be meaningful interaction. The initial attempt by the individual to communicate purposefully was a formative moment for the witness, and was viewed as evidence of the emergence from ASC and return of the patient's 'legacy self':

*'It was quite a few weeks later. She was up on the ward when she actually responded to me. It was a relief in a way. It was very emotional. Then it was only in phases, it wasn't like it was constantly that she recognised it and that was it, the light switch went on 'cos it didn't, it still took her to recognise properly'* (Mary:W114).

For Mary, not only was her daughter's ability to spell 'mum' highly significant but the fact that she believed Donna was asking for her:

*'She couldn't speak but it was like a, b, c, she would spell everything out and then one day she did actually spell it. I couldn't have been on the ward, and it was one of the physios who was very close to her, she spelt and they said she wanted me, it was like 'Mum'* (Mary:W121).

However, despite the witness' belief that the ability to communicate signified a degree of improvement, the meaning of ASC shifted when it became evident that there were significant cognitive and perceptual impairments. David's communication remained delusionary:

*'He'd say, 'I'm looking down and everything's wonderful and I can see fabulous things', very much like he was flying above everything'* (Patricia:W120)*. He was talking to me quite normally, and I was thinking, 'Oh, this is brilliant, it's really good that he's really improved', and then just as we had been chatting for a while, the man said something and he kind of threw in, 'Yeah, I used to think that when I was alive as well'* (Patricia:W147).

On these occasions, Patricia found it difficult to reconcile his delusions with his historical, articulate self and continued to search for evidence of his orientated, coherent self:

*'He just constantly referred to living as being in the past tense, so you know, 'I haven't got a heart anymore; I used to have one when I was alive', and saying to me, 'oh we've been so happy with the kids and I'm sorry that I've had to go'* (Patricia:W64).

Amir's family were frequently reminded that his prognosis and recovery from ASC would be poor, to the extent he would be unable to function independently:

'*Your brother will never walk, talk, he'll be completely bed-ridden for the rest of his life'* (Sarah:W210).

This sense of hopelessness pervaded much of the communication with staff whilst on the ward and it wasn't until he was eventually transferred to the neurorehabilitation unit that his family felt communication was more encouraging and staff had the skills to affect a more positive outcome:

*'But when he was in neuro-rehab obviously the staff there are trained to help him. The psychologist, the physiotherapist, everyone, I can't even remember their names now, but yeah obviously they helped him tremendously'* (Sarah:W241-243).

When Nina began to communicate with her daughter, she was paranoid accusing staff of harming her and stealing her possessions:

*'But then when she began to talk, she started to say that the nurses were pinching her and people coming in and stealing her bags and then at different times she'd be like, 'They took my tablets, go and get my tablets back'* (Jane: W294-298).

Staff were not forthcoming in explaining that Nina may present in this way, and it wasn't until Jane happened to meet a clinician in the hospital corridor who she had previously known, did she learn that paranoia may be a presentation of an ASC. He proceeded to advise her to '*go along with it, sort of thing, don't argue with her'* (Jane:W306).

As Nina's ability to communicate improved, Jane observed her talking to staff confused as to where she lived, her home circumstances and her dietary preferences:

*'When the nurses were talking to my mum she sounded like she was ok, because she was telling them how she had worked in the NHS for 30 years* (Jane:W318-319). 'S*he told them she had a downstairs bathroom and stuff* (Jane:W326) . *'She told them she was a vegan and she was a coeliac and she couldn't eat any of that, just weird stuff and we were like, But she isn't'* (Jane:W327-328).

Nina's animosity and rudeness persisted such that members of the family became increasingly embarrassed by her behaviour. They requested permission to stay with her outside formal visiting times to *'contain'* her behaviour and '*protect'* others on the ward.

Mary supported her daughter for many hours during her hospital admission and not surprisingly her relationship with her appeared to embody a sense of nurturing. She put her to bed and held her in a motherly sense. These physical interactions with her daughter were opportunities to reaffirm the embodied relationship she had as her mother. When visitors attended the bedside, Donna's responses, and her interactions with individuals she had previously known and developed unique relationships with prior to the ASC, were keenly observed by Mary. The way Donna related to others was used by Mary as a measure of the extent to which she would resume these legacy 'lived relations' or whether relationships would be irrevocably changed. On one occasion, Donna was visited by a male friend and her responses when 'tested' with a kiss were recognised as reflective of how she would have responded to this gesture as her ‘legacy self’. For Mary, the teasing and banter that ensued reflected normal adolescent behaviour and offered some degree of reassurance that her daughter remained ‘present’ within the ASC:

*‘Right Donna, I am going to give you a kiss, and she actually turned away and then she turned back to him as if she knew that she was teasing’* (Mary:W101).

Whilst Patricia valued the support of family members in the acute phase of his ASC, she felt that the family had little understanding of the reality of David’s limitations and the likelihood of change to his ‘legacy self’ on recovery:

*‘After the operation, yeah, he was very different. The brain injury was so subtle that it used to make me a bit frustrated sometimes ‘cos I didn’t feel like his family understood it and felt they glossed over it and that perhaps he leaned on me a lot more and I had to kind of cover for him a lot more to keep us his sense of pride with his family’* (Patricia: W184-187).

There was a sense that Patricia colluded with her husband to hide his limitations so that his historical position and future interactions with ‘lived relations’ were protected.

#### 5.8.3.2 Inter-Relations with the Healthcare Professional

Dialogue between clinical staff and the witness focused on the corporeal presentation and functional limitations of ASC rather than on behavioural and psychological manifestations. Witnesses were astute to the fact that it was the physicality of ASC which informed medical discourse. Rarely did communication focus on the patient’s behaviour *in-ASC* as distinct from, or signifier of their ‘legacy self’. However, it was patient’s behaviours presented *in-ASC* which were the most distressing for the witness and vividly remembered.

On occasions, staff made predictions about the anticipated time when recovery would be realised, but statements would be offered randomly without supporting clinical rationale:

*‘And they will actually say she should be coming round, but where doctor’s knowledge was, there wasn’t very much information coming forward really’* (Mary:W23).

When Carol challenged decisions about James’ care, particularly with respect to his transfer to another ward, staff failed to provide a sound clinical justification, but stated:

‘*Well, anywhere where there is a bed really’* (Carol:W134).

Carol sensed that his transfer was not informed by clinical need, but rather the pragmatics of bed availability. When she decided to take James home against medical advice, she perceived staff as obstructive and intent on delaying his discharge by imposing a series of orders:

*‘You must keep him in bed. You must do this, you must do that’* (Carol:W155).

There appeared to be minimal communication between staff and Amir’s family about his

ASC. When conversations took place, the tone was melancholic and focused on the disruptive nature of his behaviour. Discussions about prognosis and recovery from ASC focused on Amir's inability to physically function '*he's not going to walk, talk, eat, anything'* (Sarah:W67). There was a sense that despite clinical interventions, the outcome would be poor. Sarah frequently felt that she had to act as her brother's advocate, particularly when his behaviour was disruptive, and he uncharacteristically used offensive language. She felt nursing staff failed to appreciate that his behaviours *in-ASC* were a consequence of his brain injury. On numerous occasions, she observed staff berating him for his behaviour and on one occasion staff threatened the family with his discharge:

*'They were basically telling us that you have to take him home if he behaves like this'* (Sarah:W135).

The presence of security staff was perceived as punitive which she believed escalated his behaviour. However, the conversations that members of the family had between themselves were more positive. They had little guidance from staff as to how they should interact with Amir. Instead, they researched how they should support him to effect recovery. His brother encouraged family members to remember that he was still 'present' within the ASC despite his inability to respond:

*'When you bring mum and when you come in, he's not the same but he's still our brother. He's not the same but he's still our brother, he's still there. He won't know who you are, he won't recognise you, so don't be alarmed'* (Sarah:W52-54).

#### 5.8.3.3 The Inferred Narrative: Tension, Bargaining and Narrative Tone

For the witness, the meaning of ASC and the ABI trajectory evolved from the inferences conveyed by the actions and behaviours of staff, and what was largely unsaid rather than communicated intentionally. As importantly, was the lack of disclosure about the significance of behaviours *in-ASC*, time scales relating to treatment and management and conflicting information particularly around transfers between the 'lived spaces' of care. Clinical staff, historically embedded in a biomedical discourse, paid limited attention to this inferred narrative or the need for more direct, overt communication. It became apparent that Donna had significant visual loss and physical limitations post-injury, but these were not acknowledged by staff. Mary understood this to be because staff had limited optimism about her recovery: *'Medical staff weren't forward in telling us what was going on'* (Mary:W11). '*Obviously we didn't know she was blind, we didn't know she couldn't speak, we didn't know she couldn't sit up, none of these things were actually monitored properly. I felt that in a way they were saying that they didn't think that she was going to survive it basically and there wasn't a lot more that could have been done for her'* (Mary:W35).

Witnesses reported a lack of honesty and transparency in establishing information about the trajectory of care:

'*They don't tell you a lot so you're kind of a bit took back, you're just at the side. Like there was just no life for me it were just like you don't know what's gonna happen'* (Heather:W202-204).
'*Because they try and sugar coat some things'* (Heather:W420-421).

When there was disagreement as to what was believed to be in the patient's best interests, then tension ensued. Whilst staff provided justifications for their clinical decisions, the witness perceived staff as authoritative and paternalistic. Staff tried to facilitate James' transfer to another hospital, but Carol challenged the decision, believing staff had limited expertise, which resulted in her threatening his discharge:

*'And I said, 'I am taking him home and that's the end of it. I don't care if I have to sign him but, he's not going to* [cites name of hospital]' (Carol:W126).

In response, staff tried to dissuade her by focusing on his need for pain relief, but for Carol, their rationale was contradictory and obstructive:

*'So, they said, 'We need to review his medication and we need to make sure he can walk and manage the stairs', and all this. So, they did all the things that they were doing, and I said, 'What medication is he on?' and she said, 'Well he's on pain killers'. I said, 'Well he hasn't got any pain'. And she tried to say that that was because they were giving him pain killers. And I said, 'Well he hasn't got any pain. Why would he be on pain killers?' I said, 'We're going today', and they said, 'Well you'll have to wait for his medication'. I said, 'No, we're going home. So, we went home'* (Carol:W147-154).

A similar tension was observed in communication with Amir's family when his behaviour became increasingly disruptive. Despite challenge by his family, staff threatened to send him home. Although their initial intention was to transfer him to a rehabilitation setting, he was '*19*' on the unit's admission list. They had no understanding as to what this meant in terms of timescale or whether he would meet the criteria. A lack of clarity compounded their feelings of isolation, to the extent they felt disempowered, and unable to influence the best outcome in his recovery:

*'And they were basically telling us that you have to take him home if he behaves like this. Well, he needs help, we can't offer him the help that the professionals can. We were told that there was a waiting list for rehab and he was number 19 on the list. Well, 19 on the list, we had no idea how long people stay in rehab, you know it can be six months, it can be six years, we'd no idea* (pause four seconds). *So, we as a family felt helpless* [pause four seconds]' (Sarah:W136-139).

Mary was present at Donna's bedside for lengthy periods and became an active participant in her care. However, despite the many interactions she had with staff, she expressed feelings of isolation. She believed staff had little optimism for her daughter's recovery and purposefully obstructed her transfer for rehabilitation, to the extent that she felt her daughter had been abandoned. The criteria for her transfer shifted without reasonable explanation. The persistent redefining of these clinical parameters served to reinforce Mary's belief that her daughter was unlikely to respond to rehabilitation and although not specifically addressed by staff, she felt this was their perception too. As her daughter's advocate she attempted on numerous occasions to convince clinicians that her daughter was indeed progressing despite their pessimism:

*'He* [consultant] *actually came to visit Donna in intensive care, and he said if there wasn't, I think it was 50% improvement that he wouldn't take her rehab because he couldn't work with her'* *(Mary:W129)*.

When Donna began to communicate and could combine letters to form the word, '*mum*', evidence to Mary that her daughter had met some element of the 50% transfer criteria, the requirements changed to include her ability to maintain a sitting position unaided. Mary quickly realised that Donna's physical abilities and limitations became bargaining tools as to whether she was likely to receive specialist rehabilitation:

*'And he said that there was still not enough improvement to take her, and he would have to come back again. By this stage she was doing her A, B, C. He said obviously the sounds are coming back but she was still in a properly like a laid-back wheelchair. They'd put her out of the bed 'cos obviously she couldn't sit up for support and stuff and he said because she was at this stage, he was not willing to take her'* (Mary:W137).

Mary sensed that decisions to delay rehabilitation communicated an underlying belief by staff that active interventions would be futile:

*'I felt that in a way they were saying that they didn't think that she was going to survive it basically and there wasn't a lot more that could have been done for her'* (Mary:W37).

Advice was, at times, contradictory across clinical areas within the hospital. On the ward, the presence of visitors was not permitted outside planned visiting times. Whilst staff justified these restrictions to be in Donna's best interests, Mary was persistent in her belief that the presence of family and friends was conducive to her recovery:

*'She wasn't allowed visitors for quite a while'* (Mary:W65).

*'But we did put a few friends in when we shouldn't have done'* (Mary:W72).

Carol's presence was also discouraged on the ward, and she felt staff were dismissive of the potential role she played in effecting John's recovery. However, when his behaviour was challenging and consuming of their time, they relented:

*‘On the ICU, they didn’t care that I was there all the time. I never felt like I was in the way or anything* (Carol:W39) *...... on the ward they didn’t want me to be there all the time. I mean I used to go in in the morning and they said, ‘You can’t come in. It’s not visiting time’. I said, ‘Look, he doesn’t know where he is, he’s quite disorientated, he’s distressed, he had no idea why he’s in hospital and I’m stopping’. And in the end, they realised it was a good idea ‘cos they hadn’t the staff to supervise him’* (Carol:W95-99).

Staff also waived institutional visiting restrictions when Patricia’s husband became distressed, and they were unable to placate him:

*‘They didn’t give any explanations to me or anything and they didn’t seem to know what to do or anything with him. They just waived all visiting things ‘cos they could see he calmed down, you know, infection control, ‘cos I got in bed with him and rubbed his feet but that seemed to calm him down’* (Patricia:W112).

Sarah had a sense that staff did not expect Amir to recover to the extent that he did, and this aggrieved her. She described her family’s commitment to his care. She felt that their presence was formative to his recovery, and this was necessary as she perceived some members of staff to be perfunctory in their role. She recounted how they entered the room to perform physical care but failed to get to engage with her brother. Amir’s behaviours were regularly viewed by staff as disruptive. Rather than understanding that his behaviours were secondary to the brain injury, they blamed him for his wandering and aggressive behaviour, and Sarah felt they were punitive in their communications with him. Her perception was reinforced when security staff were called to contain him. She felt he was dehumanised by their actions:

*‘It was like he was just trying to escape* [pause four seconds]. *They made us believe that he was doing this deliberately. Well he wasn’t* (Sarah:W139). ‘H*e was obviously getting aggressive because he didn’t like to be manhandled like that’* (Sarah:W145).

Months later when he began to show improvements in his recovery from ASC, Sarah happened to meet the consultant who had initially predicted there would be minimal improvement. She recalled how the consultant recognised her, but not Amir, and was surprised as to his progress. This provided Sarah with reassurance that predictions made by staff had not been realised:

*‘Yeah, it was like a kind of relief. The same consultant had told him that he would never, he would be like a vegetable. I don’t like to use that phrase, but he was shocked to see Amir walking because he recognised me and I said, ‘hello’ and I said, ‘do you remember my brother’ and he was completely, he couldn’t believe it. He couldn’t believe that a few*

*months earlier he said, 'your brother will never walk, talk, he'll be completely bed-ridden for the rest of his life'* (Sarah:W205-210).

One of the most profound experiences described by Sarah occurred years later. Whilst visiting a health centre, Sarah happened to meet one of the nurses who had been present during Amir's hospitalisation. The family felt, that at the time, she lacked compassion and an ability to 'see' Amir within his ASC, supported by the fact they felt his behaviour changed in her presence:

'*She was quite boisterous'* [pause ten seconds] (Sarah:W250). *'She was doing her job, that's it, if you know what I mean. There was no compassion there for a person who has suffered a brain injury and that should have been there'* (Sarah:W252-253). W*e noticed a change of behaviour. He was more aggressive. He didn't like her coming near him'* (Sarah:W246-247).

The nurse had remembered Amir for his behaviour and Sarah was disturbed by this:

*'When I reminded her who I was, she immediately related to Amir trying to escape deliberately, yeah, and she was telling this story to the trainee that was in the room, and I was quite disturbed by her perception of my brother* (Sarah:W235)*. She still thought of him in that, you know, and it wasn't a very nice way of presenting him because he isn't that, and he wasn't that and he still isn't'* (Sarah:W236).

Years later she continued to feel she has to defend her brother's behaviours following the injury and that staff had little understanding and empathy of the physical and cognitive manifestations *of-ASC.*

Patricia, too, felt increasingly isolated as a witness to her husband's bizarre behaviour. She felt that staff had expectations of him that could not be realised and as his advocate, attempted to defend him:

*'They seemed to be expecting him to do a lot more than he was able to do and he was somebody that tried to do a lot of things really, you know'* (Patricia:W205).

She was active in seeking to understand the cause of his ASC but felt isolated in her endeavour:

*'And it's only through my own research that I've heard the term postoperative psychosis, and if somebody had told me that it might have made me feel a bit better'* (Patricia:W230).

Members of Amir's family were present for prolonged periods and were proactive in supporting and assisting him throughout his hospital stay. However, they felt they had to take a degree of ownership for his care and act as his advocate. On several occasions they felt the need to defend both his behaviours and his personhood. They challenged the perceptions of staff who believed his aggression and inappropriateness were intentional and that he had some degree of influence over his actions:

'*The nurses were telling us that he would get aggressive with them and that he would verbally, he would say things but* [pause six seconds] *all I can say,* [pause three seconds] *so he may use a swear word or he may say something untoward or, I'm not sure whether it was insulting or what, but I think* [pause six seconds] *they also thought that he was doing this* [pause four seconds] *being completely aware, but he wasn't'* (Sarah:W279-283).

This was particularly evident when he tended to wander off the ward, which resulted in staff threatening his discharge:

'*They were basically telling us that you have to take him home if he behaves like this. It was like he was just trying to escape* [pause four seconds]. *They made us believe that he was doing this deliberately. Well, he wasn't'* (Sarah:W139).

Their need to protect Amir was evident when security staff were called on an occasion his behaviour became increasingly challenging. They felt their presence served to escalate his behaviour. Sarah felt that the 'lived relations' Amir appeared to have with staff were perfunctory. She felt they paid limited attention to his psychological and emotional needs:

*'Well because we spent in the first four months because we spent a lot of time with him, apart from them coming to change him or doing his routine, we didn't really see that interaction'* (Sarah:W231).

Reflecting on his care, she felt that staff failed to appreciate the nuances of the presentation of his brain injury and lacked education and training in their role:

*'Yeah. So, I think the healthcare assistants need to be trained in helping people who have suffered a brain injury and I think they weren't, or if they were they would be aware that, you know'* (Sarah:W293-294).

Paul felt information was not forthcoming about his wife, with care being largely perfunctory:

'*No, I never saw any doctors* (Paul:W204). *'I had none, I mean absolutely none. I was only talking to nurses and the nurses, they just delivered care and so Alice had food and they brought her brews and what have you and that was basically what seemed to be happening. There was no interaction'* (Paul:W208-212).

Seated at the bedside, Paul felt he was an unwelcome hindrance. His metaphor poignantly reflects how as a witness, faced with the unknown territories of both ASC and ward practices, he felt isolated and disempowered, unable to position himself:

*'The stroke is like a train. Alice doesn't care where she's going on this train, she's not interested, and everyone else has been on the train a thousand times before, so they are*

*happily doing what they're doing and I'm sat there on my own, my wife's ill and I don't know a damned thing, I can't control the speed of this train and I can't control its destination'* (Paul:W246-249).

Similarly, staff rarely addressed David's delusions with Patricia or suggested strategies that may be helpful in reducing his distress or acknowledge the profound impact his behaviour had on her and visiting family members. It was Patricia who felt the need to defend his actions to his family and justify his bizarre behaviours. As a result, she became isolated in her primary role as his advocate and defence:

*'They didn't give any explanation to me or anything and they didn't seem to know really what to do or anything with him* (Patricia:W112). *'I had to kind of cover for him a lot more to keep up his sense of pride with his family'* (Patricia:W184).

The narrative tone was an important adjunct to the actual communication which took place between clinical personnel, the patient, and the witness. For Mary, the tone suggested that Donna was not recovering to the extent she should be, which served to increase her concern and perpetuate the belief that ASC recovery should be viewed as the most important indicator of prognosis. Professionals tended to discuss diagnosis and prognosis with a degree of pessimism and when predictions were made about possible outcomes, the narrative tone was melancholic and cautionary. Whilst Carol was realistic about James' prognosis, the narrative tone suggested that Carol should resign herself to the fact that James' 'legacy self' was permanently lost:

*'He was still out of it. He didn't seem to be coming round at all and they were saying to me that I had to prepare myself for him not being the same and not coming round'* (Carol: W9).

### 5.9 Summary of Findings

This chapter has presented the findings of the inquiry (see Table 12: Master Table - Summary of Findings). The phenomenon of an ASC secondary to ABI, was understood and personally constructed in and through the participants' experiences of the life-world, '*meaning structures'*: *lived spatiality, lived corporeality, lived temporality, lived relations* and the accompanying *discourse*. Both participant groups experienced the corporeality and temporality of ASC and inhabited distinct spatial realities. The participant's engagement with others and the accompanying dialogue was highly formative and revealing. Living 'through' a transitory period of ASC imposed a shared vulnerability, which risked the derailment or distortion of the patient's 'construction of self'. ASC was a dynamic and transformative mode of *being-in-the-world* which presented itself as an obstacle to the emergence and restitution of 'self', and one's relationships with others. The patient's 'self' was assessed against the pre-injury, 'legacy self' and 'searched for' throughout the chaotic and unpredictable landscape of ASC. Patients struggled to make sense of their experiences and seek coherence.

**Table 12: Master Table - Summary of Findings**

| **Superordinate '*Meaning Structure'* LIVED SPATIALITY** | | |
|---|---|---|
| **The Patient *in-ASC*** | | **The Witness *of-ASC*** |
| **Superordinate '*Meaning Essence*'** | **Subordinate '*Meaning Essence*'** | **Superordinate '*Meaning Essence*'** |
| The Territory of the Lived Spatiality *in-ASC* | The Transition | Cultural Norms and ASC Behaviours |
| | The Landscape Described | The Lived Space Tests for the Absence of Presence of Signifiers of the Pre-Injury 'Legacy Self' |
| | Sense Making | The Therapeutic-ness of the Lived Space |
| Boundaries of the Lived Spaces | | |
| **Superordinate '*Meaning Structure'* LIVED CORPOREALITY** | | |
| **The Patient *in-ASC*** | | **The Witness *of-ASC*** |
| **Superordinate '*Meaning Essence*'** | **Subordinate '*Meaning Essence*'** | **Superordinate '*Meaning Essence*'** |
| Functionality and Sentience of Lived Corporeality *in-ASC* | Lived Body functions as the Pre-Injury, 'Legacy Self' | Physicality of Body Presentation |
| | Functional Limitations Realised | Signifiers of Pre-Injury, 'Legacy Self' |
| Intentionality of Lived Corporeality *in-ASC* | | Dependency of Lived Corporeality |
| | | Contradictions of Lived Corporeality |
| **Superordinate '*Meaning Structure'* LIVED TEMPORALITY** | | |
| **The Patient *in-ASC*** | | **The Witness *of-ASC*** |
| **Superordinate '*Meaning Essence*'** | | **Superordinate '*Meaning Essence*'** |
| Subjective Temporality *in-ASC* | | Time as a Predictor |
| Objective Temporality *of-ASC* – Time Lost | | ASC and Circadian Rhythm: A Return to 'Legacy Self' |
| **Superordinate '*Meaning Structures'* LIVED RELATIONALITY AND DISCOURSE** | | |
| **The Patient *in-ASC*** | | **The Witness *of-ASC*** |
| **Superordinate '*Meaning Essence*'** | | **Superordinate '*Meaning Essence*'** |
| Lived Intra-Relations *in-ASC* | | Historicity of Relationships |
| Lived Inter-Relations *in-ASC*: The External Narrative | | Inter-Relations with the Healthcare Professional |
| Historicity of Relations | | The Inferred Narrative: Tension, Bargaining and Narrative Tone |

# CHAPTER SIX: DISCUSSION

## 6.1 Introduction

The aim of this hermeneutic, phenomenological inquiry was to understand how a transitory period of an ASC secondary to ABI, was constructed and interpreted in the immediacy of the acute phase of the ABI trajectory in the inpatient, hospital setting, from the perspective of the patient and the layperson witness.

Chapter five presented the ontological '*meaning structures'*: *spatiality, corporeality, temporality, relationality* and *discourse* which, for the patient and the witness emerged as constructs and influencers on the life-world trajectory of ASC. Whilst this chapter presents a critical discourse and synthesis of each of the *'meaning structures'* separately, it is to be acknowledged that for the participants of this inquiry, they were not experienced independently but entwined and mutually relevant. The findings support Van Manen's (1990, p. 105) position that the essences of a phenomenon '*all form an intricate unity which we call the life-world'*.

Discussion of the '*meaning structures*' is followed by a critical examination of the intersubjectivity of experiences *in*- and *of-ASC* with reference to the recognition and re-construction of the patient's 'legacy self' and identity, post-ABI. Section 6.8 examines the narrative typologies which contributed to the participant's 'chaos' and 'restitution' throughout the ASC trajectory. Section 6.9 presents a nosologic challenge to the synonym, ASC, adopted throughout this inquiry, with the limitations of method discussed in section 6.10. The chapter is summarised in section 6.11.

In line with hermeneutic approach to the literature review discussed in section 2.1, and Van Manen's (1984b, 1990) exegetical exposition of phenomena, the ensuing discussion will be supported by the deliberate employment of insights from phenomenological writings and the theoretical and empirical philosophical, psychological and sociological disciplinary literature (Moules, 2015), not initially considered at the beginning of the inquiry but which emerged as relevant following analysis of the empirical data. As Dahlberg and Dahlberg (2020, p. 462) espouse, when the construction of meaning of a phenomenon is particularly complex, then '*external data such as theory serves as a spotlight'*, by '*illuminating aspects of the phenomenon that remain dark after the first (empirical) part of the analysis'*.

To maintain and contextualise the narrational voices of the participants, and support the theoretical discussion, exemplar data extracts continue to be presented.

The gender-neutral pronoun '*they*' is adopted in preference to '*he*' or '*she*' where the pseudonym of the participants of the study is not given but where a participant group or member of a participant group is discussed.

Research on ABI is replete with evidence which supports psychological, cognitive, and functional changes post-injury (Giacino *et al*., 2014; Ommaya and Gennarelli, 1974; Rabinouitz and Levin, 2014; Snow, Douglas and Ponsfordoe, 1999) which risk affecting an individual's identity, agency, and selfhood (Anderson and Mehrnoosh, 2018; Cloute, Mitchell and Yates, 2008; Falvo, 1998; Kim *et al.*, 2019; Landau *et al.*, 2008, Lorenz, 2010; Nochi, 1998, 2000; Ownsworth, 2014; Thomas, Levack, and Taylor, 2014; Whiffin *et al.*, 2017). However, whilst the findings of this inquiry are commensurate with this empirical evidence, the first-person experience of ASC as a corollary of the post-injury ABI presentation significantly contributed to the transformation of the patient's pre-injury, 'legacy self'. The patient's construal of their 'legacy self' continued to 'shift', was evaluated and redefined throughout the phenomenological trajectory of the life-world of ASC.

## 6.2 Lived Spatiality

***'Once having been in a particular place for any considerable time, we are forever marked by that place, which lingers in us indefinitely and in a thousand ways, the whole brute presence of that place. What lingers more powerfully is this presence and, more particularly, how it felt to be in this presence'.***

**(Casey, 2001, p. 688)**

### 6.2.1 Introduction

The following discussion analyses the *'meaning structure'*, 'lived spatiality' as a contribution to the participant's interpretation and construction of meaning of ASC. Analysis will focus on the landscape of ASC, how the clinical and public spaces distinctly and collectively informed and influenced the meaning of ASC, and the nature of the spatial relationships experienced.

For both the patient and the witness, spatiality, defined as the '*totality of space that a person pre-reflectively lives and experiences, with its situations, movements, effects, and its horizons of possibilities*' (Fuchs, 2007a, p. 426), or simply a space in which human beings move (Merleau-Ponty, 2005) was uniquely and exclusively experienced throughout the trajectory of ASC. As Heidegger (1962, p. 146) reminds us *'we are bound up with space, we cannot be detached from our spatiality'.* One's sense of place and its significance largely goes unnoticed, a space which is 'taken -for-granted', *'experienced without deliberate and self-conscious reflection yet it is full of significance'* (Relph 1976, p. 55). The context-dependent world of ASC was understood and co-constituted within the socio-spatial geography of the hospital. The spatial properties and the relational dynamics which were experienced within this space, and between the witness and the patient offered a lens through which the meaning of ASC was constituted. Simmel's (1997, p. 138) view is that it is the '*spatial meanings of things and processes'* which '*render space significant'*, and impose a '*geometric personality*' (Tuan, 1977, p. 17). It was the physicality of the lived space of the hospital which shaped and was shaped by the ASC narratives of the witness. The patient was primarily immersed in his own unique dwelling space that was isolated and hidden from view from those who bore witness. Envisioning the lived space from both perspectives contributed to an emergent understanding of the phenomena of ASC.

In explicating the lived spatiality of mental illness, Fuchs reflects on the work of Willi (1999) who coined the phrase '*ecological niche'* to characterise the situated 'lived space' of an individual. Fuchs' (2007a, p. 427) position is that this '*personal niche expresses the idea that subject, and world do not exist separately, but constitute each other'.* The cultural and social dimensions, defined by Callieri (2001, cited in Mancini *et al.,* 2014, p. 425) as the *'habitability'* of space, native to the hospital ward along with the public, shared spaces within the hospital added a qualitative dimension to the experience of ASC for the witness and became their 'ecological niche'. For the patient however, it was their subjective immersion *in-ASC* which became their primary, situated niche, a previously unfamiliar and emotionally driven landscape experienced against a background of hallucinations, delusions and vivid imagery: '*even now it's hard to describe how vivid they are*' (Barry:P467).

### 6.2.2 Lived Spatiality *in-ASC:* The Patient

Whether experiences were remembered as convivial or otherwise, there was little doubt that living within the spatial confines of the perceptually disordered landscape of ASC had a profound and enduring impact. The spatial experience *in-ASC* was remembered as a temporary, yet distinct and pervasive dwelling place, analogous to the world of psychosis wherein one '*no longer inhabits the common property world, but a private world'* (Merleau-Ponty, 1962, p. 287). This new landscape was viewed and experienced through the architecture of their ASC experiences and was, on occasions, so irrefutable, that on recovery the patient found reconciliation difficult.

Commensurate with the findings of other inquiries (Bergbom-Engberg and Halijamae, 1988; Capuzzo *et al*., 2004; Dasta *et al.,* 1985; Granberg, Bergbom-Enberg and Lundberg, 1998; Jones *et al*., 2001; Kvale, Ulvik and Flatten, 2003; Löf, Berggren and Ahlström, 2006; Miller and Ely, 2006; Oldenbeuving *et al.,* 2007; Palmieri, 2003; Roberts and Chaboyer, 2004: Rotondi *et al*., 2002; Sorensen Duppils and Wikbald 2007; Stein-Parbury and McKinley, 2000) patients recalled with authenticity their profound and enduring experiences of ASC, *'like you were there, like you were living it, like it wasn't a dream, it was my life at* *the time'* (Donna:P31-32). The content of the perceptual disturbances experienced within this disordered landscape was ethereal, disturbing, and uncompromising, filled with ambiguity and remained intrusive on recovery. At times, there was a dissociative quality to the patient's experiences in that they described themselves as *'looking in, like looking through a window on someone else's life'* (Barry:P490), an external observer to the roles they played in the hallucinogenic scenes. There was a coercive feature to their experiences, akin to a performance on stage. They felt obliged and at times compelled to be the central character and active participant.

As Merleau-Ponty (2005, p. 55) points out '*our relationship to space is not that of a disembodied subject to a distant object, but rather that of a being which dwells in space'.* Dismissing the patient's experience as a fanciful untruth, served to dismiss the agency of the patient and bury their experiences of ASC amongst the collective clinical presentation of ABI. Not until the totality of narrative was told, did the witness feel they had a sense of agency and legitimacy.

The memory of place and significance for future restitution are explored by Malpas (1999). His position is that the subjective experience of place is '*inextricably bound'* (Malpas, 1999, p. 176) to one's identity and agency. Residing *in-ASC* was not simply an experience, but a place inhabited where one's sense of 'self' was considered and re-conceptualised, reflective of Malpas' (1999, p. 177) position that '*our identities are intricately and essentially place-bound'.*

### 6.2.3 Lived Spatiality *of-ASC:* The Witness

Lefebvre (1991, p. 195) recognises the affective determinants of space on the body: '*a body so conceived, as produced and as the production of space, is immediately subject to the determinants of that space'.* On these occasions, the different lived spaces of the hospital environment imposed restraints and demands, but also freedoms on the patient and their witness. Gibson (1986) defines these influences as '*valences'* or '*affordances*'. It was the culturally disparate lived spaces within the hospital which afforded different expectations and responses and were transformative in one's understanding of ASC. The technologically driven ICU and the constraining effects of ward practices served to both enable and disable the meaning of ASC. In contrast, outside these institutionally determined spatial boundaries in the public arenas of the hospital, ASC manifested itself very differently. For some, it provided opportunities or permission for the patient's 'legacy self' to emerge. For others, the behaviours and physical presentation of ASC were revealed as unwelcome reminders that recovery and restitution was doubtful.

The trajectory of ASC revealed itself in all the lived space modalities within the hospital.

In rejecting any distinction between the physical world and our experienced space, Merleau-Ponty (2005, p. 55) believed that '*our relationship to space is not that of a pure disembodied object but rather that of a being which dwells in a space'.* Our embodiment in the world is undoubtedly affected by our situatedness in these lived spaces. Restrained by equipment and confined to the ICU bed affected the patient's *'responsivity',* and their ability '*to respond adequately to the stimuli and requirements of his environment, especially to the demands of others'* (Fuchs 2007a, p. 425). Not only did the body *in-ASC* limit engagement, but the physical properties of place also constrained the extent to which the patient's corporeality was revealed.

The 'place' one inhabits then becomes a 'lived space' which affords emotional affectivity, '*a space in which we are emotionally in touch'* (Simonsen, 2007, p. 176). Tuan (1977, p. 6) discusses the relational aspects of 'space' and 'place' suggesting that '*what begins as an undifferentiated space becomes place as we get to know it better and endow it with value'.* As the patient inhabited the 'spaces' within the hospital, they became 'places' where the significance and meaning of ASC was, for the witness, realised. The spatial properties of the ward and public spaces within the hospital were unique, *'so surreal and different'* (Paul:W512) and inferred contrasting meaning. One's perception of the lived spatiality through the trajectory of ASC appeared dynamic and under perpetual construction. Massey (2005, p. 9) renders '*space a product of interrelations which is always in the process of being made. It is never finished; never closed'.* The ward was historically viewed by the witness, as a medically orientated and informed landscape wherein patients were homogenised by disease, with care informed by ritual and routine:

'*On the ward, she was just on a list of things to do… it was almost like farm animals, you know… we got all these people with a stroke to deal with* (PaulW:383-384).

The physicality of space within the hospital served to homogenise patients but also appeared to give permission for certain behaviours to be normalised or otherwise. Behaviours revealed in the public arena of the hospital cafe, corridor or even the dayroom, held greater significance. On these occasions, space appropriated activity and behaviours. The transformative nature of these hospital spaces became a milieu for subliminal learning about prognostic outcomes, and the significance or otherwise of the behavioural and cognitive presentations of the patient. For the witness, their observations of the 'performance' and behaviours of the patient in the different spaces of the hospital served either to distance the patient from their 'legacy self' or reaffirm that 'self' remained. For Patricia, she envisaged *'more people around him'* [David] in the cafe would promote *'normality'* (Patricia:W142), but his delusion that he was deceased was far more palpable and disconcerting in the communal and public terrain of the hospital than on the ward.

In summarising Heidegger's position, Plager (1994, p. 65) reminds us '*that we are so culturally and socially embedded in familiarity with our practices that we lose sight of our being from existing within this familiarity'.* Whilst the ward was familiar to hospital personnel, it was potentially alien and bewildering for the witness. The lived spaces within the hospital imposed vastly different expectations and cultural norms, which had to be understood and respected. It was as though these spaces uniquely and collectively assumed their own identity. Immersing oneself as a witness in these spaces conferred quite different meaning.

It was accepted that whilst in ICU the body was dependent, a narrative influenced by uncertainty and ambiguity. A planned transfer from the ICU to the ward was understood to be indicative of an improvement in ASC. However, the reality was quite different. Whilst the patient might have been able to breathe independently, the cognitive and physical limitations *of-ASC* resulted in the continued dependency on supplementary feeding tubes and other support.

Mary felt reassured that her daughter would be transferred to the rehabilitation unit when her ASC had improved to the extent that she was able to communicate, and likewise for James, a discharge home was promised when there were measurable improvements in cognitive functioning. The realisation that transfers between hospital facilities did not reflect an improvement or otherwise of ASC, challenged the meaning conferred by these lived spaces. Whilst immersion in these spaces became a milieu for learning, they were abound with contradictions and subliminal messages about the patient's prognosis and recovery.

These lived spaces were also imbued with contrariness. The witness' engagement within these different spaces and the extent of their involvement as active participants in care were shaped by permissions implicitly granted by space but also explicitly given by staff. As Fuchs (2007a, p. 426) reminds us *'subject and world do not exist separately but constitute each other'.* Whilst the witness was unable to provide any physical care within the ICU, they were actively encouraged to 'be with' the patient at the bedside. Their presence, the playing of music, and communication with the patient were felt to be conducive to recovery of ASC, but this advice was quickly denounced on transfer to another clinical setting.

The witness' role appeared to shift, and expectations redefined within these different clinical settings. The lived spaces imposed a script, a modality for action and prescribed a 'way of being' to be adopted by the witness. Carol's (W:39) reflection that she was welcome in the ICU and *'never felt in the way',* was in stark contrast to the ward where, *'they didn't want me there all the time'.* Feeling estranged, not solely with the organisation and function of these physical spaces but also their situatedness, meant that they were perpetually searching to find a 'place' around the bedside. This was not simply physical but symbolic of the role they had as a spouse, mother, father, relation or significant other. Understanding the boundaries of their role and their responsibilities was important. The findings suggest that the physicality of the hospital spaces and the lived space 'between' the witness and the patient were highly symbolic.

On these occasions, space became the place where one's agency or ability to be present in the world was '*itself tied to the idea of a particular subjective space - such a space is defined largely in terms of certain capacities for action'* (Malpas, 1999, p. 99). ASC was revealed to differing degrees within the culturally influenced locations within the hospital and the behaviours associated with, and manifested *in-ASC*, were shifted, and re-defined by space. One's capacity and permission to act, changed within the different spaces. Meinig's (1979, p. 66) position is that landscapes are symbolic and impose a code, the study of which involves a '*deciphering of meaning of the cultural and social significance'.* The witness was left to translate these 'codes of being' amidst their experiences *of-ASC.*

Situated within the ICU, the emergence of the patient's 'legacy self' was consumed not only by ASC but also by the technically driven properties of space. The unique socio-temporal and spatial characteristics of the hospital were projected and '*constituted through interactions, from the immensity of the global to the intimately tiny'* (Massey, 2005, p. 9). The witness was required to orientate oneself, '*I need to know my place and how I can operate in that system*' (Paul:W2), not only to the global culture of the hospital but also the practices and nuances of different hospital setting. One would imagine there are spatial 'constants' that once learned can be transferred into the next space. However, each space served to project its own socio-cultural spatial characteristics, and it was this disunity which contributed to, and re-defined the meaning of ASC for the witness.

The concept that places espouse meaning was developed by Gesler (1992, 1993) and later conceptualised by Williams (1998, p. 1193) who defined the '*therapeutic landscape'* as a geographical metaphor for '*places, settings, situations, locales, and milieus that encompass both the physical and psychological environments associated with treatment or healing'*. Whilst the witness acknowledged the therapeutic potential of certain places within the hospital, other spaces were viewed less favourably. Carol(W:223) described the ward as '*it was bedlam, really was bedlam'*. The constraints and restrictions imposed by staff and the contradictory communication across these places affected the witness' perception of the 'therapeutic-ness' deemed necessary to effect recovery. Whilst Fuchs (2007a, p. 425) asserts that a '*person seeks and shapes an environment*' to offer '*valances for its potentialities',* for the participants of this inquiry, the space was all consuming, asserting its overarching influence and transcending human agency and potentiality.

Lived spaces also appeared to resonate with a particular emotionality. Malpas (1999, p. 173) believes that '*place remains more than just a backdrop – more than just a 'location' within a physical space.* Observing the behavioural responses of those *in-ASC* as they engaged and interacted with others, served not solely as an indicator of recovery or otherwise but constituted meaning on an affective level. Patricia vividly described the physicality of the space on the occasion her husband met their children for the first time. The space was a *'small, tiny room'* (Patricia:W129), isolated from the main ward. By the time staff had *'shuffled him down the hall, he was really sobbing and howling, so that was traumatising for everyone'* (Patricia:W131-132). On this occasion, the 'space' appeared to reverberate and reflect the emotionality of the meeting and heightened the family's sense of anticipation.

### 6.2.4 The Intersubjectivity of Spatiality: The Patient and the Witness

Seamon's (2007, p. 11) commentary of '*space syntax'* identifies three distinguishing features to *'place structure'* which are relevant to the analysis of spatiality *in-ASC*. Firstly, he defines the topographical functions of space. For the participants of this inquiry, the spatial configurations of the hospital presented differing opportunities. The technically driven space of the ICU, the public spaces of the hospital corridor or café, and the ritualistic practices of the ward environment imposed different expectations on both the patient and the witness. Secondly, one's immersion in space afforded different affective qualities or ambiences. Living amidst the landscape of hallucinations and delusions was at times ethereal, distressing, and enduring, whilst for others, the space was pleasant and benign. Space was also isolating, which left the participants feeling marginalised and unwelcome. Thirdly, space affected the engagement of the body. It was within space that the patient's 'legacy self' was searched for and revealed. Despite remaining sentient in the immediate world of ASC and within the juxtaposed liminal space, through to emergence from ASC, the patient's inability to engage meaningfully affected their agency. The patient strived to situate themselves in a place which was familiar, where 'legacy self' could emerge and be recognised.

Space is a '*summative concept'*, which represents 'a *global and extremely complex entity'* (Fogel-Keck, 1994, p. 20). The lived space of ASC was uniquely and discreetly experienced for both participant groups, which resulted in feelings of detachment and isolation. It was only when recovery was realised, and the patient became increasingly orientated that each could move towards a consensual appreciation and understanding of experiences. ASC served as an untimely interruption in one's familiarity with, and fundamental 'being in the world'. Finding oneself in the unfamiliar territory of ASC and the hospital environment was profoundly disturbing. Tuan (1977, p. 175) states that one's ‘*sense of self, whether individual or collective, grows out of the exercise of power’.* For both the patient and the witness, their experience in the lived spaces was disempowering and inferred different vulnerabilities. The patient was immersed in the dynamic and ever-changing boundaries of ASC, striving to situate themselves as agents in ‘place’. Similarly for the witness, observing the behaviours of the patient *in-ASC* in the culturally diverse topography of the hospital was profoundly revealing and meaningful. Place was ‘testing’ and emerged as both an enabler and disabler of the patient’s agency.

For both the patient and the witness, the narrative trajectory of ASC was inextricably tied to place. In the lived spaces, the meaning of ASC was transformative, relational, and continually re-negotiated over time. As Fuchs (2007a, p. 426) poignantly reminds us:

*‘This space is not homogeneous, but centred on the person and his body, characterised by qualities such as vicinity or distance, wideness or narrowness, connection or separation, attainability, or unattainability, and structured by physical or symbolic boundaries’.*

Binswanger (1958), an existential psychologist, identified three inseparable dimensions to the construction of ‘self’. Whilst the experience of ASC for the patient and the witness was ontologically different, the existential essences which constructed the meaning of ASC and ultimately ‘self’ were relevant across all these dimensions. Firstly, he identified the ‘*unswelt’* or natural world, the life-world one finds himself in. Participants resided in different natural worlds: for the patient the immediate landscape of ASC and for the witness, the lived spatiality of the hospital setting. Both spaces afforded their own unique and challenging spaces where the ‘legacy self’ of the patient was tested and searched for. Secondly, ‘*mitwelt’* relates to the social world, a place where ‘self’ relates to others. It was in the lived spaces that ‘legacy self’ was realised or re-constructed through one’s engagement and relationality with others, a space where temporality, dialogue and corporeal presentation conferred meaning. Thirdly, ‘*eigenwelt’* refers to how an individual experiences his personal and immediate world. For both participants, the life-world of ASC was formative, a place where the existential life- worlds collided to construct the meaning of ASC and ultimately the patient’s ‘self’ and identity.

### 6.3 Lived Corporeality

***‘We enter upon a stage which we did not design, and we find ourselves part of an action that was not our making’.***

**(MacIntyre, 1981, p. 213)**

#### 6.3.1 Introduction

The following discussion analyses the *'meaning structure'*, 'lived corporeality' as a contribution to the participant's construction of the meaning of ASC. Analysis will focus on the corporeal presentation of ASC, the subjective experience of body presentation and performance *in-ASC* and *of-ASC* respectively, the intersubjectivity of the corporeality of the ASC experience, self-identity, and personhood.

### 6.3.2 Lived Corporeality *in-ASC:* The Patient

*In-ASC*, the body performed and responded as a sentient being. Patients became immersed in the scenes and dramas portrayed within their hallucinations and on recovery, were able to describe with conviction, their bodily and emotional responses. They became embroiled in disturbing narratives and recalled with terror and bewilderment the bizarre and threatening encounters. Reflecting on this ASC landscape, they retained a sense of agency and there was little awareness that the injury sustained has affected the 'body that was'. They recalled being 'moved', the repositioning of their body and the physicality of care. The body engaged purposefully and became situated in the lived space of ASC to the extent that *'the body in motion is not content with passively undergoing space and time, it actively assumes them, it takes them up in their original signification'* (Merleau-Ponty, 1945/2012, p. 105).

One is not always aware of the performance of the objective, corporeal body, defined by those mannerisms and bodily nuances which constitute 'self'. Limbs move characteristically in space as anatomical and physiological entities to maintain function, to the extent that, '*the overall experience of being-in-the-world is inseparable from how one's body feels in its surroundings'* (Fuchs and Schlimme, 2009, p. 571). However, as the patient began to emerge from the familiar landscape of ASC, the 'taken for granted' lived body was consumed by the stark realisation the body was no longer able to perform. There were implicit expectations of the lived body that could not be realised and a concerning disconnect between the pre-injury 'legacy body' and that which now presented itself. Normal tacit abilities were lost amidst the limitations and behaviours of bodily ASC: '*the body shows itself precisely when my body limits do not accord with the possibilities I project. In such cases my body calls attention to itself as an obstacle. There arises a dichotomy between aspiration and my facticity, between project and limit'* (Toussaint, 1976, p. 179). The belief that 'legacy self' remained was tested when the patient tried to climb out of bed but fell, was given utensils but had no recollection how to use them, and when engaged in conversation realised, they could not be heard or understood. Time *in-ASC* had hidden from view these functional and perceptual body limitations. As Gallagher (1986, p. 152) posits, *'when the lived body loses its equilibrium with the environment, it suddenly appears at centre stage, announcing itself as painful, fatigued, distorted and* *clumsy.* The lived body was transformed into an 'object' that had to be carefully and thoughtfully manipulated into action. On recovery, when the limits of the body were realised, then the 'taken for granted' body functions became deliberated and gestures lost their *'melodic character which it presents in ordinary life'* and became *'manifestly a collection of partial movements strung laboriously together' (*Merleau-Ponty, 1962, p. 105).

This objectification of the body both *in-ASC* and on emergence served to disembody 'self'. Unknowingly, in the patient's 'absence', body limitations were revealed during their time *in-ASC,* and they were unable to 'hide' their behaviours and body presentation from the witness' gaze. On recovery, when the extent of the patient's functional and cognitive limitations was realised and the patient felt berated for their behaviours, '*can you not do it yourself'* (BarryP:450), they purposefully sought to effect control of their habitual 'legacy self' and body performance. In the unfamiliar lived space of the hospital, there was a constant and deliberate pressure to reconstruct 'self' and perform as 'legacy self'.

ASC transformed the architecture of the body schema such that on recovery body presentation had to be re-negotiated. Bodily functions became deliberated, actions pronounced, and the post-injury body was revealed in all its abnormality. Polanyi (1969, p. 147) believes that to make sense of the world '*we rely on our tacit knowledge of impacts made by the world on our body and the complex responses of our body on these impacts'.* Whilst the patient retained a tacit knowledge of 'self,' this 'taken for granted' narrative 'self' was re-constructed in the lived space of the hospital. Simple tasks like being able to wash and dress oneself, drinking, eating, and mobilising, had to be re-mastered. Patients felt a sense of isolation, as they became increasingly aware their body was observed, assessed, and objectified by others. They believed on initial recovery they were 'normal', the body was tacit in its performance and there was an allegiance to their 'legacy self'. However, as they began to acknowledge their limitations, they found it difficult to reconcile the reality of their new lived body: *'I just thought I was a normal person'* (John:P234).

Alice was increasingly aware she had forgotten how to wash and dress herself to the extent that every activity expected of her had to be purposefully thought through. Her embarrassment that she was unable to perform as expected, resulted in repeated attempts to 'hide' her limitations and act 'normally'. In this respect, Alice perceived her body as subject and object simultaneously. She sensed the limitations of her subjective lived body, and yet was able to reflect on how her body performed and was perceived by others in the emerging landscape of the hospital ward. Plessner (2019) explored the relationship between the body-object and body-subject, defining '*excentricity*' as one's ability to experience the body from within whilst also reflecting on how we are perceived by others. On recovery, there was a realisation that ASC served to detach or distance the body-subject from body-object.

### 6.3.3 Lived Corporeality *of-ASC:* The Witness

Commensurate with current evidence (Giacino *et al*., 2014; Ommaya and Gennarelli, 1974; Rabinouitz and Levin, 2014; Snow, Douglas and Ponsfordoe, 1999), the ABI manifested as a complex disturbance of physiological, sensorimotor, cognitive, and affective functioning. However, in the immediate post-injury phase, it was difficult to predict the extent to which these bodily disorders would reveal themselves and whether functional limitations were likely to be permanent, or temporary and recovery realised. Witnesses came to the bedside with potentially limited understanding of ASC: '*like you just don't know what's gonna happen, it's the unknown'* (Heather:W204), and reported being naive in their expectations of recovery. ASC was initially understood as a time-limited state or one that was temporarily induced by medication during which the eyes remained closed, the patient was unable to respond, and the body was dependent on machinery and medical support to function. However, when these supportive measures were removed and the corporeal presentation of ASC was revealed, this was profoundly distressing for the witness and reflects the findings of other empirical studies (Belanger and Ducharme, 2011; Breitbart *et al.,* 2002; Bruera *et al.,* 2009; Cohen *et al.,* 2009; Jones, *et al.,* 2004; Namba *et al.,* 2007; O'Malley *et al.,* 2008, Partridge *et al.,* Stenwall *et al.,* 2008b).

Husserl (1989) defined the '*felt*', pre-reflective personal experience of the body as '*Leib'* in contrast to *'Körper',* characterised by the objectification of the body as an anatomical and physiological entity. Sartre (1943/1958, p. 330) discusses how the object body, is normally '*neglected*' and '*passed by in silence*'. Fuchs (2014, p. 405) asserts that the lived body is the '*medium of all our experience, our embodied being-in-the-world'*, to the extent that we rarely reflect on its abilities. However, when the body succumbs to illness, we become increasingly attuned to its limitations and functional losses. On these occasions, the body is perceived as an 'object' of medical attention and becomes the 'corporeal body'. For the patient *in-ASC,* it was their '*Körper', 'corporeal body',* which became the focus of the witness' gaze. The witness was attentive to the physicality of the body-*in-ASC* with all its changing, dynamic abilities and limitations. The body was 'objectified', in that the mannerisms and behaviours reminiscent of the patient's former, 'legacy self' was searched for and when found, foregrounded. The recognition of the signifiers of the patient's 'legacy self', reflects Whiffin's (2012, p. 202) concept of '*biographical attendance',* evident in this inquiry in the distinctive manner in which a husband held his wife's hand, the nuanced, albeit fleeting conversations which took place between a mother and her daughter, the characteristic gestures: '*the way you sniffed the air'* (Heather:W264), the knowing 'look' between a daughter and her father, and the familiar smile:

*‘Then she saw me, looked up and gives me a massive lopped-sided smile like, and I just knew Alice was there, the main beast as it were is still there, she’s still in there’* (Paul:W(1):139-140).

Whilst witnesses acknowledged that these actions were ephemeral in their presentation, they offered fleeting reassurances that the corporeal ‘legacy self’ remained and provided assurance that recovery may be realised. However, the brain injury resulted in other behaviours which, for the witness, were profoundly disturbing. Abnormal posturing, impulsivity, disinhibited behaviours, and the inability to respond appropriately or communicate, compounded the distress that corporeal self was somehow ‘adrift’. June’s uncharacteristic swearing and her continuing reliance on tubes to assist with feeding, intravenous lines to deliver hydration, and the urethral catheter to drain urine, reminded the witness that the patient was dependent and disembodied by ASC. The witness became preoccupied with the body as ‘lived *in-ASC’*: ‘*I wanted to know what I was getting, kind of thing, at the end of the day*’ (Paul(1):W65). When the body performed as the corporeal, ‘legacy self’ then the illness trajectory moved towards restitution and recovery.

However, when the body presented itself as unrecognisable and estranged from ‘self’, when mannerisms and behaviours were so detached and unfamiliar, then there was a foreboding sense that ASC has somehow dislocated the body from the ‘legacy self’. The witness observed body functioned not as a ‘taken for granted’ presentation but rather a series of body actions which were clumsy and incoherent. The ‘objectified lived body’ was under scrutiny against the legacy of the body. David, Patricia’s husband presented himself to his children, not as a father figure with paternal presence, but with a shuffling gait and disposition that portrayed a concerning vulnerability. This new lived and now objectified body was seen from the vantage point of who he was. On these occasions, ASC became the ‘vehicle’ for understanding both the identity of self and the trajectory of recovery.

### 6.3.4 The Intersubjectivity of Lived Corporeality

> ***‘To describe embodiment as inter-corporeality is to emphasize that the experience of being embodied is never a private affair but is always already mediated by our continual interactions with other human and nonhuman bodies’.***
>
> **(Weiss, 1999, p. 5)**

Both the patient and the witness experienced the corporeality of ASC, astute to the actions, behaviours, and responses in ASC as a recognition of, return to, or estrangement from the ‘legacy self’. However, throughout the trajectory of ASC, this comparison with ‘legacy self’ was in constant flux. For the patient, the new and unfamiliar lived territory called ASC, brought to the fore the objective body with all its functional limitations, such that the ‘taken for granted’ body became redefined not just throughout the trajectory of ASC but influenced by how others related to them. Witnesses responded to the bodily presentation *of-ASC* on an emotional level, to the extent that gestures, mannerisms, and embodied actions were meaningful. Fuchs (2014, p. 405) discusses how we are constantly affected by the bodily presentation of others. There is a continuous ‘*interplay of both partner's expressions and impression, mediating a pre-reflective reciprocal understanding'.* This shared sense of corporeality or as Merleau-Ponty (1962) terms ‘intercorporeality’ was affected by ASC. The witness became vigilant in their quest to recognise behaviours reminiscent of ‘legacy self’ and was increasingly aware that corporeal presentation informed prognosis and ultimately restitution. Corporeality or our bodily existence in the world informs how we relate to each other. It was the intercorporeality of ASC, the way in which the patient’s body presentation interacted with others that defined the relationship henceforth.

As observers, the witness held a unique and privileged position. They were privy to the emerging narrative of ASC and redefined the patient’s ‘lived body’ in the context of the corporeal changes manifested *in-ASC*, through to emergence and recovery. Whilst the witness had faith that ‘legacy self’ remained, they become attuned in the immediate post-injury period, to the possible limiting effects of the brain injury (Cruzado and Elvira de la Morena, 2013; Florian and Katz, 1991; Giovannetti *et al.,* 2015; Lezak, 1978; Perlesz, Kinsella and Crowe, 1999; Soeterik, 2017; Soeterik *et al.,* 2017; Whiffin, 2012; Whiffin *et al*., 2015; Whiffin *et al*., 2017; Whiffin, Gracey and Ellis-Hill, 2021). If as Fuchs and Schlimme (2009, p. 572) believe that ‘*the lived body also conveys the practical knowledge of how to interact with others and how to understand their expressions and actions against the background of the common situation',* then the witness had already established, the ‘practical knowledge’ during the period of ASC. In contrast, the patient emerged from ASC unaware of their ‘situatedness’ in the ASC narrative that had already been initiated and continued to evolve.

Whilst the witness’ attention was focused on the object body, both during ASC and on recovery, they strived to respond emotionally to these nuanced behaviours as evidence that the uniqueness of the pre-injury relationship remained. However, this historical ‘*bodily resonance*’ (Fuchs, 2016, p.126) was so altered that, on occasions, the witness struggled to recognise behaviours reflective of ‘legacy self’. David’s persistence he was deceased, his inability to function independently and perform socially resonated with Patricia, not just physically but emotionally. His failure to present himself as a father and maintain a socially acceptable presentation of ‘legacy self’ in the hospital café, served to highlight not solely a corporeal disconnect with self, but also threaten their spousal and family relationship henceforth.

Fuchs (2016, p. 201) discusses how an individual’s interaction with another is shaped by their biography, referring to this as ‘*inter-corporeal memory’* or ‘*dyadic body memory’.* I propose that this biography encompassed the character traits, disposition, and behaviours of the pre-injury, ‘legacy self’ and formed the basis for the witness’ search during ASC. The recognition of ‘legacy self’ was not simply about reassuring oneself that the person remained but rather and as importantly, that the essence of the relationship endured. Witnesses frequently described physical traits which were central to their relationship. It was not solely about the person’s ability to maintain independent and fundamental function, but nuanced traits which defined the nature of their relationship.
However, there were occasions when the body lost its familiarity for both the witness and patient. Behaviours did not resonate with ‘legacy self’ and whilst there were glimpses of self, the personality changes, irrational and impulsive actions were all consuming. Irarrazaval’s (2015, p. 5) study on the phenomenology of schizophrenia describes how in acute episodes, the body becomes alienated, its ‘*tacit experienced-based function, turning into an object of observation*’. *In-ASC*, despite the patient’s attempts to disguise these limitations, they failed to avert the witness’ attention in comparing the ‘body that was’:

*‘It was definitely a plate and there’s utensils and stuff, but my mum was absolutely shocked. I just picked up my left hand ‘cos obviously my right hand wouldn’t work at the time and just put it straight in my mouth, just like a baby and it missed, and it went on the top of my head and everywhere’* (June:P150-153).

Fuchs’ (2014, p. 405) interest in psychopathology and the existential life-world of depression and mania, highlight how the body loses its ability to resonate emotionally with others, ‘*resulting in a sense of detachment, segregation or even expulsion’.* This sense of dislocation and isolation was seen on emergence from ASC. Despite being able to recall physical care and communication with staff and relatives, patients’ accounts were rarely believed. Donna vividly remembered listening to the music of a particular artist being played to her whilst in ASC which was dismissed by her mother on recovery. One’s inability to resonate with another’s experience or acknowledge that there is a possibility of shared understanding had profound impact on the patient and their relationship with others. Donna had intentionally not shared any other memories of ASC with her mother or members of her family for fear of not being believed:

*‘She can’t see it really. She’s probably just imagining it’* (Donna: P426).

### 6.3.5 Corporeality and Identity

'Ipseity' refers to the '*fundamental configuration of self-awareness'* (Irarrazaval 2015, p. 6) and relates to one's internal perspective of 'self' as a projection to the outside world. Henry (2000) posits that ipseity is mediated and informed by body awareness in the moment, when attention is directed to one's proprioceptive and kinaesthetic awareness. The environment and our interactions as embodied individuals are central to our perceptions of 'self', which Neisser (1988) defines as the '*ecological self'.* During ASC, patients experienced their body amidst the perceptually disordered landscape and as a direct response to the physicality of care. June vividly described her attempts to pull the yellow snake from inside her and asking for assistance from an electrician, and James was insistent that he had witnessed a fire outside the ward. These hallucinogenic and delusional encounters were accompanied by such auditory and visual qualities it was difficult to discount them on recovery. They believed they were situated in the world authentically, which served initially to preserve their sense of '*ecological self*' and ipseity. However, with increasing awareness, they realised that their memories of ASC along with an inability to reconcile their experiences with the reality of others, challenged their sense of agency. They were unsure who they were on emergence from ASC, and who they were likely to become:

'*When I found out my head was like that it was the worst news anyone could hear. Your brain is the highest, most important thing in the whole body, so to lose that was absolutely – I've been upset for many things but that was top of them'* (Salar: P54-55).

Fuchs (2010a, p. 549) defines '*minimal self'* as that which is characterised by an: '*implicit, pre-reflective, self-awareness that is present in every experience without requiring introspection'.*

I propose that when cognisant, one's ownership of an experience along with one's ability to reflect on it as an authentic and legitimate bodily experience serves to develop one's sense of agency and identity. *In-ASC*, it was the object body, the conduit, which was left to relate to the witness and became the lens through which ASC was understood. The witness became preoccupied with the intricacies of bodily presentation, the characteristic gestures, and the knowing smile, believing these reflected attempts by the patient to reveal their '*minimal self*'. They persisted in their belief that, '*I just knew Alice was there. You know I could see there was issues, but I thought the main beast as it were, is still there'* (Paul: W1:141), refuting the opinions of others when challenged. Witnesses remained resolute that the patient *in-ASC* was able, through their body, to interact, communicate and perceive the external world, described by Plessner (2019, p. 234) as one's ability to maintain a '*mediated immediacy'*.

Paul felt his wife was objectified by the actions of the nursing staff. He recalled her being '*fed*', *watered*, '*washed*' in a perfunctory manner, repositioned, and transferred on the hoist with little regard for her dignity. The analogy of her treated '*almost like a farm animal'* (Paul: W1:395), called into question the perceived notion of care. He felt that his wife's legacy self and her pre-injury identity were lost amidst the functional inadequacy of the post-ABI, lived body, a finding reflected in other studies (Fraas, 2015; Nochi, 1998, 2000; Ownsworth, 2014; Power *et al.*, 2020). In illness, the body '*dys-appears'* (Leder, 1990, p. 83), becoming '*an obstinate force interfering with our projects'* (Leder, 1990, p. 84). In contrast, the witness strived to re-align the objective body they were presented with at the bedside with the patient's former 'legacy self', to perceive the body not solely as 'object' but a 'subject' that retained agency and capacity for recovery.

Accepting Grøn's (2004, p. 140) position that '*self-identity is not something inside the self but is at stake in the relation to others'*, then for those patients who presented with limited cognitive and communication abilities, their identity was clearly compromised. If the body is not able to engage in meaningful dialogue and there is a lack of reciprocal interaction and attunement with others, either during ASC or on recovery, then one's 'legacy self' becomes disordered. ASC is fundamentally then a disorder of 'legacy self' which extends through to recovery and beyond.

## 6.4 Lived Temporality

***'We exist within a transparent web of time'***

**(Varela, 1999, p. 266)**

### 6.4.1 Introduction

The following discussion presents a critical discourse of the patient's and the witness' experience of time throughout the duration of ASC and explores how ASC disturbed their fundamental sense of the structure and constitution of objective and autobiographical (subjective) temporality.

The existential essence of 'lived temporality' influenced and was influenced by the emerging meaning of ASC for both the patient and the witness. Merleau-Ponty (1962, p. 422) reminds us that '*we must understand time as the subject and the subject as time'* and that time *'always arises from my relation to things'* (Merleau-Ponty, 1962, p. 412). ASC, the phenomenological 'subject' was understood as it presented itself within a trajectory of objective time, with the subjective, autobiographical experience of time influenced by the events and occurrences which were observed and experienced throughout ASC.

### 6.4.2 Lived Temporality *in-ASC:* The Patient

For the patient *in-ASC*, time was uniquely constructed. It is somewhat inevitable that when there is disturbance of consciousness, time is experienced differently (Lewis, 1981). Entry into ASC disrupted the trajectory of objective time and yet, experiences remained in relation to time. Whilst some patients described being able to discern diurnal time, others reported having little sense of universal time. Time became largely understood through the trajectory and content of hallucinogenic and delusional experiences in ASC:

*'To me, time was, I'm not going to say it was normal, but I was in my little world of my own. Time was just normal'* (Simon: P119-121).

However, for some, the randomness of the storylines and plots experienced resulted in a disarticulation of time. Distressing encounters with creatures, threatening conversations and bizarre delusions were described as intrusive and enduring. Time felt protracted and drawn-out. In contrast, pleasurable encounters were fleeting. As patients gained some awareness on emergence from ASC, they found themselves juxtaposed in time, they were neither situated in the subjective time of their hallucinations nor able to re-position themselves in universal time. They existed in a 'temporal flux'. On recovery, there was a stark realisation that there could be no shared understanding of time, in fact for them, universal time was arrested and days and weeks, 'lost':

*'It's like in a way I feel like I've lost a part of my life with being in there, I've missed out on life'* (Simon:P105).

Patients were 'present' yet estranged in time. To redeem time and re-engage, they sought to determine whether there was any shared truth to their experiences. Donna realised on recovery she had not in fact been given a present by her boyfriend on Valentine's Day but was reassured that Valentine's Day had indeed, happened. The fact that her delusion held some temporal truth was affirming. However, her subjective experience of time *in-ASC* was incongruent with time as it was revealed and understood on recovery.

For those *in-ASC*, the experience of the modality of universally, constituted time was so fragmented or dislocated that these temporal domains became disordered. Merleau-Ponty (1962, p. 275) asserts that '*objective time is made up of successive moments'* but *in-ASC*, the hallucinations and delusions presented themselves randomly, they had neither a past nor informed the future, they were simply experienced in the 'present'. Whilst several delusions included characters, places and events which were recognisable, the context and content were so aberrant that patients found it difficult to reconcile their encounters with the past and situate them with respect to the future. Patients described an inability to discern present from past, their pre-reflective reality of ASC confused their perception of time and therefore it was difficult to anticipate a future when the 'present' of ASC was so alien. These experiences were not commensurate with universal time. *In-ASC* and on recovery, there were gaps in memory or patients were left with inconsistencies as to what they believed was reality or otherwise, and yet the witness had been party to their behaviours in their absence.

Husserl (1991) identified three temporal domains namely, '*retention', 'presentation'* and *'protention',* which he asserted, collectively constitute our sense of consciousness. Experience is always in relation to our past or '*retention*'. Our acts are always in the moment as directed to '*presentation*', and intention is directed to the future or '*protention*'. As Merleau-Ponty (1962, p. 411) summarises, *'the present is the consequence of the past, and the future of the present'* and always arises in 'r*elation to things*'. Time consciousness was disturbed *in-ASC*, such that for the most part 'present' experiences *in-ASC* were distinct from the past and protention was unknown. There was uncertainty as to whether ASC would end, and patients could return to common reality and a shared understanding of time. It was as though living through ASC disrupted explicit time to the extent that the past, present, and future had to be re-negotiated or re-synthesised. If as Brook (1984, p. 7) states, '*we live immersed in narrative, recounting and reassessing the meaning of our past actions, anticipating our future projections, situating ourselves at the intersection of several stories not yet completed*', then because memories of ASC were so fragmented and incoherent, one's perception of time was deranged. If we also accept Sennett's (1998, p. 1) position that, '*the experience of disjointed time threatens the ability of people to form their characters into sustained narratives*', it is not surprising that patients strived to reconcile their ASC experiences on recovery.

*In-ASC*, the patient's present reality, confused time perception. They were unable to contextualise their present experiences *in-ASC* with a relevant past and it was difficult to anticipate the future, both in the context of the present and commensurate with universal time. As patients reported being in a 'liminal' space *in-ASC*, commensurate with the empirical findings of other works (Andersson *et al.*, 2001, 2002; Darbyshire *et al.*, 2016; Instenes *et al*., 2017; Laitinen, 1996), they also found themselves situated in 'liminal' time, a temporal domain so unique, which risked influencing restitution. *In-ASC*, they became passive participants, unable to influence or direct their experiences and yet, on recovery, had to somehow reconcile their memories of ASC with the future.

Whilst several patients were accepting of their hallucinations, however bizarre they might have been, others were left trying to make sense of their experiences. They became occupied by the places they visited, people and characters they encountered in the landscape of ASC and frequently ruminated about the content and context of these experiences. Patients were unable to judge or have a sense of the continuity of time *in-ASC*, to the extent that these isolated and irrational memories hung in ‘time’. This disarticulation of time was heightened when patients were unable to discern fantasy from reality. Whilst some experiences made sense ‘in time’ others did not. The persistent quest to make sense of perceptual disorders both *in-ASC*, and on recovery affected restitution and the ‘future’. If we accept Gordon’s (1994) view that temporality is a ‘*past lived, embodied, accepted as part of one’s self and in which one’s self is rooted’* then there is a risk that one’s sense of ‘self’ is inextricably affected by ASC and likely to influence recovery.

### 6.4.3 Lived Temporality *of-ASC:* The Witness

Witnesses came to understand and define ASC as a state of being which was observed throughout a period of objective time. Whilst the patient was present in body, their inability to communicate with the witness, meant that the patient was perceived for the most part ‘absent’. The primary narrative of the witness referred to this observed period of ‘time *in-ASC*’ during which the patient became an object of scrutiny. The patient’s entry into, and emergence from ASC, were experienced as distinct and formative events in time. Eye opening, the recognition of behaviours or character traits reminiscent of the patient’s ‘legacy self’ and the belief that they could engage in meaningful way, affirmed a time when ASC was ending, and recovery would be realised. However, this temporally influenced trajectory was fraught with ambiguity and confusion. The dialogue with the professionals, decisions made about transfer to clinical areas within the hospital and the unpredictable and fleeting appearance of the patient’s ‘legacy self’, served to interrupt what was, for some of the witnesses, believed to be an anticipated and predictable timeline of recovery.

Witnesses understood prognostic outcomes as synonymous with time *in-ASC*. The longer the patient was *in-ASC* which was not influenced by medication or required dependency on ventilator support, the less likely recovery and return to ‘legacy self’ would be. However, because professionals normalised ASC as an anticipated sequela of brain injury and rarely discussed ASC as a time-dependent and evolving state, the witness became increasingly isolated in their endeavour to reconcile events over time with recovery from ASC and restitution. ‘Lived time’ becomes conscious, or as Fuchs (2010a) explains, ‘*explicit*’ when the corporeal body is affected by illness. There were expectations that time *in-ASC* heals the brain, but the reality was markedly different. The body performed and functioned so inconsistently over time that whilst some behaviours were recognised as a reminder that ‘legacy self’ remained, other more concerning cognitive and behavioural presentations acted as powerful reminders that their return to ‘legacy self’ was unlikely. For the witness, time appeared protracted when recovery of the 'lived body' was itself protracted. It is as though time was both an enabler and disabler of recovery.

The witness became astute to the behaviours of the patient as appropriated in time. If the patient was perceived to be 'sleeping' rather than *in-ASC*, and deemed able to respect universal, diurnal patterns through attention to the sleep-wakeful cycle, then this was a reassuring indication of recovery and return to self. Adherence to ward routines and the consistency in the timing of activities of care were also deemed to influence recovery. There is a socio-temporal order which orchestrates and governs ward and hospital life (Caldas, 2012; Holloway, Smith and Warren, 1998; Zebubavel, 1979; Zisberg *et al*., 2007) to the extent that care activities and institutional regimes are ritualistically ordered in time, imposing an exclusive and collective temporality. The notion of universal time was 'set aside' in hospital. The hospital ward became a unique space where activities such as medicine rounds, clinician rounds, visiting, and the washing and feeding of patients, were largely dictated in time. These activities imposed and constituted a unique temporality or '*social order*' (Gibson, 1994, p. 110) which had to be understood and respected by the witness. From the moment the patient was admitted, the witness entered this unique space and had to master this collective temporality. There was an expectation that individuals situated themselves and became familiar with this established temporal framework. If as Chandley (2000, p. 35) suggests that temporal mastery is '*a primordial human need'*, then the witness will strive to understand this unique temporality and find a position and sense of agency in their role at the bedside.

Fuchs (2010a, p. 588) defines '*implicit temporality'* as time which is experienced pre-reflectively, as an '*intrinsic feature of conscious experience*'. For the most part, we are not conscious of the duration of time. However, time becomes consciously experienced or '*explicit*' when '*implicit time'* is disrupted or interrupted. For the witness, seated at the bedside, ASC interrupted time and served to make time '*explicit*'. The witness had to adhere to the new temporal code imposed by hospital regimes, and understand that discussions about care, prognosis and recovery from ASC were governed by, and influenced in time. For example, the witness learnt that the transfer of the patient from the ICU to the ward would be recommended at a time when improvement *in-ASC* was evidenced by the patient's ability to breathe without ventilatory support, or that the transfer to rehabilitation would occur when they were able to 'perform' functionally, at a level determined by the clinician. However, when on transfer, there was no perceived improvement in the patient's ASC or the transfer to rehabilitation did not happen as anticipated, the witness' knowledge of ASC and particularly aspirations for the patient's recovery were threatened. For the witness, 'lived time' imposed an order to the trajectory of ASC and its management within the hospital setting but was fraught with ambiguity and unpredictability.

Whilst the witness conceptualised ASC within a passage of objective time, they also experienced time autobiographically. It could be argued that not only did ‘lived time’ become explicit and consciously experienced, but the routine of the hospital ward was the new ‘explicit time’. The witness became expert in their role as the watchful observer. This ‘watching’ and ‘waiting’ resulted in a disorientation of time and disturbed their familiarity with the constitution of time. Time took on a new ‘lived’, subjective meaning, and it was this profoundly unique, autobiographical experience of time which dominated. There appeared to be a distinct ‘temporality of anticipation’, whereby the witness toiled with an internal narrative which questioned the extent to which recovery would be realised over time. Time was retarded and protracted when their searching for the ‘legacy self’ was believed to be futile and when the patient’s behaviours in ASC remained estranged from their former ‘legacy self’. The bedside became such a unique lived space, which appeared to take on its own ‘time sense’.

In this space, the temporality of ASC was closely embroiled with the observed ‘lived body’. As discussed, body presentation *in-ASC* was experienced by the witness explicitly. They observed how the body functioned and performed over time, sensed its limitations, and reflected on the prior, functional ‘legacy self’. Fuchs (2005a, p. 196) reminds us that ‘*embodiment and temporality have a parallel background-foreground structure’.* It is this ‘*dialectical relationship between the embodied human subject and the world’* which Wyllie (2005, p. 182) argues constitutes a lived time that is intimately synchronised with the time of others (intersubjective time) (Wyllie, 2005, p. 182). Whilst the witness became attuned to the *‘explicit body’* (Fuchs, 2005a), one that was embodied by ASC, they simultaneously experienced an explicit and exclusive temporal reality which was distinct from that experienced by others.

For the witness, the past, present, and future took on a new meaning. For Lewis (1981, p. 612) ‘*time–consciousness is a matter of immediate experience: it is an aspect of all conscious activity; it is essential for all reality’* and as such *‘we live in time’*. At the bedside, ASC shaped the witness’ ‘present’ which directed their attention to the nuances, gestures, and presentation of the lived body and yet for the witness, the future was largely unknown. Some remained faithful in their belief that ‘legacy self’ was temporarily hidden from view, and time would be revealing. However, those witnesses who remained unconvinced were left questioning what the future might hold. ASC appeared to bring the future into the ‘foreground’. Attention to the object body of ASC in the present, informed the future meaning of ASC. Returning to Husserl’s temporal domains, ‘*presentation*’ and ‘*protention*’, these were experienced simultaneously, with ASC affecting the witness’ temporal order and organisation.

### 6.4.4 The Intersubjectivity of Temporality

For both participant groups, ASC resulted in a paradigmatic disturbance of the constitution in, and of temporality and henceforth time became '*explicitly*' experienced. For the patient, the landscape of ASC imposed a unique and exclusive temporal structure that was distinct from universal time. For the witness, the lived experience of time informed their personal understanding of the trajectory of ASC with respect to prognosis and recovery.

During engagement with others as conscious, perceptual beings, there is agreement of the constitution of 'objective time'. It is these mutual, shared experiences in, and of time, which Minkowski (1970) believes endows a '*lived synchronicity'* that is deemed important in the maintenance of relationships. However, the lived experience of the life-world of ASC detached the patient from the witness. It is on occasions like this, when we are separated from *'others to whom our lived time is primarily related, that we experience the irreversibility and the rule of time'* (Fuchs, 2005a, p. 196).

The findings revealed there were three conflicting and distinct temporalities which informed and influenced the participant's understanding of the life-world of ASC. Firstly, the patient was immersed in their unique reality of ASC where time was disordered and experienced passively. On recovery there was a stark realisation that universal time was lost and could not be retrieved. Secondly, there was the culturally imposed temporal order of the hospital ward, which directed routine, but also influenced the witness' knowledge of ASC presentation and restitution. Thirdly, the witness found themself isolated in time, juxtaposed between the temporality of the hospital, their autobiographical sense of time and historical familiarity with universal or common time. These paradoxically opposing temporalities risked fracturing a shared understanding of ASC. If we are to accept Fuchs' (2010b) position that temporality, embodiment, and an individual's inter-subjectivity with others are so intricately connected, then ASC risks decoupling each party from any shared temporal meaning and influencing one's sense of self and future agency.

Fuchs (2005a, p. 196) believes that '*temporality and the performance of the body are nearly synonymous'* in so much as when one is distracted and actively engaged in tasks, then time is experienced implicitly. However, in contrast when the lived body becomes an object of observation, time becomes explicit. For the witness, time was slowed down, fragmented, or even lost. Lived time cannot be disentangled from one's experience of embodiment of the human subject. Time is '*driven and directed towards the world in terms of bodily potentiality and capability'* (Wyllie, 2005, p. 272). For both the patient and the witness, ASC influenced the experience of temporality, but also time became influential in the perceptual understanding and collective meaning *in-ASC* and *of-ASC*.

## 6.5 Lived Relationality and Discourse

> ***'The beginning of every illness is a halt. Normal life is at an end. Another life takes its place, a life of a completely unknown nature. One suddenly becomes uncertain about most things taken for granted… the personal function in the existence of others, the necessity or even the indispensability of this function, the faith in a still unpredictable future and the faith in the integrity of the body'.***
>
> **(Van den Berg, 2012, p. 387)**

### 6.5.1 Introduction

The following discussion explores the lived relationality and the intersubjective discourse which informed the narrative of ASC, and analyses how the patient and the witness perceived self and others through the relational and discursive trajectory of ASC.

Inter-subjectivity is defined as '*the basic sense of being-with-others in a shared life-world'* (Fuchs and Röhricht, 2017, p. 134), the understanding of which *'takes the form of interaction as well as a dialogue (with the other and with oneself)* (Mooiji, 2012, p. 181). Whilst one might assume the patient is simply a passive observer and estranged from any meaningful experiences situated *in-ASC*, the findings revealed otherwise. Patients were relationally engaged with others, both within the immediate landscape of ASC (intra-relations) and during emergence (inter-relations). The patient's departure from the universal reality *in-ASC*, was subjectively and authentically experienced. For the witness, the meaning of ASC was constructed through the encounters they had with the patient *in-ASC*, but also with staff and others in the hospital setting.

An individual's co-creation of meaning is never an isolated activity but always in relation to others (Crossley, 2000). As Fuchs (2015a, p. 178) posits, we '*live in a shared life- world because we continuously create and enact it through our coordinated activities and participatory sense-making'.*

### 6.5.2 Lived Relationality and Discourse *in-ASC*: The Patient

Residing *in-ASC*, the patient described an immersive, rich, and meaningful experience. The delusional and hallucinogenic landscape invited patients to foster relations, an 'intra-relational narrative', with characters, some familiar and others fictional. It was in the juxtaposed, liminal space of ASC where patients described an increasing awareness and began to navigate their return to a universally experienced reality, where they were afforded opportunities for 'inter-relational' discourse. However, there were occasions when the witness perceived the patient as simultaneously residing in two distinct realities. This is akin to Henriksen and Parnas' (2014, p. 544) work on the lived experience of schizophrenia, where one exists in a *'double ontological orientation'*, '*the shared social world* (*the natural ontological attitude)'* and that which is defined as the '*private, psychotic world,* (*a solipsistic attitude*)'. This '*orientation'* is illustrated by Patricia's account as a witness to her husband, David's ASC. Whilst he engaged appropriately with others in the cafe of the hospital and began *'to seem quite normal by then'* (Patricia:P150-152), she believed he also resided in a delusional world, when he stated: '*yeah, I used to think that when I was alive as well'* (Patricia:P147).

For the patient then, ASC was lived '*through*' as a conscious, subjective reality, which reflects Parnas, Sass and Zahavi's (2013, p. 273) definition of consciousness, '*as a becoming, temporal streaming of a unity of intertwined experiences'.* The perceptual disturbances experienced *in-ASC* introduced the patient to a landscape which was rich in imagery. A patient's immersion in the accompanying dialogue, content and context of this intra-relational life-world of ASC was described with impassioned detail. Whilst the dramas of ASC were fleeting and on occasions disconnected and aberrant, the gestalt of the experience was enduring and remembered months or years later.

In explicating the myriad of concepts which define 'self and its relationship to the subjective experiences of psychopathology, Henriksen and Parnas (2014, p. 544) refer to the positing of self as the '*minimal*' or *'core self'*. '*Minimal self*' is defined as the *'first-person articulation of experience'* where one has the capacity '*to live a life in the first-person perspective as a self- present, single, temporally persistent, bodily and bounded subject of experience'. In-ASC*, the patient did not describe a morphing or transition of 'legacy self'. Rather the identity of the '*minimal self*' appeared to remain constant amidst the turbulence and unpredictability of the hallucinations and delusions. However, if we are to accept Jenkins' (1996, p. 20) position that '*selfhood is thoroughly socially constructed... in the ongoing processes of social interaction',* it was not surprising that experiences *in-ASC* risked being formative in defining future 'self'.

Whilst several patients recalled the distinct moment, they 'navigated' the boundary into ASC, for others the entry into and the proceeding trajectory of ASC was less well defined. Patients were immersed in the delusional and hallucinogenic scenes but increasingly perceptive to the external world of the hospital, a juxtaposed place where the reality of the external world seemed to punctuate and randomly invade their experiences. They reported remaining sentient throughout and described occasions when they strived to 'be present' and make contact. They sensed the presence of people at the bedside, '*like I remember my family being there. Now I knew everything and why aren't you listening to me*' (Donna:P121-124), and recognised familiar voices, over time becoming aware of the external world to which they once belonged. Sass and Parnas (2003, p. 430) state that one's '*sense of self and immersion in the world are* *inseparable, we are self-aware through our practical absorption in the world of objects'.*

Independent of their position along the evolving trajectory of ASC, the patient was 'absorbed' and their experiences had an irrefutable and all pervasive reality. As patients gained increasing awareness of a 'return' from the boundaries of ASC, they began to realise the extent of their functional and cognitive limitations. These limitations made the transition particularly difficult. Patients believed they could communicate, they could be heard and understood, and their actions were purposeful, but sensed they have become '*an object for the Other*' (Sartre, 1943, p. 260). The accompanying dialogue and the experiences patients had on emergence reinforced these beliefs and were particularly transformative with respect to 'self'. An individual's '*minimal*' self, normally '*an automatic, unreflected immersion in the shared-social world,'* a 'self' which historically is *'reliable, predictable and ontological secure'* (Henriksen and Parnas 2014, p. 544) was exposed and challenged through the gaze of the 'Other'. One's sense of 'self' is always relative to the 'object' (Merleau-Ponty, 1962), and it was during their time *in-ASC,* that 'legacy self' risked transformation. Functional limitations were purposefully hidden as the patient tried to regain their 'legacy self' and agency. However, the witness was privy to these limitations. The body was exposed. and 'legacy self' defined in the patient's 'absence'. Sartre (1943/1958) identifies two modes of ontological existence for the body, namely the *'body-for-itself* and the *'body-for-others'.* Macdonald and Hobza (2016, p. 276) reflect on the experience of object-subject for those with schizophrenia and identify that one constantly *'lives in the gap',* defined as an *'apex of torture',* an *'intermediary between thoughts* and *'subject-object'.* It was in the liminal space of ASC where the patient passed judgement on themselves. The body was viewed as an object. They manipulated body presentation to reconcile *body-as-object* and *body-as-subject.* For some, the 'journey' back was torturous and unpredictable. The patient was uneasy as to the prospects of a return to universal reality.

Maung (2012, p. 31) argues that '*as subjective beings each has access only to his or her own subjective world'.* Whilst for the witness, the patient's subjective world of ASC was inaccessible, they were unable to traverse the boundary: '*they're not in the same reality as you, you can't reach them, can you*? (Patricia:W2:55), the witness did have access to the corporeal presentation of ASC. Gallagher and Hutto (2008, pp. 30-31) define actions which are representative of one's inner consciousness, as the *'landscape of action'* which *'is constituted by one's embodied action and the rich worldly contexts within which they act'.* Seated at the bedside, the witness became expert in assessing the behaviours and actions manifested by the patient *in-ASC* and gained knowledge of the patient's emerging 'self', abilities, limitations, and prognosis. In the patient's 'absence', their 'self' was constructed, they could neither verify nor reject the proxy reconstructed identity and reclaim selfhood. Ricoeur's (1991, p.

32) quotation poignantly captures the potential vulnerability of the patient, as the narrative of ASC is written in their absence:

'*We learn to become the narrator and the hero of our own story without actually becoming the author of our own life'.*

Henriksen and Parnas (2014, p, 544) define ipseity as the *'persisting identity core upon which more rich and complex feelings of identity and of being a person emerge'.* It is apparent that whilst ipseity remained, behaviours witnessed during ASC contributed to a transformed self which the patient had difficulty recognising on emergence: *'I thought I was doing alright... I wasn't really aware of how bad I was'* (Alice:P286) and one that had the potential to '*throw the person into a new ontological-existential perspective'* (Henriksen and Parnas, 2014, p. 545). Recognising that in their absence, one's sense of 'self', '*like I'm more useless a little bit, I'm not able'* (Salar:P129), had been constructed through their engagement with others, resulted in deliberate efforts to realign present 'self' with 'legacy self': '*I so wanted to be normal, for me, for him, for everyone*' (Alice:P523).

Bandura's (1977) concept of '*self-efficacy'* which refers to one's evaluation of self or personal agency in the ability to perform tasks and maintain function were compromised. Patients found physical and cognitive functioning difficult. They were given tasks they could not perform and felt ashamed when they are unable to meet both the family's and therapist's expectations of recovery, to the extent they had to take ownership: '*felt like I'd sort of deal with them myself on my own, you know'* (Barry:P180).

Whilst some patients believed they had not 'performed' as their 'legacy self' during ASC, *'well, I realise now I wasn't being appropriate at all'* (Nina:P428), others felt obligated to act 'normally' as they engaged with others in the lived space of the ward. They developed strategies to 'hide' their functional limitations for fear of being berated or the extent of their losses revealed. In contrast to Ownsworth's (2014, p. 5) belief that '*the self, possesses both consistent characteristics and those continually under construction'*, for the patients of this inquiry, 'self' was at risk of reconstruction throughout the trajectory of ASC, one they were loath to reveal:

*'Yeah, it was almost a bit of a shame about it 'cos it wasn't normal, you knew it wasn't normal, so you just kept schtum about it 'cos that was the last thing you wanted to do was highlight anything that wasn't normal'.* (Alice:P2:12). *'If I'd opened my gob about it, I mean, as far as I was concerned, people would have said, she's mad'* (Alice:P2:12).

Atwood (2012, p. 45) writes: '*people who stumble into the abyss do all kinds of things to bring stability and substantiality back to their worlds*'. June was preoccupied in her attempts to hide 'presenting self', purposefully pretending to be asleep for fear that the reality of her limitations of her 'disordered self' would be revealed. Patients sensed that others had reconstructed their 'legacy self' in their absence. Jenkins (1996) identifies identity as a '*dialectic process'.* If we accept Wall's (1999, p.40) position that '*self does not form itself until the other and others intervene and bring it into existence',* then it was only when individuals engaged with others on emergence from ASC was their sense of 'self' projected back and mediated by the responses of others. It was the narrative of the witness that was the 'backstory', an account which bore witness to the reality of the clinical presentation *of-ASC*, and the lens through which the patient began to evaluate and re-construct their 'legacy self'. Whilst Barry did not take offence by a staff member's remark that '*you went a bit bonkers',* he did, on reflection, feel that staff lacked empathy of his experiences *in-ASC*. If on these occasions staff assume the patient lacks awareness and capacity for meaningful interaction, then it is not surprising they were isolated *in-ASC*.

Alice (P:227-229) felt objectified by staff: '*just like another round of tablets… you get your time that day and that was it. I liken it to prison really, you were fed three times, three meals a day'.*

Akin to depression, the patient felt '*like an isolated object in a world without relationships, there is only an abstract space around her, not a lived, embodied space anymore'* (Fuchs, 2013a, p. 229). This loss of affective resonance with others will inevitably result in a sense of *'detachment, separation and segregation'* (Fuchs, 2013a, p. 219) from the external world. Minkowski's seminal work on the intersubjective disturbances experienced in schizophrenia, identified the person has having a '*loss of vital contact with reality' ('elan personnel'*) (Urfer, 2001, p. 279), which designates one's mode of self-relatedness with others. In attempting to re-engage in a world they have been absent from; patients sense they have been defined in their 'absence'.

Unlike staff who were resigned that the outcome was unfavourable, the witness was tentative as to whether behaviours in ASC would continue, or whether 'legacy self' would emerge. In their re-engagement with others, the patient was perceptive to this uncertainty and had to re-negotiate a presentation of 'self' that was not only capable but recognised as worthy of a presence in the common life-world. For those who recognised that 'self' has 'shifted' and 'legacy self' had been redefined, they were determined to redirect the narrative:

*'I was so positive with it, that my mind tried to put itself in that position of being perfect'* (Salar:P26)

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### 6.5.3 Lived Relationality and Discourse *of-ASC:* The Witness

The evolving context and nature of the relationships informed the witness' developing narrative of recovery, prognosis and of the patient's presentation of 'self' in, and through the emergence of ASC.

Meaning was conferred by the witness observing the inter-relational dynamics between staff and the patient, and their encounters with professionals throughout the trajectory of ASC. Understanding was advanced consciously through direct observation and dialogue, but also inferred through the subtext and narrative tone which accompanied communication. As a collective, these were influential in facilitating '*the conscious processing of subliminal information'* (Van den Bussche, Van den Noortgate and Reynvoet, 2009, p. 452) and became integrated and assimilated over time.

As there is a cultural temporality and spatiality to the hospital settings, there is also a culturally embedded narrative which appears foundational to the co-constitution of meaning. The dialogue, subtext and inferences associated with ASC informed the witness' understanding of the intended management regimes, recovery, and prognostic outcomes. In the absence of information about the anticipated trajectory of ASC, the witness relied on these inferences and other 'clues' to make sense of their experiences. As Tuan (1977, p. 199) espouses: '*much is learned but not through formal instruction'.*

The role of the 'unconscious' in learning has been the focus of extensive debate in cognitive psychology. The '*lens model'* proposed by Brunswick (1952), adopted the premise that the world is viewed through a lens which '*mediates between a stimulus in the environment and the internal perceptions of the decision maker'* (Newell and Shanks, 2014, p. 1). These stimuli or properties of the environment are referred to by Brunswick (1952) as '*ecological validities'.* The hospital was imbued with such '*validities'* which were consciously and unconsciously assimilated. Patricia remembered the appearance of the neurosurgeon following her husband's surgery: '*he had blood all over them and his shoes were splattered'* (Patricia:W:167) and he *'looked really shaken by it'* (Patricia:W:167). Over time, the meaning *of-ASC* became individually and collectively constructed through these *validities,* although its emergence within the institutional structures and cultural setting of the hospital was under perpetual construction and reconstruction and was, on occasions, contradictory.

In explicating the relevance of social constructionism in illness, Brown (1995, p. 36) recognises that it is not solely the dialogue which facilitates sense-making but rather:

*'In creating meanings and interpretations, people's interactions also include how they play out their social roles, and how they relate to professional and institutional structures where interaction takes place'.*

It was the inter-relational dynamics, the 'performance' of those situated in the lived spaces and the content and context of this engagement in these 'relational moments' which were influential. As Gallagher and Hutto (2008, p. 22) remind us, '*the environment, the situation,* *or the pragmatic context is never perceived neutrally (without meaning), either in regard to our own possible actions, or in regard to the actions and possibilities of others'.*

Within the lived spaces of the hospital, interventions were fundamentally driven by routine and ritual, with care focussed on the physical and clinical needs of the patient. Principally, staff were observed '*doing to'* the patient*: 'doing her routine'* $^{\text{(Paul:W231)}}$. Gallagher and Hutto (2008, p. 22) espouse that '*one's embodied actions and expressive behaviours'* within any intersubjective situation, reveal the other's intentions and beliefs. The perfunctory, and on occasions, impersonal way staff engaged with the patient sheds *'light on the intentions (or possible intentions) of that agent* (Gallagher and Hutto, 2008 p. 22). Paul's reflection and those of others, poignantly demonstrated how the actions of the '*agent',* in this context, the staff, dehumanised the patient *in-ASC,* to the extent that for Paul, his wife became an object to be watered and fed, '*almost like a farm animal'* $^{\text{(Paul W:395)}}$, '*just on a list of things to do'* $^{\text{(Paul W:383)}}$.

The bizarre, and at times disturbing corporeal presentation *of-ASC* and for Patricia, the physical effects of her husband's brain surgery were distressing. Staff failed to appreciate the significance of his disordered 'self', such that she felt his clinical presentation was normalised by staff:

'*He was there with everything swollen and looking absolutely horrific and I was just thinking, wow, I would never bring the kids in to see him. I don't know, but I know it becomes normal life to some people'* $^{\text{(Patricia:W2:91-96)}}$.

The responsibility for the aberrant and disruptive behaviours resided with the person rather than a reflection of their experiences *in-ASC.* This is in stark contrast to Weiner's (1995, p.5) claim that if the cause of the behaviour is known, it is unlikely the practitioner's '*thoughts progress from causal attribution to an inference about the person'*. However, this was not the case. Staff made passive observations of the patient's behavioural and physical presentation *in-ASC*, asserted blame, and engaged in punitive strategies to 'contain' behaviours. There was little evidence in the narratives that some professionals engaged at a deeper level. If as McAdam (2001, p. 117) proposes, identity is '*an internalised and evolving life story*' then the shared characteristics, disruptive behaviours and the patient's performance *in-ASC* were attributes which became internalised and homogenised as representative of the collective identity of those *in-ASC.* Once these aberrant and difficult to manage behaviours became associated with the patient, thereafter, they were defined by them. Sarah felt enraged that a nurse who had cared for her brother and whom she met months later, continued to believe he had been intentionally difficult and manipulative.

Focusing on the behaviours *in-ASC* and dismissing the person 'within' resulted in inter-relational tension. Friedson (1962, p. 209) argues that the layperson-professional relationship is potentially one of conflict rather than consensus, a consequence of the '*separate worlds of experience and of reference*'. Relationships were often precarious with witnesses becoming the defender of the patient's actions and their advocate. Paul sensed his wife was defined by her cognitive and functional limitations and observed her attempting to purposefully 'hide' her difficulties from staff fearing her discharge would be delayed:

*'And so, when somebody came, she went into this performing seal to try and tick the boxes that she wanted ticking so she could leave'* (Paul W2:100-102).

Goffman's (1963) theory of '*impression management*', purports individuals actively 'manage' their performance in social interactions when they sense their presentation of self and identity are in jeopardy. In distinguishing between *personal, ego* and *social* identity, he identifies '*ego identity'* as '*the subjective sense of (One's) own situation and (One's) own continuity'* (Goffman, 1963, p. 105). Alice intentionally manipulated her presentation of 'self', fearing her limitations would define her. The intersubjective experiences of others are '*central in shaping our social encounters'* (Klinke, Thorsteinsson and Jonsdottir, 2014, p. 825) and it was these experiences which characterised the relationship thereafter. Paul's distress was palpable on the occasion he visited his wife for the first time and found she had spilt food over herself. From his perspective, staff had failed to acknowledge the impact this would have on him. Their lack of attention both to him and his wife were formative in defining and shaping his unfolding relationship with them:

*'So, I walked in the room and walked in the ward, 'Oh, she's there', that was all I got. I walked in, that was the most frightening door I've ever opened in my life, and the nurse is in there, and they were trying to make the bed, they were doing something, and like there's yoghurt everywhere, there's juice everywhere and they're doing something else'* (Paul:W2:200-214).

Reflecting on the seminal work of Goffman, Jenkins (1996, p. 27) recognises that our performance within a social sphere is a '*formative aspect of social identity'.* If professionals persist in holding their view of the person as they have presented *in-ASC*, rather than the 'legacy self' which is privileged by the witness, then the person is labelled, and this entrenched perception of the patient becomes further embedded. The witness' relationality with the patient is historical, they search for behaviours which are reminiscent of 'legacy self' and reject those not familiar or purport them to be a direct consequence of the brain injury. However, in contrast, for staff who lack this relational history with the patient, the patient's pre-injury 'legacy self' was unknown and therefore the delusional and difficult behaviours became embedded and upheld as the identity signifiers. The witness strived in privileging of the 'person that was' to shift perceptions, but this was in the main, ineffectual. Even when signifiers of 'legacy self' were recognised and privileged by the witness as indicative of recovery, they were dismissed or viewed with scepticism by staff. It was this perceptual dichotomy which lies at the heart of the problem with relationality. Staff were observed relating to behaviours *in-ASC* which was in stark contrast to the witness who pursued their search for the patient's 'legacy self'. These distinct meaning-positions or orientations paved the way for a relationship which was, at times, uncomfortable and fractious.

In attempting to reclaim the person's identity *in-ASC*, search for behaviours to reinstate 'legacy self' and privilege the pre-injury relationship, the witness asserted themselves and became the protagonist in the ASC narrative:

*'Alice's mine, she's mine, I just relinquished enough control for them to do what they had to do but at the end of the day, I didn't give them Alice'* (Paul:W2:16- 17).

Seeking the pre-injury status of the historical relationship was important for the witness and evident in their actions. Mary continued with her nurturing role as a mother and displayed family photographs around the bed space, Patricia sat in bed with her husband to relieve his distress and Amir's mother kept a vigil at his bedside. McCall and Simmons (1966, p. 67) defined 'role identity' as: '*the character and the role that an individual devises for himself as an occupant of a particular social position'.* It was important for the witnesses that they maintained the 'essence' of their relationship throughout the evolving narrative of ASC. Throughout the trajectory of ASC, the witness became attuned to the positivist discourse of biomedicine which served to define ASC with respect to functional assessment, ability and prognosis: '*they're looking at it more on a science-type of way'* (Jane:W602). However, particularly within the ward environment, the witness reported a distinct lack of information disclosure and limited opportunity to clarify their understanding, leaving them feeling marginalised and estranged from the decision-making process. The lack of a clear and informed understanding of ASC, resulted in the witness feeling disempowered and isolated at the bedside, to the extent that Paul felt he was a hindrance: '*you're in the way and they want you to leave really'* (Paul:W2:20).

There was a felt relational 'tone' or affective quality to the narrative, which moved along a continuum from one of melancholic despondency to hope of recovery. In developing the discussion of the phenomenology of affectability, Fuchs (2015b, p. 617) defines Heidegger's concept of '*mood*' in the context of psychopathology as:

'*a background through which we encounter things as mattering or not. They belong to a primordial sphere of attunement of self and world, thus serving as a basis for all specifically directed intentional states'.*

The witness was particularly attentive to the background qualities and the mood which accompanied the conversations which took place with staff. Whilst there was an appreciation that staff could not, with any degree of certainty predict prognosis, the narrative was primarily one of hopelessness, and the tone prophetic. Jensen and Pederson (2016, p. 85) argue that '*emotions are tied to our engagement with the world'.* ASC presented the witness with an emotionally nuanced and impassioned landscape in which the narrative tone and the behaviours of staff provided a subtext to conversations about the anticipated trajectory of ASC and prognosis. Whilst Patricia was reassured that her husband's brain tumour had been removed during the surgery and he had indeed survived, the neurosurgeon's *'blood spattered theatre shoes'* (Patricia:W167) betrayed the stark reality of the surgical difficulties and the impending prognosis. Further discussions confirmed that surgery had not progressed as anticipated.

For the witness, the recognition of historical signifiers of 'legacy self' were reassuring signs the person was temporarily 'hidden' from view by ASC. Concerns about cognitive and functional limitations were overlooked as they described formative moments during the trajectory of ASC when the patient showed signs they were 'present' and had the capacity to 'return'. On occasions, they were defiant in challenging the professional discourse that suggested 'legacy self' was lost amidst ASC and was unlikely to emerge. In contrast, for other witnesses, the unrelenting and bizarre behaviours in ASC were deeply concerning and there was a degree of resignation that recovery was doubtful:

'*Then when we realised how bad she could possibly be, just the things she was saying. She went from the quietest woman in the world and she could be nasty'* *(Jane:W732)*.

### 6.6 The Inter-Subjectivity of ASC through the '*Meaning Structures'*

Whilst the patient and the witness began their journey through their temporal experience of ASC from different ontological positions, analysis revealed that ASC was constituted through a mutual engagement 'in and through' the existential, lived '*meaning structures'*: *spatiality, corporeality, temporality, relationality* and *discourse*. These '*meaning structures'* were constitutive of each other in that a distinct and emerging interplay was identified. ASC affected the participant's experience of the life-worlds, whilst simultaneously the life-worlds influenced the meaning of ASC. Both participants groups experienced ASC through a derangement of time perception, they resided in unfamiliar spaces which had to be negotiated, they had relationships with others, the discourse was unpredictable, yet meaningful, and the corporeal presentation of ASC was open to endless scrutiny.

Disturbances in *temporality, spatiality, corporeality, and relationality* revealed the patient's 'self' *in-ASC* as vulnerable. ASC was a window through which 'self' *in-ASC* was measured against the pre-injury, familiar, 'legacy self'. Differences however lay in the fact that for the patient, 'legacy self' remained the same *in-ASC,* the body continued to be sentient despite one's experience amidst the deranged life-world of ASC. It was only on emergence from the liminal space that the patient had any sense they had been the subject of appraisal and in their absence, their body objectified. The functional and cognitive limitations of ASC, hidden initially, were revealed on emergence from ASC, and this was a particularly formative time for both participant groups.

The realisation that, for the patient, perceptions of 'self' had been transformed in their absence and the witness had a privileged preview of what might be, was disturbing, and affected their sense of being and agency. The patient astutely and vigilantly self-monitored and sought to 'hide' their limitations to maintain a functional and coherent emergence of pre-injury, 'legacy self'.

### 6.7 Self, Identity and Personhood as Constructs 'in and through' the Phenomenological Life-World of an ASC secondary to ABI

For the patient, ASC was the means through which 'self' presented itself. *In-ASC,* ipseity remained constant amidst the turbulent and unpredictable path of ASC. However, the patient was unable to fully author their life, and their construct of their 'legacy self' was compromised. Whilst they had ownership of their experiences as they moved through the delusional and hallucinogenic landscapes, they were unable to influence the corporeal presentation and body performance *in-ASC.* The embodiment of 'self' was constrained by ASC and limited their affectability and relationality with the external world.

Whilst it could be posited that in the immediacy of ASC, 'self' was protected, it was in the juxtaposed, liminal space where '*self became aware of itself*' (Jaspers, 1923) as the patient became increasingly perceptive to the external world, which was fraught with angst and uncertainty. In this space, the patient's fundamental habitual and historical perception of their 'legacy self' was called into question. Negotiating a return to the common life-world was equally perplexing. Personal identity is defined as '*aspects of one's biography that are shared or available in social interaction – a product of intentional self presentation'* (Goffman, 1963, p. 105). On recovery, the patient became increasingly aware of how their corporeal limitations post-injury had unintentionally affected the other's perception of their competence. Unknowingly, their presentation of 'self' had been keenly observed in their 'absence', identity re-constructed and a proxy identity ascribed. Horney's (1950) distinction between '*real self*' and *'idealised self'* highlights how the patient's performance and perception of self on emergence from ASC, was distanced from the stark reality. The patient actively managed his identity and presentation of 'self' to 'bridge' the chasm between the *real* and *idealised* self. For Jenkins (1999, p. 22), Goffman's 'impression management' is an important strategy for the construction of self-identity. These strategies '*dramatize the interface between self-image and public image. Impression management draws to our* *attention the performative aspect of social identity'.* On many occasions, patients adopted strategies to 'hide' their limitations to present a 'normal' and capable 'legacy self'. If one continues to reside in this 'gap', unable to effect contact with the external world as a competent, 'legacy self', then one's belonging to the world and '*loss of body resonance, will result in a certain degree of derealisation and depersonalisation'* (Fuchs, 2014, p. 407).

Markus and Kitayama (1991) assert that two types of self-construal exist, the '*independent self- construal*' related to an individual's uniqueness and separateness from others and the *'interdependent self-construal'*, a state of self-presentation based on our relationships with others. It is fundamental to the concept of 'self' that experiences are owned, they are belonging of me (Gallagher, 2000). Unlike in schizophrenia where there is *'diminished self-affection'* defined as a decline in one's existence as a *'subject of awareness and action'* (Sass and Parnas, 2001, p. 348), *in-ASC* the patient was attentive to their experiences and engaged in the immediacy of ASC, evidenced by the fact that they were able to give a rich and nuanced first-person account of their experiences.

Seamon (2007, p. 3) argues that:

'*human experience, awareness and action are always intentional'* always *'orientated toward and finding their significance in a world of emergent meaning, human beings are inescapably and enmeshed in their world'.*

The challenge for the patient was how they successfully negotiated a return to the common external world, re-engaged and limited the extent to which their corporeal, post-ABI 'self' and identity were transformed and estranged from their 'legacy self'.

### 6.8 The '*Chaos'* and '*Restitution'* Narrative Typologies of the Phenomenon of an ASC secondary to ABI

Introduced in section 2.6, Frank's (1995) seminal work proposed three narrative typologies, the '*restitution narrative'*, the *'chaos narrative'* and the '*quest narrative*'. Frank (1995, p. 87) discusses how the '*restitution narrative'*, a preferred narrative is about '*making the body in an image derived either from its own history before illness or from elsewhere'*, one in which there is resolution of symptoms or adaptation to illness. However, for the participants of this study, achieving restitution in the context of ASC and ABI, was far more nuanced and complex. Restitution was not solely about recovery from ASC and the recognition or re-emergence of the patient's 'legacy self'. In contrast to Frank's (1995, p. 77) conclusion that the restitution narrative '*dominates the stories of most people'*, the participants of this study found themselves consumed by the chaotic and unpredictable trajectory of ASC, their narrative positions moving between one of '*restitution'* and '*chaos'*. Whilst the participants' narratives did reflect a personal '*quest*' as they began a journey through illness, their '*quest'* challenges

Frank's position (1995, p.115) that '*quest stories meet suffering head on; they accept illness and seek to use it'*.

The following discussion considers what constituted the content and context of Frank's (1995) narrative typologies for the participants of this inquiry, conceptualises the inter-relatedness of the '*quest*', '*chaos*' and '*restitution*' narratives along the ASC trajectory and demonstrates how the '*meaning structures'* informed the construction of the participant's *chaos* and *restitution*, as unique contributions to knowledge.

### 6.8.1 The '*Restitution*' Narrative of the Phenomenon of an ASC secondary to ABI

***'By doubting the testimony of other people about themselves, or of one's own perception about itself, he deprives himself of the right to declare absolutely true what he apprehends as self- evidence. We have no right to level all experiences down to a single world, all modalities to a single consciousness'.***

**(Merleau-Ponty 1962, pp. 289 -290)**

Research has shown that following a stressful life event or when embroiled in situations we have difficulty understanding, individuals search to ascribe meaning (Schuster, 2013). Situational meaning '*refers to meaning in the context of a particular environmental encounter'* (Park, 2010, p. 258) where one appraises the event, assigns meaning and strives for resolution whether that be acceptance (Pakenham, 2007), understanding the causation (Janoff-Bulman and Frantz, 1997), achieving positive change or personal growth (Abbey and Halman, 1995), adjustment or the acknowledgement of identity change (Gillies and Neimeyer, 2006). Sense-making is defined by Park and Folkman (1997, p. 129) as '*the extent to which people have managed to reconcile their appraised (or reappraised) meaning of the event'* with respect to their existing fundamental assumptions and understood to fundamentally occur on two levels: personally, and interpersonally (Cuffari, 2014). Analysis of the corpus of data revealed the meaning of ASC for both participant groups, but the interview also served as the platform for interpersonal and interactional sense making, a '*joint product of co-enaction'* (Cuffari, 2014, p. 216). Sense-making was an important element both during the immediacy of the participants' experiences and on recovery. The findings reveal that endorsing the perceptual disturbances in the context of the reality of the hospital setting or as a continuation of their pre-injury history, moved the trajectory towards restitution. Testifying about experiences *in*- and *of-ASC* was an important part of the '*quest*' journey which afforded participants *'their most distinctive voice'* (Frank, 1995, p. 115). The '*restitution'* narrative emerged when the participant's meaning of ASC was constituted in the context of ABI, and when the character traits of the patient's 'legacy self' were recognised amidst the chaotic and rough terrain of ASC even if the patient was selective as to which were hidden from view or revealed. '*The restitution story is about remaking the body in an image derived either from its own history before illness or from elsewhere*' (Frank, 1995, p. 87).

The participants provided a rich testimony of the phenomenon of ASC, a narrative which since the injury, had been largely unacknowledged or suppressed. On recovery, being able to relate experiences and develop an affective attunement with others and as importantly for patients, to understand that some of their experiences were in the context of the common life-world of the hospital was reassuring. If the totality of the patient's experience *in-ASC* is rejected as reflected in Mary's response to her daughter: '*she did say about the dreams that she had and she used to ask me, 'did this happen' and we were like, 'no it didn't happen'* (Mary:W137-138), or the patient is not able to validate their experiences relative to the external world, then one's agency and selfhood is potentially at risk. However, for some, their '*quest'* continued following discharge despite recovery being realised:

*'Oh yeah, I mean it tormented, well it didn't torment, it drove me nuts thinking about it because I still had these, it was still going round in my head when I came home, when I was asleep'* (Nina:P:154-155).

For the patient *in-ASC*, there was a dualistic approach to meaning-making, identified as both the search for the '*comprehensibility',* and the '*significance'* or the value or worth of the event (Janoff-Bulman and Frantz, 1997, p. 91). Participants searched for understanding, to make the incomprehensibility of events *in-* and *of-ASC* comprehensible, but also to establish the significance of their experiences. Unable to reconcile their experiences, patients were left ruminating. On recovery patients questioned the authenticity, the origins, and reasons for their experiences *in-ASC*. If as Malpas (1999, p.180) posits that '*to have a sense of one's own past is to have a grasp of one's present and future',* then for the patients of this inquiry, who were unable to reconcile their past, the search for meaning and restitution will continue, one's being and existence is threatened, and chaos is likely to ensue. On recovery, Donna (P:475) recalled how her experiences *in-ASC* were dismissed: *'no one asked, no one seemed interested',* to the extent she sought support from the psychologist. Both participant groups sought to make sense of their experiences amid ASC, through to recovery and beyond. As seen in the narrative accounts, the influence and perspective of the Other '*can facilitate or impede meaning-making'* (Park, 2010, p. 292).

Researchers have argued that meaning making is not solely an individual endeavour, but one that can take place interpersonally (Clark, 1993; Lepore *et al*., 1996). Participants not only strived to make sense of their experience *in-* and *of-ASC* and establish a sense of individual and mutual coherence, but have their account believed and recognised as their reality at the time: '*the experiencing of each and every person under study must be treated as equally* *valid'* (Sages and Lundsten, 2009, p. 198). Even though the patient's and the witness' reality of ASC were fundamentally different, both life-worlds were experienced with intentionality: '*that which makes the world, the world of reality as well as that of my imagination or my dreams, meaningful to me; it is the very process of the constitution of meaning'* (Naudin and Azorin, 1997, p. 179).

Maung (2012, p. 31) argues that for individuals who experience time in psychosis, '*each has access to only his or her own subjective world. Neither appears to have access to an external criterion to judge which one of their representations of reality is accurate'.* However, when the witness and the patient participated in a shared interview, they moved towards a mutual, shared constitution of meaning and to an extent, were able to align experiences. On these occasions, sense-making was clearly relational (De Jaegher and Di Paolo, 2007). This mutuality of relationship allowed for a '*continuous co-construction of meaning'* (Fuchs, 2015a, p. 179). However, any degree of mutual validation was only possible on recovery when the patient was able to validate their experiences *in-ASC*. For most of the time, '*the patient's own and the other's point of view* were *only juxtaposed instead of being integrated'* (Fuchs, 2015a, p. 179). Acknowledging that for the patient, their narrative of ASC reflected aspects of the reality of the external world became important for the patient's selfhood and restitution.

Some patients had already begun to make sense of their experiences post-recovery, whilst for others, hearing my 'pre-understandings' as a nurse, supported their search for a degree of legitimacy of their experiences. June was reassured when her memories of being in a spa could possibly be explained by the fact it was likely she had been prescribed humidified oxygen which when administered, sounds like the bubbling of water and the '*yellow snake'* coming from her, a yellow-coloured urethral catheter draining urine:

'*In my mind I have analysed it and I think this is probably what was happening. At one time, I kept saying to somebody that I was in a hospital bed and looking at this thing, this yellowy thing going into the distance, you know, I can remember this, so I think that's a good example of the hallucination having some sort of reality'* (June: P85-91).

The integration of experiences *in-ASC* into a coherent narrative, where the delusional and hallucinatory experiences were reconciled as an anticipated consequence of the ABI or reflective of events happening in the external life-world were important in establishing one's sense of 'self' and agency on recovery. The perceptually disordered landscape experienced *in-ASC* were 'felt' experiences, in that they imposed a sense of absoluteness and reality. As Thomas and Thomas' (1928, p. 572) profound theorem states: '*If men define situations as real, they are real in their consequences'.*

For the patient, ignoring their experiences *in-ASC* or denying their existence or significance suggests that sense-making cannot happen. If as the findings reveal, the patient continues to question the authenticity of their experiences *in-ASC*, or memories are refuted or ignored, they risk being left to ruminate, and restitution will not be realised.

### 6.8.2 The '*Chaos'* Narrative of the Phenomenon of an ASC secondary to ABI

***'To deny a chaos story is to deny the person telling his story and people who are being denied cannot be cared for'***

**(Frank, 1995, p, 109)**

For the participants of this inquiry, the untimely and unexpected immersion into the phenomenological experience of ASC began a narrative informed by chaos. Chaos was heard in the participants' narratives as they navigated their way through the unpredictable and trepid path of ASC. The existential, *'meaning structures'* were the proximate source and causation of this chaos, resulting in the '*unmaking of a person's world'* (Scarry, 1985). The patient's chaos was described as they recounted their incomprehensible and undulating journey through the landscape of ASC, whereupon on emergence functional limitations and changes to self and identity were realised and their pre-injury, 'legacy self' defended. Their relationships with others, and the accompanying dialogue, along with disorders in time-perception served to further compound their chaos. Collectively, disorders of space, body, time. and relationality, left the patient at a juncture where 'legacy self', personhood and identity were vulnerable and risked transformation. Frank (1995) presents the ill person as the '*Wounded Storyteller'*, but the participants of this inquiry who were witness to ASC, were equally '*wounded*'. The witness' '*voice of chaos'* (Frank, 1995, p. 98) was heard as they gave testimony to the patient's corporeal presentations in the different lived spaces of the hospital, in their relational and dialogical encounters with staff, and their experiences of lived temporality as the patient's 'legacy self' was searched for and the meaning *of-ASC* constructed. Paul's (P243-248) metaphor poignantly captures the consuming and all-encompassing nature of this chaos:

*'The stroke is like a train. Alice doesn't care where she's going on this train. She's not interested, and everyone else on the train has been on the train a thousand times before, so they are all happily doing what they're doing and I'm sat there on my own, my wife's ill and I don't know a damn thing. I can't control the speed of this train and I can't control the destination and I've got no information and that's what I'm living with'.*

Ignoring the narrative also contributed to this chaos, whether that be with respect to the transformative experience of the patient *in-ASC* or the profound testimony of the witness, because '*until the chaos narrative can be honoured, the world in all its possibilities is being denied'* (Frank, 1995, p. 109).

If the healthcare practitioner envisages ASC to be a temporary presentation with restitution inevitable, then recovery and restitution are likely to be the dominant narrative. However, despite returning to a world of personal and situational orientation, the patients of this inquiry were left ruminating. For June, the intrusive and disturbing memories of her time *in-ASC* continued 15 years after her admission to hospital. Indeed, Roberts (2004, p. 180) asserts that '*the experience of illness or injury can have profound effects on how we narrate our lives and our self-image'*, henceforth. Failing to acknowledge the profound experiences *in-* and *of-ASC*, risked dismissing and diminishing the participant's story and '*compounding the chaos'* (Frank, 1995, p. 98).

To advance understanding and knowledge of the inpatient experience of an ABI and specifically ASC, there needs to be a commitment to the co-construction of meaning. Whilst Frank (1995) acknowledges that the chaos story is difficult to hear, continuing to define ASC by a set of behaviours or the attribution of physical characteristics, and '*deny the person telling his story'* (Frank, 1995, p.109) are likely to perpetuate the chaos.

### 6.9 Contribution to the Synonymic Challenge

'*Common sense'*, a term proposed by Polanyi in 1967 and developed by Blakenburg and Mishara in 2001, is defined by Fuchs (2010a, p. 554) as the '*way that past experience, implicitly informs our current understanding of everyday situations, thus connecting self and world through a basic habituality and familiarity'*. As a practitioner who has for many years worked in the field of neurosciences, I accept, somewhat reservedly, that my practice was perhaps '*habitual'* and to an extent '*familiar'*. My '*common sense'* knowledge of ASC and a patient's recovery from ASC, were primarily evidenced by empirical measurement of their wakefulness and responsiveness through standardised clinical neurological assessment.

Reflecting on the clinical descriptions which have historically categorised disorders of consciousness (explicated in section 1.3) and in light of the findings of this inquiry, the synonym, '*Altered State of Consciousness'*, fails to reflect, and represent a '*being-in-the-world'* which emerged as significant for the participants. The adjective '*altered'* implies a state of being which is estranged from one that is universally experienced, one understood to be distanced from the common and dominant reality. It immediately presupposes a distinction, a difference, which risks subjugating the patient's subjective experiences further. It is not surprisingly then, that the practitioner practises with what is '*common sense'*, familiar and visible, the objectively defined and measurable clinical presentation *of-ASC.* James' (1890, p. 339) historical and seminal definition of the '*hallucination*', more aptly represents the lived reality of the perceptually-disordered experiences *in-ASC* as a:

*'sensational form of consciousness, as good and true a sensation as if there were a real*

*object there. The object happens to be not there at all'.*

This thesis has demonstrated the utility of hermeneutic phenomenology in privileging the narrative, the first-person account, and in doing so enables the practitioner to develop a more nuanced understanding. To continue to define the experience as one which is 'altered' or 'disordered' perpetuates an inter-subjective distance and risks leading to empathic failures. Moving to a position which re-defines the experience as residing in an '*Alternate Subjective Reality',* a temporary, alternate space which is no less valid or formative than the reality of those whose level of consciousness is not challenged, would shift perception. If not, then for those who find themselves residing in this space risk being 'Othered', marginalised and their experiences along the illness trajectory afforded little attention. The findings reveal the experience has validity when there is a commitment to a shared understanding of the narrative experience. If we are to move towards a more empathic understanding then redefining ASC as an *'alternate subjective reality'*, makes one's lived experience more accessible. As Sartre (1943/1958, p. xxxvi) poignantly reminds us, '*all consciousness is conscious of something'*, and therefore deserves our attention.

## 6.10 Limitations of Method

The following offers a reflective, critical discourse of the characteristics of research design and methods which are identified as limitations of this inquiry.

### 6.10.1 Recruitment to the Study

The study was based on a self-selected participant sample, recruited from membership of an UK based charitable organisation, which allowed access to a homogenous group who had a lived experienced of an ASC, secondary to ABI. Whilst I visited several regional network groups, and some groups on more than one occasion, recruitment to the study was dependent on attendance of members at the time, and whilst there was a '*snowballing*' (Goodman, 1961) effect to recruitment, it was difficult to establish whether there were limits to the access of a wider participant group. The very nature and purpose of community groups is that they afford members the opportunity for peer, communal support, and a normative context for the framing of experiences (Hoey *et al.*, 2008). Whilst I valued the support and guidance of the Facilitators and Chairs of the network groups during the recruitment phase of the study, I was not privy to the relational dynamics within the group which may have influenced a member's assent to participate in the study, nor did I feel it appropriate to enquire as to whether there had been a propensity for certain individuals to volunteer or decline involvement in research studies previously.

Whilst the participants of the study met the inclusion criteria and self-reported an experience of an ASC, it was difficult in the absence of sight of the participant's clinical records to establish with a degree of certainty, the aetiology of the ASC. However, whilst this may be deemed a recruitment limitation because it imposed a heterogenicity to the sample, the aetiology of ASC was not an exclusion to participation, simply that ASC was a symptom corollary to a diagnosis of an ABI.

### 6.10.2 Influences on Narrative Telling

Whilst the participants' narratives of this inquiry emerged as rich expressions of meaning, personal accounts of lived experience are always '*partial, situated and tentative'* (Thomas, 2012, p. 214), and inevitably reflect the temporal 'truth' of experience (Sandelowski, 1993). Illness narratives are influenced by context, one's situatedness, and will never re-present a '*complete reflection of the teller's life'* (Lieblich, 2006, p. 64). Hermeneutic phenomenology is not guided by objective truths but acknowledges that an understanding of one's being-in-the-world, is always relative and temporal (Laverty, 2003; Lundgren, 2012). For the participants of this inquiry, there was a degree of heterogeneity in the time since recovery from ASC and for some, a significant period had elapsed following their inpatient experience of ASC. Whilst time did not diminish the strength nor extent of disclosure of their narrative, it was difficult to establish whether time had influenced the content of memory recall, and whether the narrative would be different had the story been told at a different stage along the illness trajectory (Crowther, *et al.,* 2017).

The reflection and articulation of one's life story is defined by Singer *et al.,* (2013, p. 570) as '*diachronic*', in that, stories '*move forwards in time and are continually amended in light of new experiences'.* A period elapsed following my initial introductions at the charitable support groups and the interviews with the participants. It was difficult to discern whether communications the participants had with members of the charitable organisation and their significant others during this time, influenced which narrative accounts they deemed important or relevant to share.

Autobiographical narratives are shaped by the storyteller's perception of the intentions and status of the listener (Bell, 2002). Whilst the strength of hermeneutic phenomenology lies in the fact that as a methodology a rich field of data is solicited, it is acknowledged that storytellers may be motivated to tell a '*good narrative'* (Garden, 2010), or one they feel obligated to tell.

The fact that it was difficult to establish the ways in which my 'historical position' as a nurse or researcher, impacted or moderated the participant's narrative telling and their construction of meaning, presented as a limitation. Kitzinger's (1994) work on the relational dynamics of focus groups recognises that disclosures by individual members may also be influenced or framed by the presence of others. Whilst there was an open and transparent dialogue between the participants during the joint interviews, it needs to be acknowledged that disclosures may have been stifled or censored by the presence of, or perceived agenda of the Other.

### 6.10.3 The Narrational 'Prism'

A limitation of the study is that active membership of the charitable organisation may have influenced the participant's decision to partake in the inquiry, and for those who participated, motivations may have been polarised. Bruner (1990, p. 54) states that '*stories inevitably have a narrational voice: events are seen through a particular set of personal prisms'.* Further work is needed to understand the nature of the '*personal prism'*, why certain narratives are privileged and the factors which influence the motivations to engage with narrative inquiry.

During this inquiry, particular metaphors and memories shared by the participants resonated with me. June's description of the '*yellow snake*' which she tried to pull out of her body, Patricia's experience of her husband's delusion that he was dead, and Paul's metaphor of his experiences akin to a train journey will stay with me forever. Further research is needed to understand what substantiates or informs the power of stories and understand why, for the listener, they have such resonance, meaning and longevity.

## 6.11 Summary

For both participant groups, the trajectory of ASC was an undulating, unpredictable and highly transformative lived experience. The findings of this inquiry offer a unique insight into the narratives which influenced, and ultimately shaped the personal construction and interpretation of the meaning of ASC. The ASC narrative was located within both the hospital and an immediate interpersonal context, which collectively steered the participant's direction of movement along the ASC, '*Quest Trajectory'*, influencing whether a degree of restitution was achieved, or chaos remained. Facilitating opportunities for reminiscence and recognising how the patient's and the witness' perception and interpretation of the '*meaning structures'*: *spatiality, corporeality, temporality, relationality,* and *discourse,* influenced their experience of the phenomenology of ASC and the construction of 'self', identity, and personhood, have the potential to move one's quest towards restitution. Alternatively, there is the potential for chaos if the patient's 'self' and identity remain estranged or dislocated from their pre-injury, 'legacy self', the narrative is unheard and limited attention is paid to their experience of ASC.

The following chapter develops the discussion by presenting a conceptual model, entitled:

‘The Phenomenological Life-World of an Altered State of Consciousness secondary to Acquired Brain Injury*: The Quest Trajectory’* as an original contribution to knowledge. The model illustrates the gestalt of the influences which constructed the meaning of the phenomenon of ASC for both the participant groups of this inquiry.

# CHAPTER SEVEN: CONTRIBUTION TO KNOWLEDGE, PRACTICE AND EDUCATION

***'Phenomenology does not seek to provide solutions, but on the basis of this understanding, I may be able to act more thoughtfully and more tactfully in certain situations – in some sense meaning questions can never be closed down, they will always remain the subject matter of the conversational relation of lived life, and they will need to be appropriated in a personal way, by anyone who hopes to benefit from such insight'.***

**(Van Manen, 1990, p. 23)**

## 7.1 Introduction.

In explicating the phenomenology of ASC, this thesis has attended to, and privileged the evocative voice of the illness narrative and established a genuine and empathic understanding of the lived experience of ASC. As Mathieson and Stam (1995, p. 284) espouse, narratives are not just '*stories, but the vehicle for making sense of, not an illness but a life'*. Acknowledging the unique and engaging life-world of the phenomenology of ASC has set this inquiry apart from the existing body of evidence. Whilst published works in the field of narrative psychology and neuropathology have examined the lived experiences of perceptual disorders, no study to date has examined the hermeneutics of the complex life-world of the phenomenon of ASC secondary to ABI, and considered the narrative positions of the patient and witness throughout a period of hospitalisation.

Section 7.2 offers a brief, discursive summary of each of the *'meaning structures*' discussed in Chapter 6. Section 7.3 synthesises the findings of this inquiry, the study's '*inceptual epiphany*' (Van Manen, 2014, p. 356) as an original contribution to knowledge, before presenting a conceptual model which represents the gestalt of influences which, for the participants of this inquiry, constructed the hermeneutics of the phenomenological life-world of the trajectory of ASC secondary to ABI (Figure 2). In section 7.4, the value and original contribution of this work for healthcare practitioners who support clients and their significant others within the neuroscience, inpatient hospital setting and undergraduate education in healthcare is presented. Section 7.5 details the dissemination strategy and pathway to impact, with recommendations for future research considered in section 7.6. The chapter is summarised in section 7.7.

The thesis is then concluded.

## 7.2 Summary of the '*Meaning Structures'*: Construction of the Hermeneutics of the Life-World of the Phenomenon of an ASC secondary to ABI

### Lived Spatiality

***'Spaces are relationally constituted, contestable and processual. They are***

> ***constituted through the objects and bodies that are placed in the world and the modes of making-sense of the meaning of particular spaces'.***
>
> **(Fuller and Löw, 2017, p. 476)**

The perceptual landscape of ASC was recounted with such detail and imagery that for the duration of ASC it became the focus of the patient's existence and remembered thereafter. For the patient, the territory of ASC presented itself as a bizarre and unorthodox collection of scenarios and characters, the memories of which, for some, continued to be intrusive on recovery. It was in the liminal space of ASC that patients began to 'sense' the landscape of the hospital but their inability to effect contact resulted in feelings of isolation and estrangement. For the witness, the spatial characteristics and qualities of the hospital setting, the physicality of space and the cultural norms which defined space and place, influenced their understanding of ASC throughout its trajectory.

### Lived Corporeality

> ***'Every time we make sense of the world, we rely on our tacit knowledge of impacts made by the world on our body and the complex responses of our body on these impacts'.***
>
> **(Polanyi, 1969, p. 147)**

For the patient, the body *in-ASC* was subjectively experienced but became a body objectified by others. The body's functional and cognitive limitations emerged as the dominant narrative, a body revealed in all its uncertainty, which risked the patient's 'legacy self' being redefined. *In-ASC,* the patient recalled a degree of sentiency and strived to function as their 'legacy self' but in the juxtaposed, liminal space of ASC, self was reflected upon. As Aho (2017, p. 121) poignantly reflects, *the lived body stretches beyond the skin, constituting a dynamic experiential field of meaning'.*

For the witness, ASC presented itself primarily 'through the body' and this embodiment became the focus of their attention. Over time, the witness understood that the body, *in-ASC,* was dynamic, unpredictable, and profoundly revealing. The privileged position held by the witness as the astute observer, was unacknowledged by staff. When behaviours and character traits were recognised as reminiscent of 'legacy self' and privileged as possible evidence of recovery and restitution or cited as concerning, and estranged from 'self', they were dismissed. The witness searched for the 'legacy self' amidst the now unfamiliar body of ASC but became increasingly isolated in their role.

### Lived Temporality

***'Persons as a whole, are beings with emotions, values and purpose, and (importantly) they are temporal beings, beings who interact with their worlds in these ways over time'.***

**(Matthews, 2002, p. 60)**

Time was experienced both objectively through the temporally influenced routines and rituals of the hospital, and autobiographically. *In-ASC*, autobiographical temporality was arrested with patients describing a loss of the sense of time with the 'flow' of time as past, present, and future inextricably reordered. ASC was an untimely interruption to the patient's perception of time, to the extent that their 'place in time' and existence as a temporal, orientated being was questioned. A sense of 'self' and personhood was established when there was continuity of life history. Within the hallucinogenic and delusional landscape time was disordered, the dramas presented as random scenes which failed to respect universal time. Experiences *in-ASC* were so discrete and at times unorthodox that they affected the future narrative of 'self'. *'A valid portrayal of human selves and behaviour necessitates an understanding of the inextricable connection between time and identity'* (Crossley 2000, p. 10). For the patient *in-ASC*, the distortion of time led to a fragmentation of identity and a questioning of who 'self' was and was at risk of becoming.

For the witness, the temporal structures abound within the hospital, contributed to their understanding of ASC with respect to prognosis and recovery. Time *in-ASC*, and its rapidly changing presentation over time, shifted the witness' understanding as to whether recovery and restitution were realised.

### Lived Relationality and Discourse

***'Our affective contact to the environment is essential for our basic sense of reality and belonging to the world'.***

**(Fuchs 2014, p. 406)**

The landscape of the hospital was replete with symbols, dialogue and inferences which provided a script through which the meaning of ASC was realised. For all participants, the relationships developed during the trajectory of ASC were complex and emerging. The patient was immersed in the perceptually disordered landscape, and whilst encounters were at times transitory, they were recalled with impassioned detail. On emergence, within the juxtaposed space, the patient attempted to communicate with others, sought to be recognised and re-engage as their former 'legacy self'.

For the witness, the discourse was revealing and at times, the subtext contradictory. This collective dialogue and engagement with others provided a powerful source of information about recovery, prognosis, and restitution of ‘legacy self’. The ‘legacy self’ of the patient became constituted throughout the trajectory of ASC, messages were internalised, and the narrative of the illness trajectory constructed.

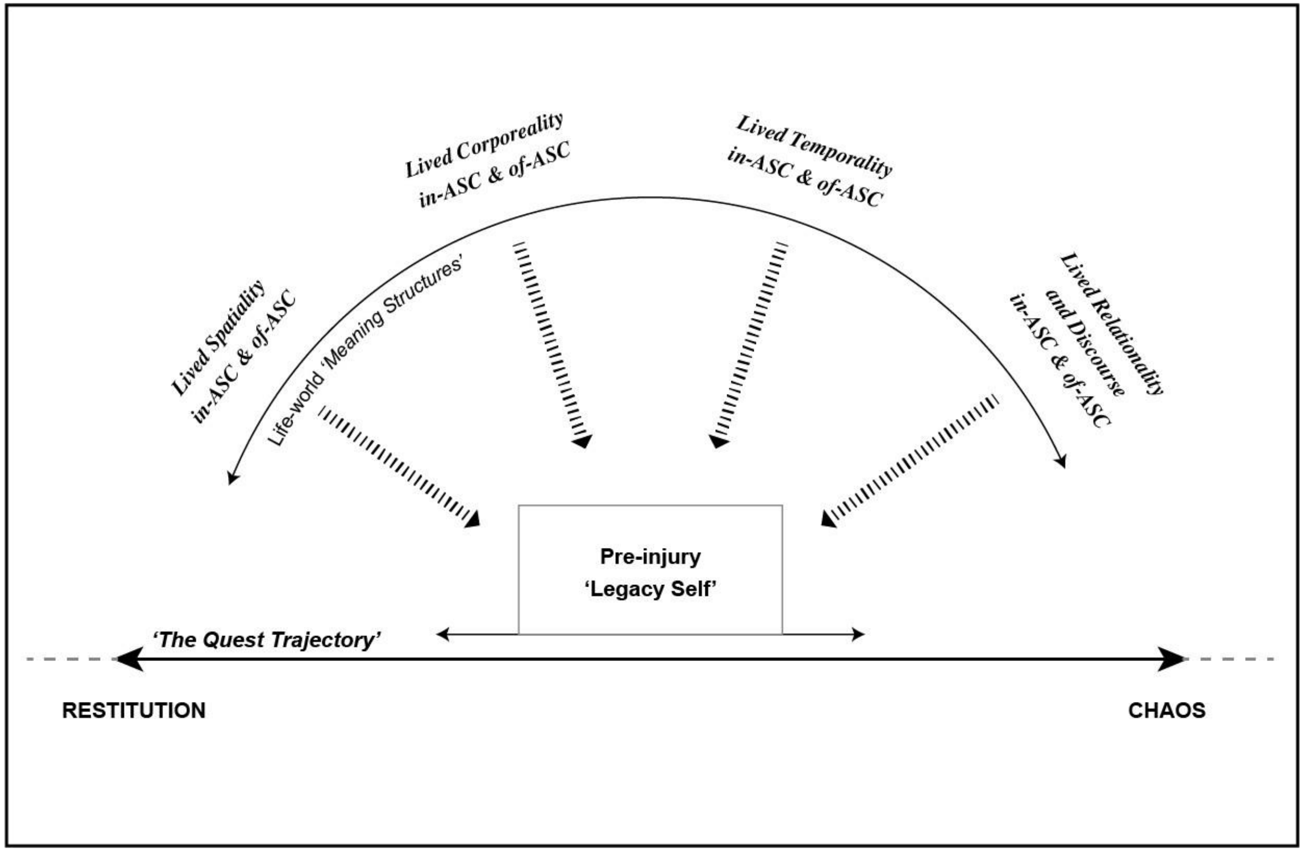
## 7.3 Contribution to Knowledge: The Phenomenological Life-World of an Altered State of Consciousness secondary to Acquired Brain Injury*: The Quest Trajectory’*

The findings of this inquiry explicate how the patient’s construct of ‘self’, identity and personhood were not solely influenced by the functional and cognitive consequences of the ABI, but constituted through the corporeality and embodiment of ASC, the influence of the inhabited lived spaces of the participants’ distinct realities, temporality, the relational dynamics, and the accompanying dialogue. Finding oneself suddenly and unexpectedly situated in the unfamiliar landscape of ASC transformed one’s ‘*being-in-the-world’* and had the potential to reconstruct the patient’s ‘legacy self’, and identity, affect one’s tacit attunement with others, mode of relatedness and inter-subjective relationality. The phenomenon of ASC emerged, not simply as a disordered state of awareness and responsiveness experienced exclusively by the patient, but a lived experience which afforded collective significance, one which was remembered with profound acuity and had consequences for the patient’s sense of ‘self’ and agency. For both the patient and the witness, living-through the phenomenon of ASC resulted in a paradigmatic disturbance of *temporality, corporeality, spatiality, relationality,* and *discourse.* In different contexts and with varying degrees of over-arching influence, these ‘*meaning structures’* served to construct the hermeneutics of ASC and had consequences for the patient’s intersubjectivity, agency and selfhood in the immediacy of ASC through to recovery. The nature of the participant’s trajectory through the phenomenon of ASC was one of ‘*quest*’ or searching. For the patient, the functional and cognitive limitations secondary to the ABI were appraised and strategies employed to present themselves as their pre- injury, ‘legacy self’. The witness’ ‘*quest*’ was notable in their search for, and privileging of, the patient’s ‘legacy self’ amidst the chaotic and unpredictable landscape of ASC. For both participant groups, the emergence and recognition of the patient’s ‘legacy self’ was formative in moving their ‘*quest*’ towards ‘*restitution’*. However, when the patient’s behaviours, character and personality traits and signifiers were dislocated or distanced from their ‘legacy self’, and sense-making did not happen, the narrative moved towards the diametrically opposed, polar position of ‘*chaos*’. Throughout this ‘*quest trajectory’*, the participant’s recognition or otherwise of ‘legacy self’ shifted, and this served to reposition their narratives along the ‘*quest trajectory’*, between ‘*restitution*’ and ‘*chaos*’. Whilst the narrative typologies of ‘*chaos’, ‘restitution’* and *‘quest’* reflect the seminal work of Frank (1995), no other studies to date have recognised how one’s lived experience of the gestalt of the life-world ‘*meaning structures’* of place, body, time, relationality and discourse, influence these narrative typologies in the context of neuropathology, and explicated their relationships along an illness trajectory.

The hermeneutics of the phenomenon of the life-world of ASC, is conceptualised in the development of a model entitled: ‘The Phenomenological Life-World of an Altered State of Consciousness secondary to Acquired Brain Injury*: The Quest Trajectory’* (Figure 2). This model represents the relationships between the first-person accounts of *lived spatiality, corporeality, temporality, relationality,* and *discourse,* on the participant’s journey or ‘*quest*’ throughout the ASC trajectory, the patient’s ‘legacy self’ and the narrative positions of *chaos* and *restitution.*

Appendix 16 summarises the stages of development of the conceptual model as a visual representation of the findings of this inquiry.

**Figure 2: 'The Phenomenological Life-World of an Altered State of Consciousness secondary to Acquired Brain Injury*: The Quest Trajectory***



### 7.4 Contribution to Practice and Education

***'One can strengthen the intimacy of the relation between knowledge and action by re-instating lived experience, itself a valid basis for practical action'.***

**(Van Manen, 1990, p. 155)**

#### 7.4.1 The Hermeneutic Life-World of the Phenomenon of an ASC secondary to ABI

***'Hermeneutics compels us as researchers and users of research to live in the world differently'***

**(Moules *et al*., 2015, p. 191)**

This thesis has demonstrated how powerful and transformative, hermeneutic phenomenology can be in bringing the personal narrative to the foreground and privileging the voice of those who experience an alternate subjective reality secondary to neuropathology. The landscape of the hospital was imbued with meaning, to the extent that for the participants of the study, ASC was contextualised and understood against this biomedical and socio-cultural backdrop. Whilst a diagnosis of ASC cannot be isolated from its positivist definitions and medically informed objective assessments, for participants of this study, ASC was experienced as a highly subjective, transformative, and nuanced way of *being-in-the-world*. Whilst both paradigms are important, that which informs the bio-medical dialogue and the other, the first-person, lived experience, the latter deserves to sit alongside and contribute to the epistemology of ASC.

The aim of this thesis was not to offer a rebuttal to the foundational positivist approach to the study of ASC but present an interpretive, ontological account of ASC, from those who found themselves uniquely positioned amid the phenomenon. The healthcare practitioner is well placed to appreciate the complexities which influence the life-world of ASC for both the patient and the witness. Whilst the 'taken-for-granted' view of ASC as comprising a set of behaviours and functional limitations is clearly one perspective, hermeneutic phenomenology seeks to present a complementary view, one that moves alongside the science of ASC but serves in its aim to contribute to a more nuanced and gestalt meaning of ASC both for those diagnosed and who bear witness:

*'The hermeneutical approach complements that which is ignored by the empiricist approach. In doing so it positions itself neither as a competitor nor as a rival. It merely*

*aims to complement, believing that reality involves more than that which can be processed in an empiricist way'* (Mooiji, 2012, p. 95).

Staff could affect the patient's and witness' movement along the trajectory of ASC towards restitution, by recognising how their relationality and the accompanying dialogue influences the participant's understanding of ASC. Within the context of my work, as one who has cared for individuals with varying degrees of consciousness, I wonder whether health care practitioners 'take for granted' the disembodiment of 'self' both *in-ASC* and on recovery and disregard the person because ASC is a temporary event, one where the 'legacy-self' is likely to re-emerge over time. This is unlike in chronic illness where a reconstructed 'self', contained by adaptation and response to deteriorating health, emerges. This reflects the earlier discussion of Franks' work and the '*restitution narrative'* and Reissman's (1993, p. 3) commitment to narrative inquiry which can be revealing, particularly on the occasions when '*there has been a breach of ideal self and society'*.

### 7.4.2 The Meaning of the Phenomenon of ASC and Implications for Healthcare Practice and Education

In contrast to human science research which informs policies, protocols, and practice, '*phenomenological research gives us a tactful thoughtfulness, situational perceptiveness, discernment and depthful understanding'* (Van Manen, 1990, p. 156), which is central to professional competence and actions, mobilising one's knowledge and understanding of the phenomenology of illness. The findings reveal that despite the privileged immediacy of their relationship, the participants of this inquiry felt that the healthcare practitioner afforded limited attention to their experience of ASC, as they became increasingly embroiled and isolated in the unfamiliar confines of the hospital. The participant's understanding of ASC and the presentation of the patient *in-ASC* fundamentally took place through dialogue, and their observation of the inter-relational behaviours and actions of staff within the socio-cultural and biomedical context of this landscape. On occasions, the witness sensed the patient was objectified by staff who failed to view the 'person' *in-ASC*. Clinical interventions were perceived as task orientated, with priority afforded to the corporeal presentation of the patient *in-ASC* and their functional limitations. The witness became increasingly isolated in their residency at the bedside as they moved through the emotional chaos of expectation and despondency. They were estranged from the 'legacy self' of the patient *in-ASC*, but also unfamiliar with the culturally influenced and ritualistic practices which defined the hospital spaces. Ignoring the personal experience of ASC and allowing the ritualistic practices of the hospital to consume the reality and validity of this discourse, affected the patient's agency and personhood. The findings indicated that there was limited reference made to prognosis and on the occasions, it was alluded to, the information shared was contradictory and ambiguous.

The participant's experience of an ASC was recalled with impassioned detail. The vividness of their memories had not dimmed over time, and still held significance months and years later. Acknowledging the profound and solitary experiences which accompanied ASC as authentic and reflective of their reality at the time, would have re-positioned the participant's autobiography as a primary source of evidence for clinical practice. Stories of ASC need to be believed as authentic experiences, not viewed by the practitioner as simply a temporary interlude along the illness journey but listened to and privileged without challenge or dismissal. Significant chaos is likely to remain if individuals are not given permission to be heard. During their time in hospital, none of the participants had been afforded the opportunity to tell their story and reflect on their experiences. As Frank (1995, p. 23) poignantly reminds us, whilst stories need action, they first '*need a listener'.*

The healthcare practitioner is well placed to recognise that the existential life-world '*meaning structures'* collectively informed the ASC narrative and served throughout '*The Quest Trajectory'* to search for the presence of 'legacy self' and influence the meaning of the patient's sense of 'self' and identity. Affording the participants of this inquiry permission to tell one's story and understanding the risk to an individual's psychological and emotional wellbeing upon discharge, would have contributed to restitution, but also positioned both the patient and their witness as the central characters within the ASC narrative. Clinical management is not solely about responding to the clinical presentation of ASC as an anticipated sequela of an ABI but developing an attunement to the patient's and witness' inter-subjective experiences. Maung's (2012, p. 32) work on the experience of psychosis recognises that recovery is not about the '*silencing of symptoms'* but realised by supporting the '*person's ability to function safely and meaningfully in an intersubjective world*'. Privileging the first-person accounts of an ASC and seeking opportunities for authentic, participatory sense-making would move an individual's *quest* towards *restitution*. For this inquiry, dismissing the experience of ASC and failing to validate the patient's and witness' subjective reality risked leaving them in *chaos*. The actions of staff, and as importantly, their inactions, contributed to the participant's understanding of how ABI and ASC had the potential to affect one's sense of 'self', identity, and restitution, and ultimately predisposed to one's vulnerability both in hospital but on discharge. Healthcare practitioners were frequently described by the witness as berating or reprimanding the patient for their behaviours, which served to define the patient henceforth. In their developing role as an advocate, the witness found themselves challenging the practitioners' perceptions, reminding them that the patient's behaviours, albeit acknowledged on occasions as disruptive and challenging, were uncharacteristic of the patient's former, 'legacy self'. Firstly, healthcare practitioners need to acknowledge that the experiences *in-* and *of-ASC* are profound, that ASC influences the emergence or distancing of 'legacy self' and recognise that the actions and inactions of the healthcare practitioner risk imposing further vulnerabilities on both the patient and the witness. Secondly, the search for the patient's 'legacy self' was fundamental to the witness' and the patient's quest. The search for 'legacy self' became an important endeavour for the witness but was rarely acknowledged by staff as central to the restitution narrative. When character traits and behaviours of the patient are recognised as reminiscent of their 'legacy self', these need to be acknowledged and endorsed as reassuring evidence that 'self' remains.

### 7.4.3 Challenging the '*Natural Attitude*' of the Healthcare Practitioner

***'The challenge to medicine, then, is to recognise the limits of methodologism not because it is ineffective but because it invariably distorts and covers over the experience of 'what it means' and 'what it feels like' to be ill'***

**(Aho, 2017, p. 125)**

In the context of this inquiry, the hermeneutics of illness has offered a perspective of the complexities of the distinct realities of ASC, secondary to ABI. The participant groups found themselves embroiled in a remote and uncompromising landscape, which had to be negotiated through at a time when they were at their most vulnerable. Unless there is a commitment to the privilege the hermeneutics of illness, to hear the profound messages which emerge, and understand how illness risks the disruption of the life narrative, then it is not surprising the long-term narrative risks becoming one of *chaos*. Participants like Carol and Paul were able to assert their influence and sought a degree of mastery and control through the *chaos*, and advocate for their loved ones. Others like June, Barry, Salar, and Sarah, were left stranded, vulnerable, and struggling with the deference of staff.

Despite an increasing interest in illness narratives as a source of evidence, health care practitioners and educators working in the field of clinical neurosciences, need to make a paradigm shift by developing a commitment to the hermeneutic tradition, a philosophical approach to research which seeks to understand the meaningfulness of the life-world of illness. The alternative risks homogenising medical diagnoses to one description. Both the healthcare practitioner and educator are uniquely positioned to further the co-creation of meaning of illness through hermeneutic work and recognise the utility of narrative testimony as a valid contribution to the ontology of illness. The alternative is the medicine threatens *'to expunge its primary subject – the living, experiencing patient'* (Leder, 1999, p. 9).

I was invited on several occasions to share my initial findings with clinical staff who worked within the acute, inpatient critical care, and neuroscience services. I sensed that staff tended to pathologise ASC, expecting me to relate solutions or how they might best 'manage' those *in-ASC*. Staff appeared defensive and suspicious of my agenda, initially reticent to hear how the actions and behaviours of the healthcare practitioner, albeit well intentioned, had been perceived by the participants of the study. I recognised that colleagues perhaps *'work within a culture that imposes many taken-for-granted assumptions'* (Clegg 2004, p. 186). I hoped staff would engage with the narratives, acknowledge the transformative power of the lived experience and in doing so, appreciate how hermeneutics has the potential to compel the '*users of research to live in the world differently*' (Moules *et al.,* 2015, p. 191. The participant's use of metaphor during the interviews continued to engage me and seemed to hold a linguistic power of their own. The phenomenological text did indeed, '*seduce me with its familiarity and provoke me with its otherness'* (Schuster, 2013, p. 198) and I hoped staff would feel the same. With permission from the participants, relaying aspects of their narratives helped to 'open up their thinking', and reflected Abma's (1990, p. 191) position that '*transformations of a professional's practice start with the confrontation of ambiguity'*. At the time, I had unknowingly invited them to enter the 'hermeneutic circle'. Through discussion, their '*taken-for-granted'* (Van Manen, 2014, p. 298) assumptions and '*natural attitude'* (Moran and Mooney, 2002, p. 5) of the patient's and witness' lived experience of ASC, were challenged personally and professionally. They began to acknowledge their prejudices and develop a '*phenomenological attitude*' (Van den Berg, 1972, p. 77), a new horizon of thinking. My experience during these sessions reflected Koskinen and Nyström's (2017, p. 178) concept of the '*hermeneutic room'*, a place where '*discussion between different horizons, theory and praxis may take place',* a space *'created by the people who through dialogue are characterised by presence, openness, wonder and searching'.* Educationalists working within the field of clinical neurosciences and undergraduate healthcare provision are well placed to develop the concept of the '*hermeneutic room'* as a metaphorical 'space' in which health and social care practitioners could develop their understanding of the philosophy of illness, reflect on their '*natural attitude'* and challenge their '*prejudices*'. The seminal works of Gallagher and Zahavi (2008, p. 24) advocate that by making a '*distinction between the* *subject conceived as an object within the world and the subject conceived as a subject for the world*', phenomenology can move the practitioner to a more person-centred appreciation of the first-person perspective.

Narrative pedagogy (Diekelmann, 2001; Goodson and Gill, 2011; Goodson and Scherto, 2014; Nehls, 1995) is a form of inquiry which invites the learner to critically reflect and analyse the individual's biographical, narrational experiences. Working with narratives is '*profoundly humanising'* (Goodson and Scherto, 2014, p. 2) and has the potential to shift the learner's self-narrative by '*providing opportunities to 'dis-embed stories from certain underpinning assumptions and beliefs and deconstruct the script we might have uncritically inherited*' (Goodson and Scherto, 2014, p. 94). The conceptual model 'The Phenomenological Life-World of an Altered State of Consciousness secondary to Acquired Brain Injury*: The Quest Trajectory',* presented in this thesis as an original contribution to knowledge, could be adopted as a tool to support the pedagogy and practice of practitioners and under-graduates in healthcare. Encouraging reflexivity and the critical engagement with biographical narratives has the potential to challenge assumptions and shift perceptions of the priorities of care and develop person-centred support strategies in the immediacy of the post-injury ABI trajectory.

### 7.4.4 The Utility of the Conceptual Model - 'The Phenomenological Life-World of an Altered State of Consciousness secondary to Acquired Brain Injury: *The Quest Trajectory*'

The findings of this inquiry have recognised that attending to the meaningful-ness of illness (Broom, 2007) rather than the objective observation of the manifold symptomatology of disease moves attention away from the bio-medical paradigm. For the participants of this study, the construction of meaning of ASC was constituted through the unfolding of the philosophical life-world '*meaning structures'* : *spatiality, corporeality, temporality, relationality* and *discourse*.

Understanding the experiential structures of meaning which comprise the life-world of individuals has been advanced in the field of psychopathology (Fuchs, 2010a; Gallagher and Zahavi, 2012; Garza and Landrum, 2015; Mancini *et al*., 2014; Stanghellini and Ballerini, 2004; Stanghellini and Mancini, 2017; Zahavi, 2005). By accepting that '*each psychopathological experience is accompanied by a personal meaning or value that the person attributes to it'* (Stanghellini and Mancini, 2017, p.15), then an individual's lived experience becomes accessible. Stanghellini and Rossi's (2014, p. 240) work on schizophrenia recognises the limits to the diagnostic assessment of the symptomatology of disease, by characterising the '*trait-like features'* of the personal '*experience and action'* of the life-world of schizophrenia as an individual's unique '*pheno-phenotype'.*

The development of the '*Abnormal Bodily Phenomena Questionnaire'* (Stanghellini, Ballerini and Cutting 2004) encourages the individual diagnosed with psychosis secondary to schizophrenia, to rate the frequency and the subjective nature of their perceptual disorders, and the impact on their sense of self and agency. Parnas *et al*., (2005) developed the *'EASE': Examination of Anomalous Self-Experience',* a more comprehensive symptom checklist which assesses the extent to which the subjective experiences of disorders of self-awareness, commonly seen in schizophrenic spectrum disorders, affect one's construct of self and identity. More recently, Sass *et al.*, (2017) developed a phenomenological-informed interview / assessment tool known as the EAWE (The Examination of Anomalous World Experience: EAWE) to assess an individual's disturbances in the lived-world of psychopathology.

In clinical neurosciences, assessment tools principally measure the degree to which wakefulness and awareness are affected by an ABI, from the outsider perspective. Limited attention is paid in supporting patients to reflect upon and articulate their experiences of ASC on recovery. Similarly, there is no formal assessment which captures the lived experience of those who are witness to the behaviours manifested *in-ASC.* 'The Phenomenological Life-World of an Altered State of Consciousness secondary to Acquired Brain Injury*: The Quest Trajectory'* could be developed as an assessment tool within neuroscience clinical practice to support the articulation of first-person accounts and assess the extent to which space, body, time, relationality and discourse, influence, impact and characterise the experience of ASC. The outcome of the assessment could inform the implementation of psychological and behavioural support strategies to limit the extent and nature of '*chaos*' in the immediacy of the ABI trajectory, following recovery from ASC and upon discharge from services.

### 7.5 Dissemination Plan and Pathway to Impact

This section envisions the dissemination plan, pathway to knowledge exchange and the potential reach and scope of impact.

The development of an '*interest-influence matrix*' (Reed, 2016, p. 115) (see Appendix 17) served to initially identify, categorise, and prioritise the potential stakeholders, collectively defined as individuals, groups, or organisations who may have interest and influence, lay claim, or be affected by research outputs (Bryson, 1995; Freeman, 1984; Reed, Bryce and Machen, 2018). Since the inception of this inquiry, there has been significant interest and curiosity from individuals and stakeholder communities as to the aim, context, and pragmatics of the conduct of the research. Dialogue with stakeholder groups across clinical neuroscience communities, and voluntary and third sector organisations who have supported the study have, to date, been formative in identifying opportunities for the dissemination of findings of this inquiry. A scoping exercise has been undertaken with regional neuroscience units and providers of inpatient neurological services to evaluate how engagement with relevant stakeholder groups at both operational and strategic levels could be advanced. The development of a '*hermeneutic room*' (Koskinen and Nyström, 2017, p. 178) discussed in section 7.4.3, with healthcare practitioners is in its infancy, and collaborative discussions with clinical leads aims to consider pragmatically how a pathway of engagement to facilitate knowledge exchange, impact and influence could be envisioned. A dissemination plan involves the forging of alliances with academics whose interests lie in the symptomatology of ABI, and ASC across a range of neuropathology and other aetiologies. Developing educational and clinical opportunities to empower and engender individuals to engage in critical discourse have the potential to drive change at a personal and organisational level, influence policy and strategic decisions and advance scholarship in the field of clinical neurosciences.

The publication of the findings of the inquiry will be advanced through outputs in scholarly and discipline-focused publications, particularly those applicable to the ABI and neuroscience community.

## 7.6 Future Research

The following section considers the directions for future research.

### 7.6.1 Exploration of the Meaning of ASC from the Perspective of Healthcare Practitioner.

The actions and behaviours of the healthcare practitioner within the landscape of the hospital emerged as highly formative in the construction of the meaning of ASC for the participants of the study. The practitioner's relationality and associated discourse informed movement along the '*Quest Trajectory'*. From the participants' perspectives, the practitioner emerged as a central character within their narratives. Research to understand the meaning of ASC, and what constitutes the chaos and restitution narratives from the healthcare practitioner's perspective, would contribute to the collective construction of the hermeneutics of ASC.

### 7.6.2 The 'Legacy Self'

The term 'legacy self' was introduced within this thesis as a theoretical definition to further conceptualise the term '*pre-injury self'* originally proposed by Cantor *et al.,* (2005). Further research is needed to explore the patient's and layperson's perceptions of this term and establish the feasibility of its adoption within the wider brain injury community as to whether it better represents the lived experience of the character traits, identity signifiers, behaviours, and presentation of 'self', prior to the ABI.

### 7.6.3 The Subtext and Messages in Dialogue, Silence, and Actions: The ‘Hidden Dialogue’

The findings of the study revealed that the meaning of ASC evolved not solely through communication with the practitioner but also through a lack of dialogue and what was inferred by the situated subtext, inferences, and the silences. The hospital landscape and the inter-relational dynamics along with the institutional cultures and practices informed the participant’s understanding of the diagnosis and prognosis of ASC. Whilst practitioners might assume information disclosure is the primary source through which the patient and witness come to learn about diagnosis and prognosis, the study has revealed that knowledge acquisition is far more complex and nuanced. Further research is needed to explore the nature and context of the subtext, inferences, and silences and how these influence the patient’s and layperson’s understanding and assimilation of knowledge of the inpatient experience.

### 7.6.4 The Life-World of Prolonged and Deteriorating ASC

Unlike dementia where ‘legacy self’ emerges intermittently but becomes increasingly and irreversibly lost amongst the cognitive and functional decline, this inquiry has demonstrated that living-through a transitory state of altered consciousness, restitution is achieved when ‘legacy self’ of the patient is recognised or restored. Understanding the influence of spatiality, corporeality, temporality, relationality, and discourse, on one’s interpretation of consciousness when it deteriorates over time or in ‘Prolonged Disorders of Consciousness (PDOC) would contribute to the evidence base for practice. Similarly, the hermeneutic approach to life-world research in the context of the illness trajectory, and an understanding of the influence of the ‘*meaning structures*’ could be adopted to explore the meaningful-ness of illness in the context of other neuropathological disease trajectories.

Whilst no hierarchy to the ‘*meaning structures’* emerged in the construction of meaning of ASC, it would be interesting to establish whether there are interpretive positions in which one is privileged over another, and whether the emergence of a hierarchical order shifts meaning, and one’s interpretation of the meaning of disease.

### 7.6.5 Defining Disease: The Synonymic Challenge and Understanding Interpretive Difference

This inquiry has proposed a re-defining of an ‘*Altered State of Consciousness’* secondary to neuropathology, as an ‘*Alternate Subjective Reality*’ to better represent the first-person perspective of perceptual disturbances. Further research needs to focus on how the diagnostic labels which classify neuropathology are interpreted by the patient, layperson and professional, and establish whether interpretive positions or labelling disparities, influence the illness narrative and the construction of meaning of disease.

## 7.7 Chapter Summary

Chapter seven has synthesised the findings of this inquiry as an original contribution to knowledge. The existential, life-world structures: *spatiality, corporeality, temporality, relationality,* and *discourse* which constructed the meaning of the phenomenon of an ASC secondary to ABI for both participant groups, is conceptualised in a model entitled: 'The Phenomenological Life-World of an Altered State of Consciousness secondary to Acquired Brain Injury*: The Quest Trajectory'.* This model provides a visual representation of the gestalt of influences which informed the narrative positions of the patient and the witness throughout the ASC trajectory. These life-world '*meaning structures'* independently and collectively influenced participants' perceptions and sense-making regarding the recognition and recovery of the patient's 'legacy self', identity, and personhood along the '*Quest Trajectory'*. This trajectory situated participants between one of two, diametrically opposed narrative positions, defined as '*chaos*' or '*restitution*'. Throughout the '*Quest Trajectory'*, the patient's pre-injury, 'legacy self' was searched for, and privileged. The construction of the patient's 'self', identity and personhood was not solely determined by the pathological changes associated with an ABI but constructed throughout the complex and formative trajectory of ASC.

The original contribution to knowledge is summarised as:

The hermeneutics of the phenomenon of the life-world of ASC, is conceptualised in the development of a model entitled: 'The Phenomenological Life-World of an Altered State of Consciousness secondary to Acquired Brain Injury*: The Quest Trajectory'*. This model represents the relationships between the first-person account of *lived spatiality, corporeality, temporality, relationality,* and *discourse,* on the participant's journey or '*quest*' throughout the ASC trajectory. In the acute phase of the ABI trajectory, the existential life-world '*meaning structures'*: *spatiality, corporeality, temporality, relationality* and *discourse,* independently and collectively influenced the construction and interpretation of the meaning of a transitory experience of an ASC within the inpatient, acute clinical setting for the patient and the layperson witness. Whilst an ABI risks the transformation of the patient's pre-injury, 'legacy self', identity and personhood, the hermeneutics of a transitory period of ASC directly contributed to and compounded the reconstruction of the patient's 'legacy self' and identity transformation. Throughout the trajectory of ASC, the patient's 'legacy self' is situated along a '*Quest Trajectory'* between the narrative positions of *chaos* and *restitution.*

The findings of this inquiry have implications for healthcare practitioners working in the field of clinical neurosciences, and educational provision. The contribution to practice and education are summarised as follows:

- This inquiry has presented the hermeneutics of the phenomenon of a transitory period of an ASC secondary to ABI, from the patient's and witness' perspective. By adopting the '*phenomenological attitude*' and a philosophically-informed approach to care, the healthcare practitioner would be better positioned to appreciate how the ontological, experiential '*meaning structures*': *spatiality, corporeality, temporality, relationality* and *discourse*, influence the individual's construction and interpretation of meaning of ASC and the risk to 'legacy self' throughout the post-ABI trajectory.
- The findings of this inquiry challenge the '*natural attitude'* of healthcare practitioners and educators embedded in the positivist discourse of the symptomatology of ASC secondary to ABI, to move towards a more philosophically informed narrative position.
- As an original contribution to knowledge, the model: 'The Phenomenological Life-World of an Altered State of Consciousness secondary to Acquired Brain Injury: *The Quest Trajectory*' conceptualises the findings of this inquiry and has the potential to be developed as an assessment tool to support individuals in articulating their subjective experience of ASC. The outcome of the assessment would enable the healthcare practitioner to better appreciate how the existential structures of space, body, time, relationality, and the associated discourse construct the meaning of an ASC secondary to ABI and inform the delivery of focused psychological and behavioural support strategies in the immediacy of the ABI trajectory, following recovery from ASC and upon discharge from services.

## Concluding Remarks

This inquiry contributes to the body of evidence by attending to the voice of the post-injury trajectory of ABI and acknowledging the complexity of the ASC autobiographical narrative as it is fundamentally 'lived through' within the acute, inpatient hospital setting. The findings provide a unique contribution to the hermeneutics of the phenomenon of an ASC in the context of ABI, not previously examined from an interpretive, philosophical position. An ASC was a profound and uncompromising life-world experience, which had for the participants of this study, significance in the immediacy of the ABI trajectory and beyond. The first-person experience of the existential '*meaning structures': temporality, corporeality, spatiality, relationality, and discourse,* during a transitory period of ASC were profoundly influential in the unfolding and constitutive perception of the patient's pre-injury, 'legacy self', personhood and identity.

An ASC was not simply an anticipated manifestation of ABI but afforded meaning 'in and of itself'. It was the lens through which the patient and their significant others experienced and constructed 'self' and identity. Ignoring this 'lived-through' experience as a transformative state of being secondary to an ABI, risked leaving the participants of this inquiry in '*chaos*' and limiting the patient's agency and sense of self during the acute inpatient admission and upon discharge. Understanding the narrative threads which constructed the rich tapestry of the patient's and witness' phenomenological experience of an ASC have the potential to shift the perceptions of the healthcare practitioner, who is in the privileged position of supporting individuals and significant others throughout the post-ABI trajectory.

No other studies to date have recognised the extraordinary life-world of ASC and how the existential '*meaning structures'* served to construct and inform the participant's emerging narrative. ASC was not simply a transitory alteration in the patient's and witness' perception of reality but a formative experience which resided with them and had consequences for the patient's identity and future positioning and construct of 'legacy self'. Understanding the hermeneutics of the phenomenon of ASC from both the patient's and the witness' perspective repositions the narrative in the hierarchy of evidence and contributes to the epistemology of the care of individuals who experience an ASC secondary to neuropathology. The findings have implications for healthcare practitioners and educators within the field of clinical neurosciences.

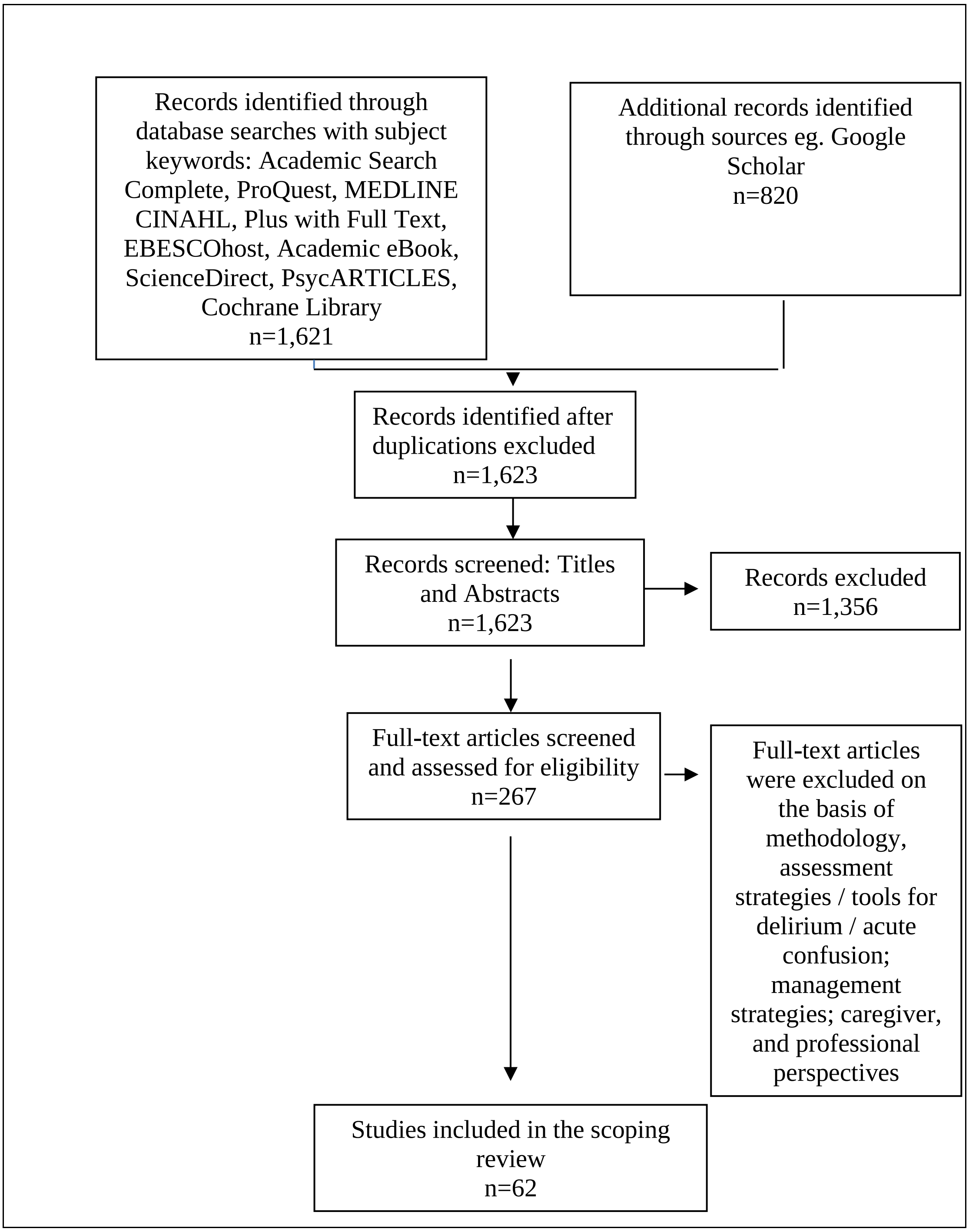
I am indebted to the participants of this inquiry who gave of themselves, freely and unconditionally. They have inspired me personally and professionally in many ways, not least to continue to advocate for those who experience an alternate subjective reality as a corollary to ABI, but challenge those embedded in the positivistic, biomedical paradigm to privilege and respect the hermeneutics of the illness narrative as a compelling and authoritative voice.

As I conclude this thesis, I would like to share Burch's (1989, p. 192) quote which poignantly captures the power of phenomenology, and has stayed with me throughout this journey:

> ***'Phenomenology does not simply iterate what is already given and understood in lived experience in the way it is given and understood, it seeks a transcending, theoretical understanding that goes beyond lived experience to situate it, to judge it, to comprehend it, endowing lived experience with new meaning'.***

| **APPENDIX 1: PRISMA EXTENSION FOR SCOPING REVIEWS (PRISMA-ScR): Explanation and Elaboration (Tricco *et al.*, 2018)** | |
|---|---|
| *Item 1* | Title |
| *Item 2* | Structured Summary |
| *Item 3* | Rationale |
| *Item 4* | Objectives |
| *Item 6* | Eligibility Criteria |
| *Item 7* | Information Sources |
| *Item 8* | Search |
| *Item 9* | Selection of Sources of Evidence |
| *Item 10* | Data Charting Process |
| *Item 11* | Data Items |
| *Item 12* (Optional) | Critical Appraisal of Individual Sources of Evidence |
| *Item 18* | Characteristics of Sources of Evidence |
| *Item 20* | Results of Initial Sources of Evidence |
| *Item 24* | Summary of Evidence |

## APPENDIX 2: Illustration of *Item 10* (PRISMA-ScR): Selection of Sources of Empirical Evidence: The Patients' Perspectives of an Altered State of Consciousness



## APPENDIX 3: Illustration of *Item 18* (PRISMA-ScR): Characteristics of Sources of Evidence (Bibliographic Matrix Summary): The Patients' Perspectives of an Altered State of Consciousness

| Study / Reference Citation | Aim / Objectives | Design<br>Data Collection | Sample | Key Findings |
|---|---|---|---|---|
| Anderrson, E.M., Hallberg, I.R., Norberg, A., and Edberg, A.K. (2002) 'The Meaning of Acute Confusional State from the Perspective of Elderly Patients'. *International Journal Geriatric Psychiatry* July 17(7) pp. 652-663 | To explore the older person's lived experience on recovery from an acute confusional state in the acute orthopaedic ward. | Hermeneutic Phenomenology<br>Narrative Interviews | N=50 (67-96 years of age) | Vivid recall of memories during acute confusion, collection of unreal and real experiences, difficulty in understanding boundaries of reality. Recommendations: support patients with recall of experiences during confusional state and on recovery. |
| Belanger, L., and Ducharme, F. (2011) 'Patients and nurse's experiences of delirium: a review of qualitative studies. *Nursing in Critical Care* Vol 16, No 6, pp. 303-315 | Review of qualitative studies of the experiences of individuals diagnosed with delirium and nurse's perspectives | Literature Review | | Failings of nurses to comprehend the patient's experience of discomfort secondary to delirium with limited consensus of strategies for support. Recommendations include the need to understand and support individuals and seek opportunity to encourage reflection and recall of experiences |
| Boehm, L.M., Jones, A.C., Selim. A.A., Virdun, C., Garrard, C.F., Walder, R.L., Ely, E.W., Hosie, A. (2021). Delirium-related distress in the ICU: A Qualitative Meta-analysis of Patient and Family Perspectives and Experiences. *International Journal of Nursing Studies.* Volume 122, October. 104030 | Review of qualitative findings of the patient's and family's experience of delirium-related ICU distress. | Systematic Review | N=13 | Distress and emotional responses to ICU-deliriium common. Patients and families value human empathy and kindness. Need to acknowledge the many facets of delirium-related distress during critical care. |
| Breitbart, W., Passik, S., Gibson, C., and Tremblay, A. (2002) 'The Delirium Experience: Delirium Recall and Delirium-related distress in Hospitalised Patients with Cancer, their Spouse/Caregivers and their Nurses'. | Systematic examination of the experience of delirium from the perspective of hospitalised patients | Delirium recall assessed by Delirium Experience Questionnaire | N=154 | On recall, delirium distress significant for all participants. Prompt recognition and treatment of delirium is critically important to reduce suffering and distress. |

| | | | | |
|---|---|---|---|---|
| *Psychosomatics*, 43, pp. 183-194 | admitted with cancer diagnosis, spouse/caregivers and primary nurses | (DEQ) | | |
| Crammer, J.L. (2002) ‘Subjective Experience of a Confusional State’. *British Journal of Psychiatry*, 180, pp. 71-75 | Autobiographical reflection of impairment of consciousness, cognition and memory during hospital admission | Autobiographical account | | Detailed profound experiences during confusional state. Need to rationalise experiences |
| Cuthbertson, B., Hull, A., Strachan, M., and Scott, J. (2004) ‘Post-Traumatic Stress Disorder after Critical Illness required Intensive Care’. *Intensive Care Medicine.* 30(3), pp. 450-455 | To establish incidence and severity of symptoms related to the diagnosis of post-traumatic stress disorder (PTSD) in a cohort of general ICU patients. | A prospective cohort study 3 months after general ICU discharge. Telephone assessment using Davidson Trauma Scale | N=78 | High incidence of symptoms consistent with PTSD & psychological morbidity 3 months after ICU discharge. Incidence prevalent in younger patients and those who sought GP or mental health support with psychological symptoms. |
| Daffurn, K., Bisho, G.F., Hillman. K.M., and Bauman, A. (1994) ‘Problems following discharge after intensive care’. *Intensive and Critical Care Nursing* 10, pp. 244-251 (Sydney, Australia) | Identify and describe the sequelae of ICU admission, 3 months post-discharge. | Longitudinal (6 month) study Qualitative, Semi-structured Interview | N=54 | Patients returning to pre-admission health status but reported mild-moderate physical and psychological sequelae, sleeping difficulties, fatigue. 30% reported depression, irritability, loneliness; 34% - no recall of ICU admission; 29.6% reported unpleasant memories including nightmares and hallucinations. Over 75% required referral to specialist services or targeted support. A more comprehensive discharge process recommended. |
| Danon, L.M. (2016) ‘Between My Body and My ‘Dead Body’: Narratives of Coma. *Qualitative* | Explore corporeal experiences during | Qualitative narrative | N=17 | Identification of narrative protagonists: ‘*dead-alive’,* |

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| *Health Research*, 2(2), pp. 227-240<br>(Israel) | coma states and rehabilitation. | methodology. | | *'rational'* and '*emissaries*' |
| Darbyshire, J.L., Grig, P.R,. Vollam, S., Young, J.D., Hinton, L. (2016) 'I Can Remember Sort of Vivid People…but to me they were Plasticine'. Delusions on the Intensive Care Unit: What do Patients Think is Going On? *PLOS ONE*, *11*(7). | Personal experiences of sleep and delirium | Secondary of analysis of interviews | N=77 | Description of a liminal existence, threshold of consciousness and sense of self exposed.<br>Degree of disorientation unacknowledged by practitioners.<br>Recommend early psychological interventions |
| Ely. E.W., Siegel, M.D., Inouye, S.K. (2001a) 'Delirium in the Intensive Care Unit: An Under-Recognised Syndrome of Organ Dysfunction'. *Seminars in Respiratory and Critical Care Medicine*. 22 (2). pp. 115-126 | Review of delirium definitions, presentation, assessment tools and pharmacological management for ICU nurses and physicians | Literature Review | | A discussion paper which reviews definition and salient presentations associated with delirium, assessment tools and ICU management. |
| Ely, E.W., Inouye, S.K., Bernard, G.R., Gordon, S., Francis, J., May, L., Truman, B., Speroff, T., Gautam, S., Margolin, R., Hart, R.P., and Dittus, R. (2001b) 'Delirium in mechanically ventilated patients – validity and reliability of the confusion assessment method for the Intensive Care Unit (CAM-ICU). *Journal of the American Medical Association*, 286(21), pp. 2703-2710 (USA) | To validate a delirium assessment instrument for the ICU-ventilated patient and establish the rate of occurrence of delirium | Prospective cohort study | N=111 | Established that the CAM-ICU tool has validity and reliability in the diagnosis of ICU-delirium and has utility for research and clinical purposes. |
| Ely, E.W., Margolin, R., Francis, J., May, L. Truman, B., Dittus, R., Speroff, T., Gautam, S., Bernard, G.R., Inouye, S.K. (2001c) 'Evaluation of delirium in critically ill patients: validation of the Confusion Assessment Method for the Intensive Care Unit'. *Critical Care Medicine* 29(7), pp. 1370-1379 | To examine the relationship between the Intensive Care Unit-delirium experience and outcomes | A prospective cohort study | N=48 | Mean onset of delirium 2.6 days.<br>Mean duration 3.4 +/- 1.9 days.<br>81.3% (39) developed delirium.<br>Duration of delirium correlated with the length of stay in the ICU. |
| Fagerberg, I., and Jonhagen, M.E. (2002) 'Temporary Confusion – a Fearful Experience'. *Journal of Psychiatric and Mental Health Nursing*. Vol 9, pp. 339-346 | Lived experience of the older person's experience of acute confusional state on | Qualitative: Phenomenology. Interview | N=5 | *'Being temporarily confused' and 'Reasoning* about experiences of temporary confusion |

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| | recovery. | | | |
| Fuller, V. (2016). Delirium Recall – An Integrative Approach. *Journal of Clinical Nursing.* Vol. 25 (11-12), pp. 1515-1527 | Review of delirium recall & related experiences | Literature Review | N=12 | Delirium recall: perceptual disturbances and psychological distress. Common themes: incomprehensible experiences, strong emotional feelings and fear. |
| Gaete Ortega, D., Papathanassoglu, E., and Norris, C.M. (2020) 'The Lived Experience of Delirium in Intensive Care Unit Patients: A Meta-Ethnography, *Australian Critical Care,* 33(2), p. 193-202. | Synthesise of qualitative findings on patients' lived experience of delirium in the intensive care unit (ICU) and to identify meanings and potential existential issues that affect them during and after their experience. | Meta-ethnographic synthesis | N=9 | Existential themes of uncertainty, self-perceived helplessness and death result in delirium being a highly distressing experience. |
| Granberg, A., Bergbom-Enberg, I., and Lundberg, D. (1998) 'Patients' experience of being critically ill or severely injured and cared for in an intensive care unit in relation to the ICU syndrome'. Part 1. *Intensive Critical Care Nursing* 14(6), pp. 294-307 | Describe patients' experiences and memory recall, during and after a stay in the ICU. | Qualitative Hermeneutic Phenomenology Interview (1 and 4-8weeks following discharge) | N=19 | Person descriptions of chaos, vulnerability, fear and instability. Nursing staff influential in providing security and support, and limiting psychological impact of admission and ICU syndrome |
| Granberg, A., Bergbom-Endberg, I., and Lundberg, D. (1999) 'Acute Confusion and unreal experiences in intensive care patients in relation to the ICU Syndrome'. Part II Intensive and Critical Care Nursing 15 (1), pp. 19-33 | Examine the patient's experiences of an acute confusional state and associated disorientation and perceptual disturbances during and following an ICU stay. | Qualitative Hermeneutic Phenomenology | N=19 | Personal descriptions of fear during ICU syndrome, loss of control and trust in others. The intensity and duration of the patient's experiences can be prevented by the development of caring relationships by nurses and relatives. |

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| Griffiths, R.D., and Jones, C. (2007) ‘Seven Lessons from 20 years follow-up of intensive care unit survivors’. *Current Opinions in Critical Care*, 13, pp. 508-513 | Exploration of historical and contemporary evidence relating to the consequences of ICU admission | Position paper / Literature Review. | | Greater appreciation of the physical, psychological, and cognitive problems following critical care admission<br>Early and active approach to rehabilitation for patient and involvement of family in decision making, to optimise recovery |
| Grover, S and Shah, R. (2011) ‘Distress Due To The Delirium Experience’, *General Hospital Psychiatry*. 33(6), pp. 637-639. | Level of distress examined of delirium after recovery | Mixed Method Questionnaire | N=53 | Those who could remember delirium experience (28.3%) had moderate (26.7%), severe (40%) and very severe (33.3%) level of distress, describing it as a state of fearfulness, anxiety, confusion and feeling strange, hallucinations and illusions. |
| Harding, R., Martin, C., Holmes., J. (2008) Dazed and Confused: Making Sense of Delirium after Hip Fracture. International Journal of Geriatric Psychiatry, 23 (9), pp.984-986 | Understanding of delirium experience | Interpretative Phenomenological Analysis | N=9 | Patients struggle to comprehend the experience of delirium. |
| Instenes, I., Gjengedal, E., Eide, L., Kuiper, K.K.J., Ranhoff, A.H., Norekyal, T.M. (2017) ‘Eight Days of Nightmares…’ Octogenarian Patients’ Experiences of Postoperative Delirium after Transcatheter or Surgical Aortic Valve Replacement. *Heart, Lung & Circulation.* Vol. 27 (2). Pp. 260-266 | To explore the patient’s experience of postoperative delirium | Qualitative<br>(6 and 12 months post-discharge) | N=10 | Profound and distressing memories post-discharge |
| Johnston, L.B. (2011) ‘Surviving Critical Illness: A Case Study in Ambiguity’. *Journal of Social Work in End-of-Life and Palliative Care*, 7, pp. 363-382. | To investigate the psychological ambiguities on recovery from a period of critical illness. | Qualitative Case Study approach | | The emergence of constructs which included the concept of liminality, and ambiguous dying and loss |
| Jones, C. (2007) ‘Memories of Critical Illness: what do we know?’ *Acta Anaesthesiologica Scandinavica* 51, pp. 653-654 | Review of strategies to reduce incidence of ICU sequelae and propose | Editorial paper / Position paper | | Need to review sedation protocols in ICU to reduce incidence of delusional memories / |

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| | future research | | | hallucinations.<br>Examine interventions e.g. ICU diaries, through quantitative methodology to establish effectiveness in resolution of experiences in ICU |
| Jones, C., Griffiths, R.D., and Humphris, G. (2000) ‘Disturbed Memory and Amnesia related to Intensive Care’. *Memory* 8, pp. 79-84 | To investigate the nature and extent of ICU memories following critical illness. | Systematic Review | N=25 | Delirium and sleep disturbances prevalent in ICU, exacerbated by medication use. Hypnagogic hallucinations and delusion memories prevalent rather than factual recall of events.<br>Memories likely to have impact on psychological health. |
| Jones, C., Griffiths, R.D., Humphris, G., and Skirrow, P.M. (2001) ‘Memory, Delusion and the Development of Post-Traumatic Stress Disorder-related Syndrome after Intensive care’. *Critical Care Medicine* 29, pp. 573-580 | A prospective study to examine the relationship between the levels of anxiety and development of PTSD-related symptoms, and memories of an ICU admission. | Case Series.<br>Mixed Method | N=45 | Factual memories correlated with less anxiety and PTSD-related symptoms than delusional memories. |
| Kiekkas, P., Theodorakopoulou, G., Spyratos, F., and Baltopoulos, G.I. (2010) ‘Psychological distress and delusional memories after critical care: a literature review’. *International Nursing Review*, Vol 57, Issue 3, pp. 288-296 | Investigate and synthesise existing literature relating to delusional memories of adults admitted to ICU and the associated psychological distress. | Literature Review | N=10 | Recall of delusional memories associated with increased risk of Post-Traumatic Stress Disorder related symptoms. Further research to establish correlation with other psychological disorders. |
| Kuusisto-Gussman, E., Hőckelmann, C., Von der Lűhe, V., Schmadig, R., Baltes, M., Stephan, A. (2021) Patient’s Experiences of Delirium: A Systematic Review and Meta-Summary of Qualitative Research. Journal of Advanced Nursing. 15 May: 1365-2648 | Review of delirium experiences | Systematic Review & Meta-summary | N=24 | Range of themes emerged which reflected altered in perception, emotional effects, engagement with others and effect on future life. |

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| Kvale, R., Ulvik, A., and Flatten, H. (2003) ‘Follow-up after Intensive Care: A Single Center Study’. *Intensive care Medicine* 29, pp. 2149-2156 | To study health problems, quality of life, functional status, and memory following discharge from ICU.<br>. | Prospective Cohort Study Semi-structured Interviews, & Quality of life Indicator & consultation (6 & 7-8-months post-discharge) | N=346 | ‘*At follow-up 67.6% of consultation patients continued most activities, 75% looked after themselves, and 64.7% were non-workers, compared to 40.4% before the ICU admission. During and after the ICU stay, 40% lost more than 10 kg body weight. (43%) could not remember anything from their ICU stay. At follow-up only 22 (16%) could remember having received information during their ICU stay. Three patients needed referral to other specialities’*<br>Recommendations: optimisation of symptom management post-discharge |
| Laitinen, H. (1996) ‘Patient’s Experience of Confusion in the Intensive Care Unit following Cardiac Surgery’. *Intensive Critical Care Nursing* 12, pp. 79-83 | To describe and reflect upon the patients' experience of confusion in the intensive care unit (ICU) following cardiac surgery. and accepted. | Hermeneutic Phenomenology | N=10 | Memories of anxiety and confusion significant, which were compounded by the ICU environment. Experiences incomprehensible, difficult to reconcile. Emphasised importance of professional’s engagement and presence |
| Lange, S., Medrzycka-Dabrowska, W., Friganović, A., Religa, D and Krupa, S. (2022) ‘Patients’ and Relatives’ Experiences of Delirium in the Intensive Care Unit – A Qualitative Study, *International Journal of Environmental Research and Public Health,* 19(18), p. 11601 | Exploration of delirium experiences during ICU stay of patients and their relatives | Phenomenology | N=8 | Patients reported feelings of shame, and embarrassment about their behaviours during delirium episode, fearing reaction of family. Need for more information giving. |
| Lee-Steere, K., Liddle, J., Mudge, A., Bennet, S., McRae, P., Barrimore, S.E. (2020). ‘You've got to keep moving, keep going’: Understanding | To explore older inpatients' experiences and perceptions of | Interpretive descriptive methodology | N=23 | Delirium results in psychological, emotional, and physical effects. Delirium prevention needs to adopt |

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| older patients' experiences and perceptions of delirium and nonpharmacological delirium prevention strategies in the acute hospital setting. *Journal of Clinical Nursing.* July; 29 (13-14). pp. 2363-2377 | delirium and non-pharmacological delirium prevention strategies (NDPS). | | | a more person-centred approach and be respectful of the individual's values and preferences. |
| Lingehall, H.C., Smulter, N., Olofsson, B., Lindahl, E. (2015*)* 'Experiences of undergoing cardiac surgery among older people diagnosed with postoperative delirium: one year follow-up'. *BMC Nursing.* March 30; 14 (17)<br>(Sweden) | Exploration of delirium experiences post-cardiac surgery | Qualitative | N=49 | Physical impact of surgery associated with fatigue, risk of death and being drained of '*viability*'. Associated hallucinations left participants feeling '*trapped*'. Feeling supported, safe and recovery were important elements of good care. Staff need to improve knowledge regarding the prevention, detection, and treatment of delirium. |
| Löf, L., Berggren, L., and Ahlström, G. (2006) 'Severely ill ICU Patients Recall of Factual Events and Unreal Experiences of Hospital Admission and ICU stay, 3 and 12 months after discharge, *Intensive and Critical Care Nursing,* 22(3), pp. 154-166. | Exploration of recall of ICU experiences of patients 3- and 12-months post-discharge. | Qualitative | N=12 | Little variation of recall of experiences 3 and 12 months post-discharge. Experiences traumatic and emotionally charged. |
| Magarey, J.M, and McCutcheon, H.H. (2005) 'Fishing with the Dead' – Recall of memories from the ICU'. *Intensive and Critical Care Nursing. Dec.* 21(6), pp. 344-354 | Exploration of the patient's memories of a short-term ICU admission. | Qualitative, descriptive | N=50 | Range of memories reported which include nightmares, perceptual disturbances, paranoia, pain, thirst and anxiety<br>Need for reassurance and information giving |
| McCurren, C., and Cronin, S.N. (2003) 'Delirium: Elders tell their stories and guide nursing practice'. *Medical Surgical Nursing* Volume 12 (5). Pp. 318-323.<br>(USA) | To examine the subjective experiences of older individuals with delirium | Phenomenology | N=14 | Implications for nursing practice are derived from their reality and insight |

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| Nouwen. M.J., Francina, A.M., Klijn, F.A.M., Brigitte, T.A., Van den Broek, B.T.A., Arjen, J.C., and Slooter, M.D. (2012) 'Emotional Consequences of Intensive Care Delirium and Delusional Memories after Intensive Care Unit Admission: A Systematic Review'. *Journal of Critical Care* 27, pp. 199-211 | Exploration of the emotional consequences of delusional memories associated with delirium for patients admitted to ICU | Systematic Review | N=14 | No association of adverse emotional outcomes and delirium. Contradictory evidence of relationship for delusional memories and emotional outcome. |
| O'Malley, G., Leonard, M., Meagher, D., O'Keeffe., S.T. (2008) 'The Delirium Experience: A Review. *Journal of Psychosomatic Research.* Vol. 65 (3), pp. 223-228 | Review of the delirium experience from the position of the patient, family and staff | Literature Review | N=16 | The review highlighted the emotionally distressing responses to delirium, the accompanying perceptual disturbances, long-term sequelae and impact for patient and families |
| Oyesanya, T. (2017) 'The Experience of Patients with ABI and their Families During the Hospital Stay: A Systematic Review of Qualitative Literature'. *Brain Injury*. 31(2), pp. 151–73. | Systematic review and synthesis of literature relating to the patient's and family's experience of ABI during hospital admission | Systematic Review | N=11 | Negative perception of rehabilitation environment from the patient's perspective, need for more information. Family experiences – difficulty in adjusting to patient's injury, inconsistently in staff support and more information disclosure<br>Need for more family, person-centred support |
| Palmieri, T.L. (2003) 'Intensive Care Delirium in the Older Patient'. *Current Surgery.* Vol. 60, Issue 4. pp. 356-360 | To develop and validate a screening tool to detect delirium in the intensive care unit | Prospective trial of newly created checklist for delirium administered over 3 months in an intensive care unit | N=15 | The authors conclude that the Intensive Care Delirium Checklist is a reasonable screening tool for detecting delirium in the intensive care unit. Because of its lack of specificity, however, psychiatric consultation may be helpful for those with a positive test to confirm the diagnosis. |
| Richman, J. (2000) 'Coming out of Intensive Care Crazy: Dreams of Afflictions'. *Qualitative Health Research*, 10 (1), pp. 84-102 | Autobiographical account of ICU & hospital experiences. | Autobiographical narrative | | Author's perception of a 'medical object and mechanical appendage'. Nurses are well placed to facilitate |

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| | | | | ownership of patient's dreams to aid understanding of illness. |
| Ringdal, M., Johansson, L., Lundberg, D., and Bergbom, I. (2006) 'Delusional Memories from the Intensive Care Unit—Experienced by Patients with Physical Trauma'. *Intensive and Critical Care Nursing*. 22, pp. 346-54. | To describe trauma patients' memories of their stay in the ICU, factors that may influence delusional memories, problems experienced after discharge from the ICU and the patients' return to work. | Multi-centre study. Quantitative, Self-administered questionnaire | N=239 | Delusional memories less likely to be recalled than factual memories (26% versus 83%).but the former more common in the younger adult and associated with feelings of panic on discharge from ICU. |
| Ringdal, M. Plos, K. Lundberg, D, Johansson, L. and Bergbom, l (2009) 'Outcome after Injury: memories, health-related quality of life, anxiety and symptoms of depression after intensive care'. *Journal of Trauma: Injury, Infection and Critical Care.* 66 (4) pp. 1226-1233<br>(Sweden) | To examine the relationship between delusional memories from ICU stay, health related Quality of Life, anxiety and symptoms of depression in patients with physical trauma, 6-18 months post-ICU stay | Multi-Centre study Quantitative Survey | N=239 | Patients with trauma had significantly lower Quality of Life indicator. 26% experienced hallucinations, delusional memories, nightmares. This group reported lower Quality of Life indicator, anxiety and symptoms of depression. |
| Roberts, B., and Chaboyer, W. (2004) 'Patient's Dreams and Unreal Experiences following Intensive Care Unit Admission'. *Nursing in Critical Care.* 9(4), pp.173-180 | Explores the patient's subjective recall of dreams 12-18 months after intensive care discharge. | Qualitative Semi-structured interviews | N=31 | 74% reported the occurrence of frightening hallucinations and dreaming, with 2 participants reporting negative sequelae long-term. |
| Roberts, B.L., Rickard, C.M., Rajbhandari, D., and Reynolds, P. (2007) 'Factual memories of ICU: recall at two years post-discharge and comparison with delirium status during ICU admission – a multicentre cohort study'. *Journal of Clinical Nursing.*16, pp. 1669-1677 | To examine the relationship between observed delirium in ICU and patients' recall of factual events within two years following discharge. | Prospective cohort study Interviews | N=41 | 44% experienced delirium and 56% non-delirious Most patients have factual memories of their ICU stay. Those who experienced delirium, had less factual memories. Recommendations included follow-up to involved explanations to fill the *'missing gaps'*. |

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| Rotondi, A.J., Lakshmipathi, C., Sirio, C., Mendelsohn, A., Schulz, R., Belle, S., Donahoe, M., Im, K., and Pinksy, M.R. (2002) 'Patients' recollections of stressful experiences while receiving prolonged mechanical ventilation in an intensive care unit'. *Critical Care Medicine* 30(4), pp. 746-752 | To describe the experiences of adult patients who received mechanical ventilation for >48 hours in ICU | Prospective cohort study | N=150 | Two thirds of patients remembered the endotracheal tube and / or being in ICU, described as moderately to extremely bothersome. Stressful events included: pain, fear, lack of sleep, nightmares, loneliness, lack of control. |
| Samuelson, K.A.M. (2011) Unpleasant and pleasant memories of intensive care in adult mechanically ventilated patients – findings from 250 interviews. Intensive and Critical Care Nursing. 27, pp. 76-84<br>(Sweden) | To describe unpleasant and pleasant memories of the ICU stay in adult mechanically ventilated patients. | Qualitative | N=250 | Of the 81% who had memories of their ICU stay. 59% of individuals were pleasant and 71% unpleasant. Distress was physical and emotional and compounded by their perceptual disturbances, environment and care activities. |
| Schmitt, E.A., Gallagher, J., Albuquerque, A., Tabloski, P., Lee, H.J., Gleason, L., Weiner, L.S., Marcantonio, E.R., Jones, R.N., Inouye, S.K., Schulman-Green, D. (2019) 'Perspectives on the Delirium Experience and Its Burden: Common Themes Among Older Patients, Their Family Caregivers, and Nurses'. *Gerontologist*. March 14:59(2), pp.327-337<br>(Boston, US) | To explore the delirium burdens from the perspectives of patients, family caregivers, and nurses | Qualitative Semi-structured interviews. | N=18 (patient)<br>N=16 family / caregiver<br>N=15 nurses | Recognised that the delirium experience is shared and the need to acknowledge and reduce symptom-burden, the emotional burden and responses to delirium and the situational burden which includes lack of attention , knowledge and the unpredictability of delirium presentation. |
| Schofield, I. (1997) A Small Exploratory Study of the Reaction of Older People to an Episode of Delirium. Journal of Advanced Nursing, 25 (5). pp. 942-952 | To retrospectively explore older peoples' experience of an episode of delirium. | Grounded Theory Methodology | N=19 | Range of delusional and hallucinogenic experiences described, from pleasant to frightening. Memories of hearing commands from nurses. Limited evidence of therapeutic communication with nurses once the delirium resolved |
| Sorensen Duppils, G., and Wikbald, K. (2007) 'Patient's Experiences of Being Delirious'. *Journal of Clinical Nursing.* Vol 16, No5, pp. 810-818 | To describe patients' experiences of being delirious. | Qualitative | N=15 | Delirium experiences recalled as dramatic scenes which results in emotional feelings of fear, panic and anger. Important to understand |

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| | | | | experiences during delirium in order to focus professional care |
| Stein-Parbury, J., and McKinley, S. (2000) ‘Patients’ experiences of being in an intensive care unit: a select literature review’. *American Journal of Critical Care*, 9(20), pp. 20-27. | Patient experiences of ICU | Literature Review | N-26 | Positive (safety and security) and negative (impaired cognitive functioning, sleep deprivation, pain and anxiety). Need for better understanding of patient experience. |
| Stenwall, E., Jonhagen, M.E., Sandberg, J., and Fagerberg, I. (2008a) ‘The Older Patient’s Experience of Encountering Professional Carers and Close Relatives during an Acute Confusional State: An Interview Study’. *International Journal of Nursing Studies.* 45 (11), pp. 1577-1585 | To explore the experiences of older patients with Acute Confusional State when encountering professional carers and close relatives. | Qualitative (Latent Content Analysis) | N=7 | Patients described loneliness, feeling an ‘outsider’ and unsafe, and strived to understand and make sense of their experiences. |
| Storli, S.L., Lindseth, A., and Asplund, K. (2008) A journey in quest of meaning: a hermeneutic phenomenological study on living with memories from intensive care. Nursing in Critical Care, 13, pp. 86-96 | An exploration of the meaning of living with memories from intensive care. | Hermeneutic Phenomenology | N=10 | Longevity of memories particularly those which were emotional and intrusive. Evidence of post-admission anxiety and flashbacks. Ongoing need to understand experiences. Bedside relatives source of support. Need for supportive, follow-up meetings |
| Svenningsen, H., Tønnesen, E. (2011) Delirium incidents in three Danish Intensive Care Units. *Nursing in Critical Care.* Vol 16 (4) pp. 186-192 | To evaluate the incidence of delirium during ICU and correlate with the use of sedatives, opioid analgesics and age | Prospective study | N=139 | Incidence of delirium, 40% (assessed using CAM-ICU tool). Those sedated had 10-fold increased risk of delirium. Risk increased with use of fentanyl |
| Svenningsen, H., Tønnesen, E.K., Videbech, P., Frydenberg, M., Christensen, D., Egerod, I. (2014) ‘Intensive care delirium - effect on memories and health-related quality of life - a follow-up study‘. *Journal of Clinical Nursing.* | To investigate the effects of delirium in the ICU on health-related quality of life, healthcare dependency | Observation, multi-centre-design. Interviews 1 week, 3- and 6-months post- | N=360 | Delirium incidence 60%. Intensive care unit diaries with follow-up did not affect health-related quality of life and healthcare dependency Recommendations: frequent |

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| Vol 23 (5-6). pp. 634-644 | and memory after discharge.<br>To explore the association between health-related quality of life and memories, patient diaries and ICU follow-up | discharge | | assessment to prevent, detect and treat delirium, with a follow-up support programme on discharge. |
| Svenningsen, H., Egerod, I., Dreyer, P. (2016) 'Strange and scary memories of the intensive care unit: a qualitative, longitudinal study inspired by Ricoeur's interpretation theory'. *Journal of Clinical Nursing.* Vol.25 (19-20). pp. 2807-2815 | To explore patients' memories of delusions in ICU | Hermeneutic Phenomenology | N=325 | Memories of delusions persisted up to 6 months for 114 participants. Delusional memories comprised of fact & fiction with time, place and motion disturbed. |
| Tembo, A.C., Parker, V., and Higgins, I. (2012) 'Being in Limbo: The Experience of Critical Illness in Intensive Care and Beyond'. *Open Journal of Nursing*. 2, pp. 270-276. | To explore the experience of critically ill patients in ICU and beyond. | Phenomenology | N=12 | The ICU experience results in biographical and temporal distortions. Feelings of entrapment and uncertainty of outcomes. Need to reclaim their pre-injury identity. |
| Tosch, P. (1988) 'Patient's Recollections of their Posttraumatic Coma'. *Journal of Neuroscience Nursing*. 20(4), pp. 223-228.<br>(USA) | To explore patients' recollections of post-traumatic coma as viewed retrospectively were explored in this descriptive study. | Retrospective, Descriptive study | N=15 | 7 participants had no recollection of being in a coma. 8 were able to recall experiences with 3 themes: imprisonment, sensory & death-like experiences. For those who have awareness, nursing management should acknowledge and incorporate strategies |
| Van Rompaey, B., Van Hoof, A., Van Bogaert, P., Timmermans, O., Tinne, D (2016) 'The Patient's Perception of Delirium: A Qualitative Research in a Belgian Intensive Care Unit'. Intensive and Critical Care Nursing, Vol 32, pp. 66-74 | To describe the patient's perception of delirium during ICU. | Hermeneutic Qualitative study | N=30 | Memories recalled the unrealistic and distressing experience of delirium, the effects of delirium on sleep and time perceptions, and impact on recovery. Need for better insight of the patient's experience and targeted interventions. |
| Wade D. M., Brewin C. R., Howell D. C., White | To investigate the root | Mixed method | N=17 | 88% of participants experienced |

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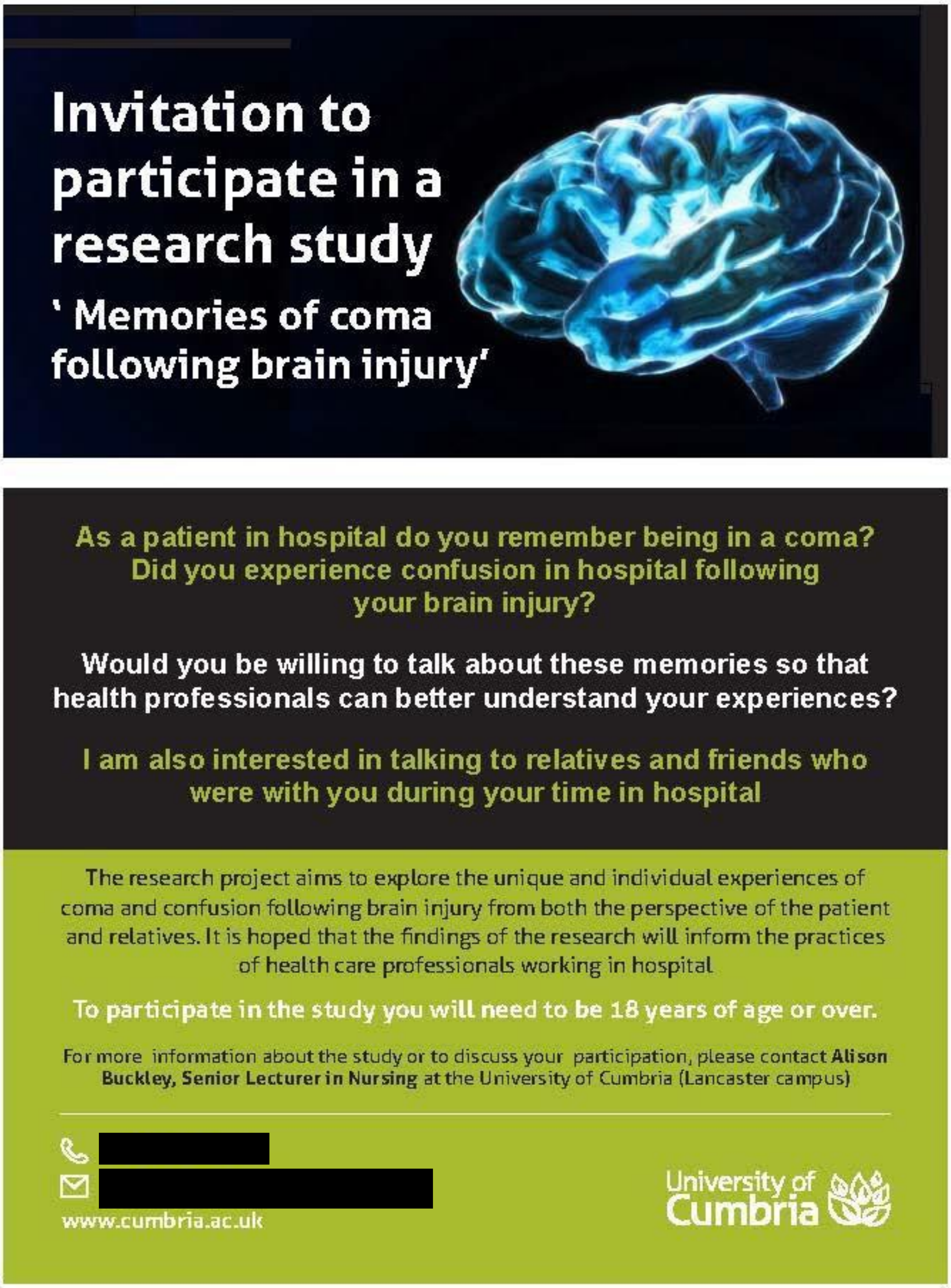
| E., Mythen M. G., Weinman J. A. (2015) 'Intrusive memories of hallucinations and delusions in traumatized intensive care patients: an interview study', *British Journal of Health Psychology,* 20(3), pp. 613-631. | causes of post-intensive care trauma | investigation | | traumatising hallucinatory and delusional memories, which predisposed to symptoms of post-psychosis PTSD. |
| Weir, E., O'Brien, A.J (2019) 'Don't go there – It's not a nice place: Older adults' experiences of delirium'. *International Journal of Mental Health.* Vol 28 (2), pp. 582-591 | To explore the experience of delirium for older adults during hospitalisation | Descriptive, Qualitative Design | N=7 | Perceptual disturbances and sense of confusion described along with the emotional responses to delirium. Need to develop strategies for improvements to detection, awareness and management of delirium. |
| Whitehorne, K., Gaudine, A., Meadus, R. and Solberg, S. (2015) 'Lived Experience of the Intensive Care Unit for Patients who Experienced Delirium', *American Journal of Critical Care,* 24(6), pp. 474-479. | Exploration of patient's experience of delirium in the ICU | Hermeneutic Phenomenology | N-10 | Four themes: '*I can't remember', 'Wanting to make a connection', 'Trying to get it straight', and 'Fear and safety concerns*'.<br>Need for improved communication |
| Wright, D.K., Brajtman, S., Cragg, B., Macdonald, M.E. (2015) Delirium as letting go: An ethnographic analysis of hospice care and family moral experience. *Palliative Medicine.* Vol 29 (10), pp. 959-966<br>(Canada) | To illustrate how hospice caregivers conceptualise end-of-life delirium and significance for relationships formed with patient's families in the hospice setting | Ethnography | N=28 | Delirium an anticipated symptom of the dying process and caregivers draw on this to enable families to accept death. |
| Yang, Z., Pituskin, E., Norris, C., Papathanassoglou, E. (2020). Synthesis of Intensive Care Nurses' Experiences of Caring for Patients With Delirium. *Connect: The World of Critical Care Nursing*. Vol.14 (2), pp. 55-77 | Synthesis of ICU nurses' experiences of caring for patients with delirium | Systematic Review | N=9 | Emerging themes focused on assessment and screening protocols. Supporting an individual with delirium is emotionally and physically exhausting, perception that patients are low priority & inconsistency in delirium management. |

**APPENDIX 4: Diary Extract**

*I have just returned from the first meeting at ……….. in ……… I met individuals who had acquired brain injuries, caused by trauma, stroke and some of their spouses and family members. There was so much support within the group and all very welcoming of me and my work. I was nervous – not sure why – perhaps a little out of my comfort zone and I really wanted the group to accept me and appreciate how important that a nurses we understand their perspective, but at the same time, I didn't want to intrude and be seen as someone who was simply there to ask for volunteers (but yet, that was my main reason for attending!). I introduced myself and discussed my research – all listened intently and then asked questions, mainly about me and where I have nursed. I explained I was a nurse who had worked at different hospitals (was I doing this to try and reassure them I had some experience?) and this was important – I felt that they valued me and hopefully could see how committed I was (really hope so!), but I did feel it was important to say that I didn't want members to feel obliged or coerced in any way. I asked what their experiences had been like in hospital after their injury as patients and relatives. There were so many sad stories – I felt a bit overwhelmed by peoples' experiences and couldn't help but be bothered by what I had heard. One lady's story was just so sad – she was there because her son had sustained a brain injury and been left with what sounded like profound personality and behaviour change. She described what it was like in hospital for them both, the devastating effect it had on his personality and him as a person. She remembers being there for hours with him, how she got involved in his care and realised very early on the seriousness of his brain injury traumatic brain injury. She explained that the doctors had been wonderful, but the nurses were so busy and there were many occasions she had to 'get on with it', and that some staff hadn't really understood what it was like for her and how because her husband had died a few years before, she was the only family member who could visit. She travelled for two hours on the bus ever day! Nobody really explained things to her, and she learnt very quickly it was going to be a 'long haul'. It is now twelve months since her son's brain injury, and he is back living at home with her. She explained how difficult it is she is in receipt of benefits and because he cannot work because of his aggression, no one wants to know. The group kept her 'sane' and she explained she* wouldn't know what she would do if she didn't have the friends from the group to support her. She explained her son was learning to manage himself better but that she had no idea at the time that things would continue to be so difficult. The group was in a particularly deprived area and on the way home, I couldn't help but think how on earth does she manage to navigate her way through her struggles, particularly when there is very little support. We do so much in hospital to preserve life and yet, there is so little out there! Not that I was surprised, but the members were all very forthcoming in telling me about their hospital experiences – as a nurse I must have represented the hospital to them – the facilitators explained that the group frequently reflect on what it was like but that they do not normally have nurses attendings – but she said it was good they had opened up and had a chance to talk about what it had been like. This made me think about how important it is to listen and learn – we can learn so much and need to be more open as nurses? Why don't we listen more? These stories are so powerful and just giving people a chance to tell us what it's been like is so important. I feel really saddened – not sure why but wonder if we have let them down in some way. Could we prepare people better? Why aren't services there to support people after discharge? It was difficult during the meeting to 'steer' the discussion to my research and there were times when I felt a little awkward (and embarrassed) about doing this! Perhaps their stories are much 'bigger' than my research? After my talk, I was able to sit with some of the members and ask them specifically whether they remember being in a coma, experienced hallucinations etc. two ladies came forward to say they would be interested in being involved as they had vivid memories – again, I was conscious I didn't come across in any way as persuasive and stressed the importance they needed some time to think about their involvement.

I am worried that their time is so precious – particularly people like the lady who is supporting her son – would people like her really have time for me?

## APPENDIX 5 Study Flyer: Invitation to Participate in Research Study



# Invitation to participate in a research study

## ' Memories of coma following brain injury'

**As a patient in hospital do you remember being in a coma?**
**Did you experience confusion in hospital following your brain injury?**

**Would you be willing to talk about these memories so that health professionals can better understand your experiences?**

**I am also interested in talking to relatives and friends who were with you during your time in hospital**

The research project aims to explore the unique and individual experiences of coma and confusion following brain injury from both the perspective of the patient and relatives. It is hoped that the findings of the research will inform the practices of health care professionals working in hospital

**To participate in the study you will need to be 18 years of age or over.**

For more information about the study or to discuss your participation, please contact **Alison Buckley, Senior Lecturer in Nursing** at the University of Cumbria (Lancaster campus)

☎ [redacted]
✉ [redacted]
www.cumbria.ac.uk

University of Cumbria

## APPENDIX 6: Participant Information Sheet (The Patient)

### Title of Project
### A Study to Explore the Experiences of Coma (an ‘Altered State of Consciousness’) from the Perspective of the Patient and their Witness

Lead Researcher: Alison Buckley, Senior Lecturer, Department of Nursing, Health and Professional Practice, University of Cumbria

***Participant Information Sheet – Patient***

This pack contains information about a research project to explore the experience of coma (an ‘altered state of consciousness’) from the perspective of patients and informal carers ie relatives and friends

I would like to invite you to take part in a research project. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and do not hesitate to contact me if you wish to discuss any issues further:

Lead researcher: Alison Buckley
*(contact details supplied)*

### Introduction and Purpose of the Study

The purpose of the research project is to investigate how patients experience a period of coma (‘an altered state of consciousness’) and what they remember about their experiences during this time.

The period of coma or an ‘altered state of consciousness’ may have been caused by a brain injury or a condition affecting the brain which required you to be admitted to hospital. It may be that you were unconscious for a period but have some memories of this and remember the time when you were regaining consciousness and increasingly aware of your surroundings. I would like to ask questions about what it is like for you, your thoughts, and your feelings and how this experience is remembered.

I am also interested in how your relatives / spouse experienced this period of time when they visited you during your hospital stay. If they would like to be involved, then please ask them to contact me to discuss further.

I am hoping that an understanding of how you, and those supporting you during your time in hospital, will offer an important insight into what matters to patients when they are receiving care in hospital.

The research project is part of a PhD project I am studying in my role as a nurse lecturer within the Department of Nursing, Health, and Professional Practice at the University of Cumbria

Please be assured that the research project has been reviewed and approved by the ethics committee at the University of Cumbria, a group of people experienced with research to ensure that your interests are protected.

You are welcome to phone me or contact me via email if you would like any further information

Please do not hesitate to ask if anything is unclear.

## Some questions you may have about the research project:

### Why have you invited me to take part?

You have been invited to take part in this project because during your admission to hospital as an in-patient, you experienced a period of coma (an ‘altered state of consciousness’) but have subsequently recovered and may be able to discuss what you remember about this time.

Whilst your involvement may not benefit you directly, we feel that your experiences as a patient can contribute much to our understanding and knowledge of the condition and inform the education of nurses and other healthcare staff

### What will I be asked to do?

If you would like to be interviewed, please contact Alison Buckley by telephone…..or by email….If I am unable to answer the phone then you will be able to leave a message and I will return your call as soon as possible. I would be grateful if you could leave your contact details and suggest a convenient time when I can speak to you. I will explain the project in more detail, go through the Information Sheet if you so wish and answer any questions you may have.

If you agree to take part in the project then I will ask you to complete a consent form.

Once you have agreed to take part, I will then arrange a convenient date and time for the interview.

### Where will this take place?

The interview will take place in a location convenient to you, but I will ensure that it is private and comfortable. I will ask your permission to record the interview using a Dictaphone but if you prefer not to be recorded, I can take notes about what you say during the interview. If following the interview, you would like to listen to your recording or refer to my notes, or request that the interview recording is erased, then that is fine. If you would like to stop the interview for a short rest or withdraw from the interview, then your request will be wholly respected.

**How often will I have to take part and for how long?**

The interview should last no longer than an hour. Following the interview, I will type up what you have said in the interview and produce what is known as a ‘transcript’. You are welcome to have a copy.

With your agreement, I can arrange to see you later, to go through this written transcript and share my thoughts about your experiences. Participating in this follow-up discussion is entirely your decision and I will ask you at the initial interview whether you would like further contact with me.

The Mental Capacity Act (2005) is very clear about the legal responsibilities of the researcher if you should become unwell or your condition means that you lose capacity following the completion of the initial interview. If this happens, then the Lead Researcher will not expect you to partake in the follow-up discussion but would like to retain the interview data and transcript for analysis. However, if you prefer that the recording of the interview and transcript are destroyed then you will have the opportunity to confirm this when signing the consent form.

**Will I receive any reimbursement for my time?**

Unfortunately, I am unable to provide financial support for your time but will reimburse any travel costs.

**When will I have the opportunity to discuss my participation?**

I will give you an opportunity to discuss my findings with you once I have collected the information and had the opportunity to review the data. However, I will be contactable throughout the duration of the project should you wish to speak to me about your involvement and / or the project in general

**What happens to the research data?**

The interview will be recorded using a Dictaphone and following the interview a written copy will be made. This is known as the ‘interview transcript’ and will be what you have said on the tape. The audio recording and the written transcript will be kept secure in a locked cupboard in my office at the University of Cumbria and I can assure you that I will not include your name in any of the information I collect or reveal any personal details. Only I as the lead researcher, the supervisory team at the University of Cumbria and you, will have access to the materials.

Later, and with your permission, I may play the recording of your interview to colleagues but if you prefer me to show the interview transcript instead then that is fine

The audio tapes and interview transcripts will be destroyed two years after the end of the study.

Your response will be treated in full confidence and anyone who takes part in the research will be identified only by code numbers or false names. You can request a copy of the interview transcript if you wish.

Please be assured that as a researcher, I will have no contact with your GP, local hospital, or any staff members you may refer to during the interview.

**How will the research be reported?**

Once I have undertaken all the interviews and analysed the data, I will be required to compile a thesis. This is a written piece of work. Throughout the duration of the study, I intend to publish and share my work with you, other health care professionals and University staff at conferences and seminars.

Please be assured however, that any personal details i.e., your name and other personal details will not be included, and your anonymity will be assured throughout. If you would like to receive a copy of any work published in journals or books, then I am more than happy to let you have a copy on request.

**Who will be responsible for all the information when the study is over?**

As the Lead Researcher, I will be responsible for ensuring that all data collected from the interviews is kept securely for a period of 2 years after completion of the project. This will allow me to review the findings and continue to work with the data I have collected during the research.

**Who will have access to it?**

The only individuals who will have access to it will be I, as the Lead Researcher, my supervisory team at the University of Cumbria and those involved in the interviews, i.e., you, the patient.

**How long is the whole study likely to last?**

It is envisaged that the study will last 6 years and so there may be opportunities throughout this time for you to contact me if you so wish. However, please be assured that once you have completed the interviews you will not be expected to continue with your involvement, unless of course you would like to.

**What if I do not wish to take part?**

As your participation in the study is entirely voluntary, then it is entirely up to you whether to take part. However, if you do decide to take part, then you are still free to withdraw at any time without giving reason.

The interview will be guided by me, but you do not have to answer any questions or take part in the discussion if you do not wish to do so. You do not need to give any reason for not responding to any of the questions or for refusing to take part in the interview.

I fully appreciate that talking about your experiences may be upsetting for you. You are free to stop the interview at any time if you do not wish it to continue. If the interview upsets you and you feel you would like some additional help after the interview, I will be able to advise you who to contact, for example, a member of your local…..support group.

I will give you an opportunity at the end of the interview to review your remarks and you can ask to modify or delete any of the recordings or my notes if you do not agree or if you did not understand correctly.

**Will I need to sign any documentation?**

You will be asked to sign a consent form before participating in the study. Prior to signing the consent form, I will need to establish that you have full mental capacity such that you can understand fully the nature of your involvement, the interview process and the information contained within the Participation Information Sheet. I will use the Mental Capacity Act (2005) to guide my assessment of your mental capacity at the time of my discussion with you:

- you understand the information relevant to the decision (ie on this occasion, your consent to participate in the research study)

- you are able to retain the information (ie on this occasion regarding your role in the research study, storage of data and the sharing of the research findings)

- you are able to use or weigh up the information as part of the process of making the decision (ie participation in the research study)

- you can communicate that you consent to participate in the research study.

**How can I find out more information?**

As the lead for the project, I am contactable at the University of Cumbria on ……… where you can leave a voicemail if I am out of the office. I am also contactable via email on ……or you can write to me at:

Alison Buckley, Senior Lecturer, Department of Nursing and Midwifery University of Cumbria, Bowerham Road, Lancaster, LA1 3JD

**What if I want to complain about the research?**

If you have any concerns about your involvement in the study or the conduct of the study, then you should speak to me in the first instance. However, if you feel unable to approach me, do not feel satisfied with my response or wish to make a more formal complaint you should contact (*name supplied*), Director of Research Office, University of Cumbria, Bowerham Road, Lancaster, LA1 3JD *(contact details supplied).*

## APPENDIX 7: Letter of Introduction (Patient Participant)

*Alison Buckley*
*Senior Lecturer, Department of Nursing and*
*Midwifery University of Cumbria*
*LA1 3JD*
*(telephone number*
*supplied) Email*
*address: (supplied)*

Date:

To whom it may concern

My name is Alison Buckley, and I am a Senior Lecturer in the Department of Nursing at the University of Cumbria.

I am involved in a research study to understand the memories individuals may have following a period of unconsciousness or coma after a brain injury.

The period you were in a coma or unconscious may have been caused by a brain injury or a condition affecting the brain which required you to be admitted to hospital. It may be that during the time you were unconscious, you have some memories of this, and remember the time when you were regaining consciousness and increasingly aware of your surroundings.

I would like to ask you questions about what it was like for you, your thoughts, and your feelings and how your experience is remembered. I am also interested in how your relatives / spouse experienced this period when they visited you during your hospital stay. If they would like to be involved, then please ask them to contact me to discuss further.

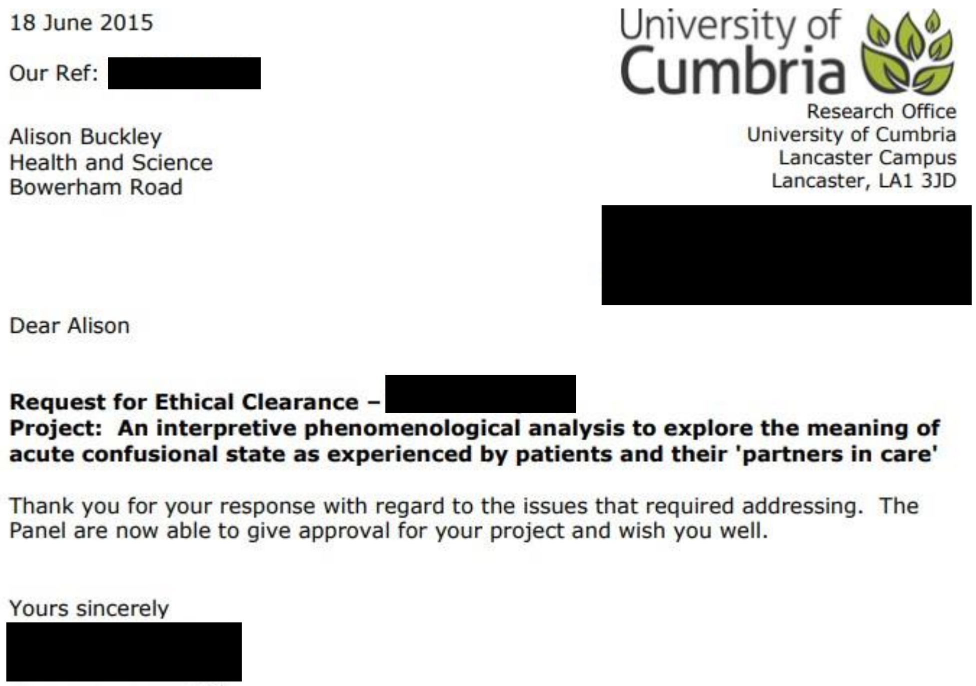
If you decide to participate, you will be invited to an interview facilitated by myself, at a time and location convenient to you. The interview will be informal and should last for approximately one hour. With your consent, the interview will be audio recorded using a Dictaphone. However, if you feel uncomfortable, I am more than happy to take notes during the interview. You can refrain from answering any questions asked and can ask to listen to the recording and any notes taken at any time after the interview. Any travel costs will be reimbursed.

If you would like further information and / or feel able to partake in the study, please do not hesitate to contact me either by telephone …… (there is an answerphone if I am not in the office) or via email: *(address supplied*)

Looking forward to hearing from you

Kind Regards, Alison Buckley

## APPENDIX 8: Initial Ethical Approval Confirmation (University of Cumbria)



18 June 2015

Our Ref: [redacted]

University of Cumbria
Research Office
University of Cumbria
Lancaster Campus
Lancaster, LA1 3JD
[redacted]

Alison Buckley
Health and Science
Bowerham Road

Dear Alison

**Request for Ethical Clearance –** [redacted]
**Project: An interpretive phenomenological analysis to explore the meaning of acute confusional state as experienced by patients and their 'partners in care'**

Thank you for your response with regard to the issues that required addressing. The Panel are now able to give approval for your project and wish you well.

Yours sincerely

[redacted]

## APPENDIX 9: Participant Debriefing Letter

### PARTICIPANT DEBRIEFING SHEET: *PATIENT / WITNESS*

### Title of Project

### A Study to Explore the Experiences of Coma (an 'Altered State of Consciousness') from the Perspective of the Patient and their Witness

Dear Participant (include name / pseudonym)

Many thanks for taking part in the study and sharing your experiences. Your participation is greatly appreciated, and I am sure that your contributions to the interview will be valuable in helping us to understand how an altered state of conscious following a brain injury is experienced. We realise that some of the questions asked, and the discussions, may have provoked some difficult memories for you, so if you would like further support or to discuss your involvement, please do not hesitate to contact:

……………………………………………………………………………………

If you decide later that you do not wish your contributions to be part of the research study, then please contact me:
Alison Buckley (Lead Researcher, University of Cumbria) on (*telephone number supplied*) or email.................
Your decision will be wholly respected, and you will not be asked to explain the reasons why.

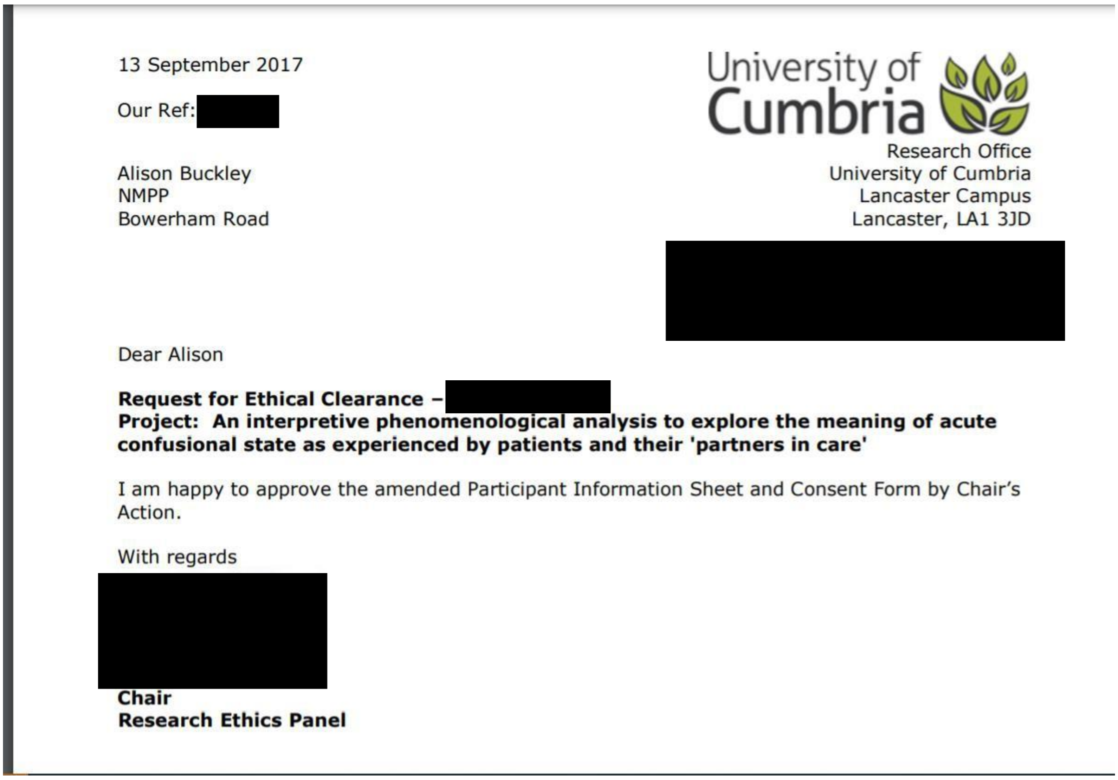
If you would like me to keep in contact with you to discuss the progress of the study and / or to provide some information about the findings later, then please leave your contact details after the interview. Please be assured that your personal details will be held securely.

If you have any questions or concerns that come to mind regarding the study, its purposes or conduct, please feel free to contact me, the Lead Researcher, Alison Buckley (see contact details above)

Once again, thank you for your involvement.

Kind Regards, Alison Buckley.

## APPENDIX 10: Ethical Approval (amendments) Confirmation



University of Cumbria
Research Office
University of Cumbria
Lancaster Campus
Lancaster, LA1 3JD
[redacted]

13 September 2017

Our Ref: [redacted]

Alison Buckley
NMPP
Bowerham Road

Dear Alison

**Request for Ethical Clearance –** [redacted]
**Project: An interpretive phenomenological analysis to explore the meaning of acute confusional state as experienced by patients and their 'partners in care'**

I am happy to approve the amended Participant Information Sheet and Consent Form by Chair's Action.

With regards

[redacted]

**Chair**
**Research Ethics Panel**

## APPENDIX 11: Participant Consent Form (Revised): The Patient

## PARTICIPANT CONSENT FORM: *THE PATIENT*

### Title of Project
### A Study to Explore the Experiences of Coma (an 'Altered State of Consciousness') from the Perspective of the Patient and their Witness

Name of Lead Researcher: Alison Buckley, Senior Lecturer, Department of Nursing and Midwifery, University of Cumbria

Please initial in the boxes as evidence of your agreement with the statements below:

| | |
|---|---|
| I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily | |
| I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason | |
| I understand that data collected during the study may be looked at by individuals from the University of Cumbria, and any regulatory authorities where relevant | |
| I understand that the information collected about me may be used to support other research in the future and may be shared anonymously with other researchers and education staff | |
| I agree to take part in the study | |

Your signature will certify that you are deemed to have full mental capacity (Mental Capacity Act, 2005), assessed, and confirmed by the Lead Researcher, Alison Buckley).and that you have voluntarily decided to take part in the research study, having read and understood the information provided in the 'Information Sheet'. It will also certify that you have had adequate opportunity to discuss the study with the researcher and that all your questions have been answered to your satisfaction.

Once the interview has taken place and the transcription (a written record of what you have said during the interview) has been completed, there will be an opportunity for you to receive this transcript and / or for you to discuss my initial thoughts about your experiences during a further interview. Participating in a follow-up interview is entirely your decision.

| **Please delete as appropriate** |
|---|
| I **would like / would not** like you to contact me to discuss my initial thoughts about my experiences |
| I **would like / would not** like you to provide me with a written report of my interview |

The Mental Capacity Act (2005) is very clear about the legal responsibilities of the researcher if you should become unwell or your condition means that you lose capacity following completion of the interview. If you lose capacity, then the Lead Researcher will not expect you to partake in the follow-up discussion (should you have agreed to this) but will retain the interview data and transcript for analysis.

However, if you prefer that the recording of the interview and transcript are destroyed then please tick the box which applies:

| | | |
|---|---|---|
| If I become unwell and lose capacity after the interview, I agree that the interview recording and the transcript can be retained for research purposes | | |
| If I become unwell and lose capacity after the interview, please destroy the recording and the interview transcript | | |
| Signature of Participant<br>Print Name | | Date: |
| Signature of Researcher<br>Print Name | | Date: |

APPENDIX 12: Participant Consent Form (Revised): *The Witness*

## PARTICIPANT CONSENT FORM: *THE WITNESS*

### Title of Project
### A Study to Explore the Experiences of Coma (an 'Altered State of Consciousness') from the Perspective of the Patient and their Witness

Name of Lead Researcher: Alison Buckley, Senior Lecturer, Department of Nursing and Midwifery, University of Cumbria

Please initial in the boxes as evidence of your agreement with the statements below:

| | |
|---|---|
| I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily | |
| I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason | |
| I understand that data collected during the study may be looked at by individuals from the University of Cumbria, and any regulatory authorities where relevant | |
| I understand that the information collected about me may be used to support other research in the future and may be shared anonymously with other researchers and education staff | |
| I agree to take part in the study | |

Your signature will certify that you have voluntarily decided to take part in the research study, having read and understood the information provided in the 'Information Sheet'. It will also certify that you have had adequate opportunity to discuss the study with the researcher and that all your questions have been answered to your satisfaction.

Once the interview has taken place and the transcription (a written record of what you have said during the interview) has been completed, there will be an opportunity for you to receive this transcript and / or for you to discuss my initial thoughts about your experiences during a further interview. Participating in a follow-up interview is entirely your decision.

| | | |
|---|---|---|
| **Please delete as appropriate** | | |
| I **would like / would not** like you to contact me to discuss my initial thoughts about my experiences | | |
| I **would like / would not** like you to provide me with a written report of my interview | | |
| Signature of Participant<br>Print Name | | Date: |
| Signature of Researcher<br>Print Name | | Date: |

## APPENDIX 13: Participant Interview Extract: Illustration of Transcript and Analysis (*Witness*)

| Line | Data Extracts from Verbatim Text Interview Transcript: Lines 112-233: Interview 1 with Patricia (*Witness*)<br>Phrases of significance / singular statements/ '*rhetorical gems'* (Van Manen, 2014, p. 320) | Field notes / Diary Extracts Narrative Tone & Emotions of Context | Initial / Naïve Interpretations Subtext / Inferences | Superordinate '*Meaning Essences'* | '*Meaning Structure'* |
|---|---|---|---|---|---|
| 112 | ***They didn't give any explanation to me or anything and they didn't seem to know really what to do or anything with him.*** | Tone: frustration, despondency | Lack of information<br>Questions clinical decision making | Inter-relations with the Healthcare Professional | Lived Relationality and Discourse |
| 113 | *They just* ***waived all visiting things*** *'cos they could see he calmed down, you know, infection control…* | | Waiving of routine / policies to accommodate behaviours of ASC | Cultural Norms and Behaviours | Lived Spatiality |
| 115 | ***got in bed with him and rubbed his feet****, but that seemed to calm him back down* | Sense that she had tried to personally affect his behaviours as other measures had not been effectual<br>Pensive | As his wife, felt that physical contact with her husband would effect change in his behaviour | Historicity of Relationships<br>Cultural Norms and Behaviours | Lived Relationality and Discourse<br>Lived Spatiality |
| 116 | *I think the* ***touch*** *thing and the* ***sense of grounding from that definitely did something.*** | Privileged 'touch' as a therapeutic means of affecting his behaviour<br>Optimistic | Actions to enforce reality | Historicity of Relationships | Lived Relationality and Discourse |
| 118 | *But in the days after that he still was very kind of feeling - this would be* ***four or five days*** *after the operation* | Pensive, Worried, Despondency | Time frame remembered | Time as a Predictor | Lived Temporality |
| 119 | *you'd go in and he went* ***like he was on drugs, like tripping, his pupils were big*** | Deepening concern, emotional response to his presentation | Physical presentation and behaviours observed *of-ASC* | Physicality of Body Presentation | Lived Corporeality |

| | | | | | |
|---|---|---|---|---|---|
| | | Alarmed | | | |
| 121 | ***'I'm looking down and everything's wonderful and I can see fabulous things', very much like he was flying above everything.*** | | Description of Landscape<br>Sense Making | Time as a Predictor<br>Historicity of Relationships | Lived Temporality<br>Lived Relationality and Discourse |
| 124 | ***It was really weird. Well, I'm not easily shocked 'cos literally every day was a different thing. Bear in mind we have three children, and I hadn't taken them in at this point, and I think around that time they thought I should bring the children in 'cos he needs a reality check*** | Recognises her limits to acceptance of his behaviour but presentation unpredictable and behaviours revealed over time | Unpredictability day-day<br>Strategies suggested by staff to promote re-orientation | Inter-relations with the Healthcare Professional | Lived Relationality and Discourse |
| 128 | ***and that was really badly managed*** | Anger, frustration, powerless | Evaluating decision to introduce his children to him as poorly managed and harmful | Inter-relations with the Healthcare Professional | Lived Relationality and Discourse |
| 129 | *They said they'd take us into a private room, and it* **was a little, small room** *and my sister was with us* | Emotionality of preparing for their children to meet their father – sense of anticipation<br>Pensive, Afraid | Space remembered as significant: claustrophobic and imposing<br>Dimensions of the room significant and imposed emotionality of context | Inter-relations with the Healthcare Professional<br>The 'Therapeutic-ness of the Lived Space | Lived Spatiality |
| 130 | *and the minute he saw the children* **he shuffled down the hall***, he got really upset, but he was really* **sobbing and howling***,* | Anger as predictions realised | Physical presence of her husband infers vulnerability.<br>Remembered her husband's posture and demeanour<br>Husband's behaviours distressing | Signifiers of Pre-injury, 'Legacy Self' | Lived Corporeality |
| 132 | ***So that was traumatising for everyone*** | Sense that her predictions of the planned meeting were realised | Effects of his corporeal presentation and behaviours felt | | Lived Relationality and Discourse |

| | | | | | |
|---|---|---|---|---|---|
| | | Frustration<br>Worried | | | |
| 134 | *No, he says when he looked back, he* ***just looked at them with regret that he wasn’t here anymore and he still didn’t think he was alive, so he wasn’t thinking, ‘oh it’s lovely to see my children again’, he was thinking that he’d lost them*** | Realised that because he was delusional, he believed his children were also dead<br>Worried<br>Sadness | His delusions described<br>His profound delusion that he was ‘dead’ influenced his perceptual understanding of events and affected relationships henceforth | Historicity of Relationships | Lived Relationality and Discourse |
| 139 | *Yeah, I mean there was no way I could have got into his mind set at the time. And I think the day after that,* ***‘cos me and my mum and my sister were constantly thinking what we could do to get him back*** | Sense that she couldn’t ‘connect’ with her husband<br>Hopeless<br>Afraid | Considered strategies to re-orientate and ‘return’ to legacy self and relationship | Historicity of Relationships | Lived Relationality and Discourse |
| 141 | *you* ***know, we took him in the chair up to the café to think more people around, more normality*** | Anticipation<br>Apprehension | Public space of hospital café – opportunity for re-orientation | The Lived Space Tests for the Presence or Absence of Signifiers of Pre-injury, ‘Legacy Self’ | Lived Spatiality |
| 143 | ***and he was looking fearfully around him all the time but the reality thing seemed to be good*** | Hopeful | Sense that he was disturbed by his environment, but Patricia felt that the reality imposed by the ward was beneficial | The ‘Therapeutic-ness of the Lived Space | Lived Spatiality |
| 144 | *and we were thinking it had gone quite well. Then we went to the day room when we came back and there was a man that had come for day treatment that he was talking to quite normally and I was thinking,* ***oh, this is brilliant, it is really good that he is really improving..*** | Hopeful<br>Expectancy | Initially reassured that his behaviours and interactions with others were normal | The Lived Space Tests for the Presence or Absence of Signifiers of Pre-injury, ‘Legacy Self’<br>Signifiers of Pre-injury, ‘Legacy Self’ | Lived Spatiality<br>Lived Corporeality |
| 148 | *And then just as we had been chatting for a while, the man said something* | Hopeless<br>Despondency | Delusion that his was dead remained persistent despite | The Lived Space Tests for the | Lived Spatiality |

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|  | *and he kind of threw in,* ***'yeah, I used to think that when I was alive as well'*** |  | her belief he was improving. | Presence or Absence of Signifiers of Pre-injury, 'Legacy Self'<br>Presence or Absence of Signifiers of Pre-injury, 'Legacy Self' | Lived Corporeality |
| 151 | *And it was kind of bizarre because he was starting to* ***seem quite normal by them, relatively speaking*** *and the man kind of looked at him. It got less every day.*<br>*There was still kind of paranoia there*<br>*I think the last of it was he'd woken up the morning after he'd come home and probably holding his head, and* ***I said, 'have you got a headache?' and he looked at me and said, 'oh, how do you know!' like really horrified.*** | Concern persisted as to his level of orientation<br>Anticipation<br>Optimistic followed by despondency | Reminder that despite the initial reassurance he was improving, his actions and behaviours suggested that he remained delusional | Historicity of Relationships | Lived Relationality and Discourse |
| 161 | *Still paranoid, yeah. And he looks back on it, when we have spoken about it, he did feel there was a bit of* ***a near-death experience somewhere in there***<br>*Oh, and at one point in that week****, he did look at me and say that he'd felt the blood run out of him and gone cold, which was really chilling to hear*** | Affected by the extent and content of his delusions | ASC perceptual disorders persisted | Historicity of Relationships | Lived Relationality and Discourse |
| 166 | *Because that is exactly what had happened and* ***when the doctor spoke to me, they had blood all over them and their shoes were splattered, so I think it had been quite shocking experience for them*** | Alarmed<br>Fear<br>Pensive | The physical presentation of the surgeon influenced her understanding of the seriousness of her husband's situation and challenges of the surgery | Inter-relations with the Healthcare Professional<br>The Inferred Narrative: Tension, Bargaining and Narrative Tone | Lived Relationality and Discourse |

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| 168 | *And he seemed to -* ***I suppose the anaesthetic would have maybe taken its hold,*** *he seemed to have some awareness of that time. And he went on to study hypnotherapy afterwards, so* ***he was very interested in the fact that people still have awareness when they're under anaesthetic or the unconscious mind*** *and that* ***surgeons should be careful what they say when people are under anaesthetic.*** | | Sense making – attempts to provide justification and rationale for his ASC behaviours and presentation | Inter-relations with the Healthcare Professional<br>The Inferred Narrative: Tension, Bargaining and Narrative Tone | Lived Relationality and Discourse |
| 179 | ***He was*** *really different* ***after he'd had his brain operation, like*** *really different* | Concern and fear about his behaviours and actions | Changes to self, realised | Physicality of Body Presentation | Lived Corporeality |
| 185 | ***It used to make me a bit frustrated sometimes*** *'cos I didn't feel like his family understood and I felt they glossed over it and* ***that perhaps he leaned on me a lot more*** | Frustration<br>Pensive | Lack of family understanding and support<br>Advocacy and dependency | Historicity of Relationships | Lived Relationality and Discourse |
| 187 | *I had to* ***kind of cover for him a lot more to keep his sense of pride with his family*** | Protects her husband<br>Sense of his vulnerability | Need to 'hide' his behaviours *of-ASC* from family members<br>Advocacy | Historicity of Relationships<br>The Inferred Narrative: Tension, Bargaining and Narrative Tone | Lived Relationality and Discourse |
| 208 | *There's a big lack of understanding in* ***how people are left*** | Frustration<br>Sadness | Lack of understanding of the effects of brain injury<br>Sense of isolation | Historicity of Relationships<br>The Inferred Narrative: Tension, Bargaining and Narrative Tone<br>Physicality of Body Presentation | Lived Relationality and Discourse<br>Lived Corporeality |
| 214 | *I think I was, by his bedside we were* | Pensive | Assessments made of | Time as a Predictor | Lived Temporality |

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| | *only* ***thinking, the only timespan we could think in at that point was minute by minute****. Me and my sister and my mum just kind of said, ‘we’ll just take it minute by minute and kind of* ***minute by minute, he seemed to improve over night****.* | | progress or otherwise over time | | |
| 220 | *Well,* ***he didn’t go downhill, you know, when the nurses came round and did the observations and whatever.*** | Optimistic | Outcome of observations reassured her regarding possible outcome | Inter-relations with the Healthcare Professional<br>The Inferred Narrative: Tension, Bargaining and Narrative Tone | Lived Relationality and Discourse |
| 222 | ***They were pleased with whatever they found*** | Optimistic | Outcomes of assessments and observations made by staff reassuring with respect to prognosis | Inter-relations with the Healthcare Professional<br>The Inferred Narrative: Tension, Bargaining and Narrative Tone | Lived Relationality and Discourse |
| 222 | *Like the swelling, I mean, when we went to him his whole face and neck and everything was really swollen up and you could* ***see the swelling going down during the night, so you could actually*** *see that he was looking a bit better as well* | Optimistic Expectancy | Physical appearance remembered and reassured by his improvements | Physicality of Body Presentation | Lived Corporeality |
| 229 | ***They didn’t really do anything.*** *They were really nice and I think stretched, you know, between a lot of people* | Resigned Despondency | Perceived lack of interventions | Inter-relations with the Healthcare Professional | Lived Relationality and Discourse |
| 231 | *and it’s only through my* ***own research that I’ve heard the term postoperative psychosis*** | | Searching for information<br>Isolation | Inter-relations with the Healthcare Professional | Lived Relationality and Discourse |

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| 232 | *and if somebody* ***had told me that it might have made*** *me feel a bit better* | Frustration | Lack of Information<br>Need for reassurance<br>Isolation | Inter-relations with the Healthcare Professional | Lived Relationality and Discourse |
| 233 | ***‘cos I didn’t know whether he’d just always be like that*** | Anticipation<br>Nostalgic<br>Expectancy | Questioning prognosis and potential or otherwise for recovery | Historicity of Relationships<br>Presence or Absence of Signifiers of Pre-injury, ‘Legacy Self’ | Lived Relationality and Discourse<br>Lived Corporeality |

## APPENDIX 14 Illustration of Matrices of Data Analysis of the Superordinate ‘*Meaning Structure*’: Lived Corporeality *in-ASC* and *of-ASC*

| **Superordinate ‘*Meaning Structure*’: Lived Corporeality *of-ASC*** | | | | |
|---|---|---|---|---|
| **Field notes / diary entries/ reflections / context of emotions / Narrative Tone** | **Data Extracts of Verbatim Text (Witness) Phrases of significance / singular statements/ ‘*rhetorical gems’* (Van Manen, 2014, p. 320)** | **Naïve / Tentative Interpretation Subtext / Inferences** | **Subordinate ‘*Meaning Essence’*** | **Superordinate ‘*Meaning Essence*’** |
| Despondency / Hopelessness | ‘*And it got to about the third or fourth week and they said that the ventilator, they couldn’t switch it off because she wasn’t responding to anything really*’(Mary:W7) | Body not responding, Risk that if artificial ventilation was discontinued, her daughter, Donna would not survive.<br>Dependency on ventilation to survive | | Dependency of Lived Corporeality |
| Willingness to try and effect improvement but despondent and concern. Highly emotional to witness the bodily effects of the ABI and not be able to effect improvement<br>Tone: Foreboding, Ominous, Uncertainty | *‘And then her arms and legs went stiff and went into complete spasm, and went into the cerebral palsy stage and every time we tried to straighten her arm, we couldn’t do it’ ’(Mary:W14-16)* | Abnormal body presentation: reaffirmed concern regarding Donna’s prognosis | | Physicality of Body Presentation |
| Tone: sense of abandonment by staff Anger | *‘We didn’t know she was blind, we didn’t know she couldn’t speak, we didn’t know she couldn’t sit up’(Mary:W56)* | Extent of possible functional limitations realised – visual impairments, lack of speech and unable to maintain sitting position<br>Lack of information disclosure | | Physicality of Body Presentation |
| Tone: prophetic, despondent, | ‘*She just slept and couldn’t do any physio, any speech and* | Unable to engage in rehabilitation<br>Persistent ‘sleeping’ | | Physicality of Body Presentation |

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| concerning. Doubtful that recovery would be realised | *language, she couldn't do anything'*(Mary:W146) | | | Dependency of Lived Corporeality |
| Observing her daughter's presentation was distressing. Not able to calm her or effect changes to her behaviour | '*When she was distressed. It was horrendous, absolutely horrendous. She would scream 24 hours, just totally scream. She didn't respond to any of our voices*'(Mary:W45)<br>'*Screaming and it was a constant scream*'(Mary:W58) | Incessant behaviour which was uncontrollable or managed. Haunting presentation / prophetic outcome | | Physicality of Body Presentation |
| Tone: relief, hopeful, reassured | '*He seemed quite himself and I felt quite relieved that I felt like I could joke with him a bit and he seemed OK*' (Patricia:W37) | Recognised behavioural signifiers of her husband, David | | Signifiers of Pre-Injury, 'Legacy Self' |
| Anticipation<br>Apprehension | '*To see whether he could breathe on his own, so that was a big step that when he could do without the breathing things*'(Patricia:W35-36) | Attempts to discern whether Patricia's husband, David (his body: corporeal being) would survive independent of artificial ventilation | | Dependency of Lived Corporeality |
| Assessment of her husband's behaviour was concerning in comparison to his pre-injury 'legacy self'<br>Worried | '*I think he was taking some medicine and I said: Oh, knock it back, and he looked at me really confused. And anything you say, I can't think of another example but he would literally take things as you said them, which was strange*' (Patricia:W75) | David's behaviours and responses unusual – takes language literally. Comparison with pre-injury 'legacy self' | | Signifiers of Pre-Injury, 'Legacy Self' |
| Reassured that he would recover<br>Optimistic | '*I just knew with him being a big, strong bloke that eventually he would get this stuff out of his system and that he would come round'* | Reminiscent of husband, James' physicality prior to ABI. Conviction that he would be able to effect recovery independently | | Physicality of Body Presentation |

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| | (Carol:W11) | | | |
| Despondency, Sadness, highly emotional | ‘*All I remember him saying was that he doesn’t know who I am. He opened his eyes, but he doesn’t recognise anyone, and he couldn’t speak. He’s basically a vegetable* (Sarah:W44). *I could see he’s not the same person, if you know what I mean. I think he was able to move one of his hands but nothing else really apart from moving his legs. He couldn’t do anything else’* (Sarah:W57-62) | Lack of recognition despite eye-opening.<br>Described the physicality of his inabilities | | Physicality of Body Presentation |
| Hearing the prognosis from the consultant was emotional and distressing – realisation of extent of ABI<br>Despondent<br>Worried<br>Pensive | ‘*The consultant kept saying that he would never be the same, never walk, talk, and be like a vegetable’* (Sarah:W206-207) | Sarah’s observations of her brother, Amir’s responses not aligned with those of medical staff | | Contradictions of Lived Corporeality |
| Nostalgic | ‘*Apart from being fussy about his eating habits and* [pause] *he didn’t like wearing pyjamas’* (Sarah:W216) | Sarah reflects on her brother, Amir’s pre-injury habits / preferences | | Signifiers of Pre-Injury, ‘Legacy Self’ |
| Reassured, relief that prognosis may not be as poor as initially predicted<br>Optimistic | ‘*So those kind of things were still there’* (Sarah:W288) | Sarah reflective of her Brother Amir’s pre-injury self with respect to preferences<br>Tone: reassured, hopeful | | Signifiers of Pre-Injury, ‘Legacy Self’ |
| Frustration | *‘He’s not the same but he’s still our brother. He’s not the* | Persistent in reminding family members that still their brother | | Signifiers of Pre-Injury, ‘Legacy Self’ |

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| | *same but he's still our brother'* (Sarah: W53) | amidst the ASC & ABI behaviours | | |
| Reassured | '*I just knew him being a big, strong bloke that eventually he would get this stuff out of his system and that her would come round'* (Carol:W11) | Reminiscent of husband, James' physicality pre-injury.<br>Hopeful that he would independently be able to affect his recovery | | Physicality of Body Presentation<br>Signifiers of Pre-Injury, 'Legacy Self' |
| Nostalgic<br>Optimistic | '*Well, he wasn't frightened of me, and I was holding his hand and he was holding my hand back. I think I just assumed that he knew who I was. I kept giving him a drink and he was like, OK, It was like every day a little bit more of him came back*' (Carol:W45-48) | Reciprocal hand holding reflective of pre-injury relationship. Sense that self was returning despite the ABI | | Signifiers of Pre-Injury, 'Legacy Self' |
| Initially humoured by his behaviour but turned to concern and despondency<br>Embarrassment | '*He was being promiscuous to the nurses, so I was like, pack it in. I were like, this is not Barry. This is not Barry'* y(Heather:W224) | Behaviour very unlike pre-injury, 'legacy self' | | Signifiers of Pre-Injury, 'Legacy Self' |
| Optimistic | *'I could see at times that he seemed to know, if I spoke to him or anything. I felt there was some kind of understanding there from him, like he would squeeze my hand a bit now and then'* (Patricia:W27-29) | Behaviours suggested that David was 'present' despite his delusions | | Signifiers of Pre-Injury, 'Legacy Self' |

**Superordinate '*Meaning Structure*': Lived Corporeality *in-ASC***

| **Field notes / diary entries/ reflections / context of emotions / Narrative Tone** | **Data Extracts of Verbatim Text (Patient)<br>Phrases of significance / singular statements/ '*rhetorical gems'*** | **Naïve / Tentative Interpretation Subtext / Inferences** | **Subordinate *'Meaning Essence'*** | **Superordinate *'Meaning Essence'*** |
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| | **(Van Manen, 2014, p. 320)** | | | |
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| | ‘*legs being in a spa*’ (June:P104)<br>‘*more upright, not lying flat’* (June:P108)<br>*‘very, very uncomfortable at the end’* (June:P108) | Recall of physicality of body during ASC. Able to recall body positioning, responsivity of body, discomfort. Illusions of body presence | Lived Body functions as Pre-Injury, ‘Legacy Self’ | Functionality and Sentience of Lived Corporeality *in-ASC* |
| Alarm<br>Distressed<br>Fear | *‘Later that night somehow, I was on the way to sleep, thinking about sleeping and I touched my head because of a little prick or something. So, I felt it and I then found out that I’d lost half of my head. There was a big gap and then I was absolutely lost. I was in tears. I was thinking what’s happened to me? I was fine before and then I woke up and I was like this’* *(Salar:P15-19)* | Able to recall sleeping (normal circadian rhythm)<br>Recalls sensing physicality of body and realising physical injury through touch. Emotional response to realisation of extent of injury. Unable to comprehend circumstances as cause of injury. Remembers pre-injury status.<br>Tone: devastated, confused. | Lived Body functions as Pre-Injury, ‘Legacy Self’ | Functionality and Sentience of Lived Corporeality *in-ASC* |
| Optimistic that he could affect recovery, but followed by alarm, fear and realisation of reality | ‘*Like I thought in my head I could get back up and it weren’t till I literally tried to get out of bed or I’d try to move and I think, I can’t do this, you know*’ (Salar:P145) | Imagined himself as being able to function as pre-injury self.<br>Realisation that unable to move and function physically. | Functional Limitations Realised | Functionality and Sentience of Lived Corporeality *in-ASC* |
| Conviction | ‘*I was in bed, I was in bed, and I was moving round on a hoist*’ (Donna:P152-153) | Recalls being in bed and position in hoist during ASC | Lived Body functions as Pre-Injury, ‘Legacy Self’ | Functionality and Sentience of Lived Corporeality *in-ASC* |
| Frustration<br>Anger<br>Alarm | ‘*I remember thinking, I need the toilet, why is no one listening to me? I need the toilet, I was catheterised at the time, but I remember thinking, I need the toilet, I need the* | Recalls feeling able to recognise need for toilet. Persistent requests not heard.<br>Tone : frustrated, angry | Lived Body functions as Pre-Injury, ‘Legacy Self’ | Functionality and Sentience of Lived Corporeality *in-ASC* |

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| | *loo. I needed to pee. You just take me to the toilet here, right now*' (Donna:P174-176) | | | |
| Optimistic | '*The mind thinks there's nothing wrong*' (Salar:P29) | Belief that brain functioning normal, but reality of limitations very different | Functional Limitations Realised | Functionality and Sentience of Lived Corporeality *in-ASC* |
| Initially optimistic but followed by despair and alarm | '*Yeah, I thought I was perfect. I could do everything but obviously, I couldn't*' (Salar:P122) | Belief that he was able to function as pre-injury self but limitations quickly realised | Functional Limitations Realised | Functionality and Sentience of Lived Corporeality *in-ASC* |
| Alarm<br>Embarrassment | '*picked it up with my left hand and put it straight into my mouth like a baby and it missed and went on top of my head and everything*' (June:P151-152) | Recalls movement of hand but unable to feed herself | Functional Limitations Realised | Functionality and Sentience of Lived Corporeality *in-ASC* |
| Frustration<br>Alarm<br>Fear<br>Despondency | '*I was sat looking at my hands and absolutely nothing worked. I just had no idea what to do. I didn't know how to pick up my hands. I had no knowledge of what to do with your fingers to make a pen*' (June:P280-282) | Reflects on physical body and presentation. Unable to affect movement of hands. Difficulty in comprehending why he was not able to function normally. | Functional Limitations Realised | Functionality and Sentience of Lived Corporeality *in-ASC* |
| Optimistic | '*What I did was, I made a plan, I thought with this finger and then I moved it into my thumb, then at the same time I imagined moving my thumb on the other hand' (Salar:P41-43)* | Purposefully tried to effect strategies to move hand. Utilise strength of imagination<br>Intentional body actions | | Intentionality of Lived Corporeality *in-ASC* |
| Strength of conviction | '*So, I had this heart – it was like a Tiffany necklace, and I had it in my hand… I would not release it from my hand….. cos I thought it was in my hand*' (Donna:P105-107) | Purposeful actions and conviction<br>Intentional actions | | Intentionality of Lived Corporeality *in-ASC* |

## APPENDIX 15: Summary Table: Criteria for Rigour in Hermeneutic Studies

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| De Witt, L., and Ploeg, J. (2006) 'Critical Appraisal of Rigour in Interpretive Phenomenological Nursing Research', *Methodological Issues in Nursing Research,* Vol 55, Issue 2, pp. 215-229 | Balanced Integration<br>'Openness' to scrutiny<br>Concreteness<br>Resonance of research findings |
| Munhall, P. (1994) *Revisioning Phenomenology: Nursing and Health Science Research.* US, National League for Nursing | Readability Resonance Reasonableness<br>Recognition<br>Raised Consciousness Relevance<br>Responsibility<br>'The Phenomenological Nodding' |
| Van Manen, M. (1990) *Researching Lived Experience. Human Science for an Action Sensitive Pedagogy*. State University of New York Press, USA, p. 151. | Orientation<br>Strength<br>Richness<br>Depth |
| Van Manen, M. (2014) *Phenomenology of Practice: Meaning-Giving Methods in Phenomenological Research and Writing,* Walnut Creek, CA, Left Coast Press, pp. 355-356. | Heuristic Questioning Descriptive Richness<br>Interpretive Depth<br>Strong and Addressive Meaning<br>Experiential Awakening<br>Inceptual Epiphany |
| Finlay, L., and Evans, K. (2009) (eds) *Relational-Centred Research for Psychotherapists: Exploring Meaning and Experiences*. Chichester, Sussex: Wiley-Blackwell. | Rigour<br>Relevance<br>Resonance<br>Reflexivity |

## APPENDIX 16: Stages of Development in 'The Phenomenological Life-World of an Altered State of Consciousness secondary to Acquired Brain Injury*: The Quest Trajectory'*

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| STAGE 1 | The patient's and witness' '*quest*' or pursuit in search of the patient's pre-injury 'legacy self' and the meaning of the phenomenon of ASC in the context of the acute phase of the patient's ABI, is represented by a horizontal line, defined as '*The Quest Trajectory'* |
| STAGE 2 | At diametrically opposed, polar positions of '*The Quest Trajectory'* are cited '*Restitution*' and *'Chaos'*, which reflect the narrative positions of the patient and the witness. At these positions, there is a dashed line which represents the '*Restitution*' and '*Chaos*' narratives following the patient's recovery, when they gain personal and situational awareness, and upon discharge from the acute, inpatient services. |
| STAGE 3 | The patient's pre-injury, 'legacy self' is positioned on the '*Quest Trajectory*'. The extent to which the patient's pre-injury 'legacy self' is recognised, and character traits, signifiers, identity, and personhood aligned to pre-injury 'legacy self' 'moves' the patient's and the witness' narrative towards '*restitution*'. The dislocation, distancing or derangement of the patient's presentation, identity, and personhood from their pre-injury 'legacy self' and lack of sense-making move the patient's and witness' narrative towards '*chaos*'. |
| STAGE 4 | The superordinate *'meaning structures': lived spatiality, lived corporeality, lived temporality, lived relationality and discourse*, sit on a conceptual arc and directly influence the meaning of ASC both for the patient and the witness, along the '*Quest Trajectory'*. The arc illustrates how the *'meaning structures*' do not influence in a linear or hierarchical manner but dynamically and to varying degrees throughout the patient's and the witness' experience of an ASC. This dynamic influence is represented by a vertically, dashed line. |

**APPENDIX 17: Interest-Influence Matrix of Stakeholder Analysis (adapted from Reed, 2016, p. 115)**

| | | |
|---|---|---|
| **High** ↑ | **Context Setters**<br>Policy makers<br>Neuroscience community policy makers | **Key Players**<br>Engage with key influencers within the neuroscience, ABI communities<br>Clinical practitioners within neuroscience provision<br>Voluntary & Third Sector organisations<br>Engagement with academics in the field of clinical neuroscience networks<br>Undergraduate & Postgraduate educators |
| **Influence** ↓ | **Crowd** | **Subjects**<br>Individuals affected by an ABI & perceptual disorders associated with neuropathology<br>Patient and Public Involvement groups<br>Voluntary & Third sector organisations<br>Coalition & alliances with practitioners and educators |

**Low** ← **Level of Interest** → **High**

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