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EMMA HART BSc Hons

AN EXPLORATION OF INFLUENCES ON RECOVERY FROM ACQUIRED
BRAIN INJURIES

Section A:

A literature review of the experience of hope in recovery from acquired brain
injuries for individuals and their family members

Word Count: 7987 (319)

Section B: A qualitative exploration of the experience of service user
involvement in the context of personal recovery from acquired brain injuries

Word Count: 7995 (80)

Overall Word Count

15,982 (399)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

APRIL 2018

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

CANTERBURY CHRIST CHURCH UNIVERSITY
Doctorate in Clinical Psychology (D.Clin.Psychol.)

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NAME

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WORK TO BE ASSESSED

(e.g. Clinical Portfolio Part 1, Child PPR, QIP)

Major Research Project

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15982 (399)

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Thank you to my supervisors, Dr Edyta Monika Hunter, and Dr Leigh Emery, for your invaluable advice and support throughout this project.

Thank you to Will for your unrelenting belief in me, and for keeping me functioning. Thank you to my family and friends for being endlessly supportive and patient with me.

Thank you to my nan, Maureen Conway, for always believing I could succeed at anything I put my mind to.

Summary of the Major Research Project

Part A: consists of a literature review of the experience of hope during recovery from acquired brain injuries for both individuals and their families. Thirteen studies were identified using a systematic literature search for inclusion in the review. The results of the studies were synthesised, and a methodological critique was provided. Findings suggested that hope was experienced as a future-orientated life force that served as a coping mechanism to manage distress and uncertainty, and as a driver for action to obtain hoped for recovery outcomes. The implications for research and clinical practice were considered.

Part B: consists of an empirical study that investigated the experience of service user involvement (SUI) in the context of personal recovery from acquired brain injuries (ABI). Semi-structured interviews were conducted with ten participants. The results were analysed using Interpretative Phenomenological Analysis. Three main influences were identified. SUI provided participants with a sense of connection to their life before ABI. It increased their sense of agency in recovery by empowering them. It also provided vital opportunities for social connection with others. These findings were discussed in relation to extant literature, and implications for future research and clinical practice were considered.

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Section A:

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CANTERBURY CHRIST CHURCH UNIVERSITY

Abstract

Background: The impact of acquired brain injuries is complex, and recovery is often lengthy and uncertain for both the individual and their family members. Hope may be an important experience that leads to better adjustment and improved recovery outcomes.

Aim: This literature review aimed to understand the experience of hope in recovery from acquired brain injuries for the individual and their families.

Method: A systematic literature search of four databases identified thirteen studies (n= 9 qualitative studies, n= 4 cross-sectional studies) that met specific inclusion criteria for this review. Studies were assessed for quality and results were synthesised.

Results: Hope was experienced as a future-orientated life force that served as a coping mechanism to manage distress and uncertainty, and as a driver for action to obtain hoped for recovery outcomes. Individuals fluidly moved between experiencing general hope, specific hopes, and at times, loss of hope. Several influencing factors were identified. However, difficulties with measurement of hope and recovery, and gaps in the literature meant it was not clear if these results were generalisable.

Conclusions: Further research is needed to determine if the results of this review apply to the acquired brain injuries population as a whole.

Key words: acquired brain injuries, family members, hope, recovery.

1. Introduction

1.1 What is hope

“There is no medicine like hope, no incentive so great, and no tonic so powerful as expectation of something tomorrow.” *- Orison Swett Marden*

Hope is recognised as a central part of the experience of chronic illness and disability, as it enables individuals to cope with the losses and changes to their life circumstances, particularly when the outcome is uncertain (Korner, 1970). It is said to support individuals to feel more positive, behave more adaptively, and have more fulfilling relationships (Fromm, 1968), and leads to better physical outcomes and psychological adjustment (Snyder, 2009). But what is hope? For decades, theorists and researchers have grappled with this question, and a consensus has not yet been reached (Snyder, 2000). Currently, hope is widely regarded to be a dynamic and multi-dimensional concept, which evolves and changes as life progresses and with important life events (Duggleby et al., 2012). Dufault and Martocchio (1985: p 380) defined hope as “a multidimensional life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant.”

Two conceptualisations of hope are presently used. Farran, Herth and Popovich’s (1995) hope process framework positioned hope as a multi-dimensional experience that encompassed ways of thinking, feeling, behaving and relating to oneself and others’ worlds. This experience is described as fluid and could also still be present even if the desired outcome did not occur. They described four key attributes of hope that co-occurred; hope as an experiential process, as a spiritual/transcendent process, as a rational thought process and as a relational process. They suggested hope may be present throughout life in a superficial way, but that difficult life experiences such as a life-threatening illness may awaken a deeper

superordinate hope representative of an individual's highest hopes for life. Snyder's (2000) theory of the concept of hope positioned this as a goal-oriented cognitive thought process that was based on pathways thoughts and agency thoughts. Pathways thoughts were the routes that individuals conjured to achieve their goal. Agency thoughts were the motivational and willpower related thoughts that enabled individuals to take steps to achieving their goal. Emotions were considered a consequence of this cognitive thought process. Those who could imagine multiple pathways to achieving their goals were more likely to be able to overcome barriers, as they had alternate routes to goal achievement available.

1.2 ABI, impact, and recovery process

People with acquired brain injuries (ABI) have repeatedly expressed that hope is an important part of their recovery (Levack, Kayes & Fadil, 2010, Pearce et al., 2008; Salter, Hellings, Foley & Teasell, 2008). Acquired brain injury (ABI) is an umbrella term for sudden-onset injuries to the brain that are non-progressive and occurred after birth and the neonatal period (Royal College of Physicians, 2003). ABI's are a major health concern for the NHS in the UK, as they are one of the leading causes of death and long-term disability (Headway, 2015; Public Health England, 2017). There are many types of ABI, including traumatic brain injury, stroke, infections, injuries due to lack of oxygen (anoxia), and injuries due to other toxic or metabolic insults (Royal College of Physicians, 2003). Traumatic brain injuries and strokes are the most common types of ABI (Headway, 2015).

There are several factors unique to the experience of an ABI that means that hope in recovery may be of particular importance. The sudden onset and wide-ranging impacts of ABI can disrupt people's lives to the core (Yeates, Gracey & McGrath, 2008). The biological consequences of ABI alone are brain damage that can affect any range of physical, cognitive, emotional and behavioural domains (Turner-Stokes, Nair, Sedki, Disler & Wade, 2005).

However, the impact of ABI stretches even further to psychological and social consequences in addition to the biological consequences (Ellis-Hill, Payne & Ward, 2008; Williams & Evans, 2003). Bury's (1982) theory of biographical disruption suggested that a sudden onset of chronic illness drastically disrupts an individual's life, as it creates new and qualitatively different conditions that ruptures an individual's sense of continuity over time. This disruption challenges everyday physical, emotional and social lives, and leaves a person in a state of uncertainty. Meta-syntheses of the experience of traumatic brain injury (Levack et al., 2010) and stroke (Pearce et al., 2008; Salter et al., 2008) provide support for the relevance of this theory. All three reviews found that individuals commonly reported experiencing a sudden sense of catastrophe and loss that endures for many months and sometimes even years after the injury. Participants reported not recognising the person they were now compared to their pre-injury life. Their bodies had become unpredictable, leading to loss of sense of control and independence. They reported changes in relationships and roles, leading to social isolation and withdrawal. Participants reported suffering because of these impacts; they experienced these changes as intensely distressing, reporting uncertainty and fears about the future, grief and loss, depression, anger and helplessness. This suffering and uncertainty could form the grounds for deeper hopes essential to life to come to the forefront of an individual's life and mind (Farran et al., 1995).

The complexity of the consequences of ABI means that recovery is also not without its challenges. Surprisingly, there is no clear definition of recovery in the context of long-term and chronic illness. Therefore, for the purpose of this review, recovery is defined as the process by which individuals come to lead a personally satisfying life in the context of the biological, social and psychological sequelae of illness. In ABI, this process involves several tasks. Individuals may need to complete functional rehabilitation to regain skills or learn to compensate for lost skills (Robertson & Murre, 1999). They may need to re-think their life

story and self-concept to incorporate the ABI, and re-integrate into a social world (Levack et al., 2010; Pearce et al., 2008; Salter et al., 2008). This process is often described as lengthy, slow and stalled, and filled with uncertainties because of difficulties in predicting outcomes due to the complex nature of brain injuries (Creutzfeldt & Holloway, 2012; Kirkevold, 2002; Maas, Stocchetti & Bullock, 2008). Individuals may experience several transitions, for example, from acute care to neuro-rehabilitation, and from neuro-rehabilitation to home, and at each point new losses may emerge, or existing losses may be re-enforced (Chamberlain, 2006). Therefore, the recovery process towards achieving a satisfying life can stretch over many years and may involve ongoing professional input. Hope may be a crucial factor in developing understanding about how individuals are able to cope with this lengthy process and sustain efforts to work towards recovery despite significant uncertainty about what might be achieved.

1.3 Family members of individuals who experience ABI

Family members play an important role in the recovery from ABI for the individual. Their involvement in supporting the person with ABI has been shown to improve recovery outcomes (Sander et al., 2002), yet family members experience their own needs that may impact their ability to provide support. They may experience shock, anxiety and despair upon learning the individual has experienced an ABI (Cecil, Thompson, Parahoo & McCaughan, 2012; Verhaeghe, Defloor & Grypdonck, 2005). They may need to adjust to becoming the primary caregiver for the person with ABI, which can be physically demanding (Bakas, Austin, Okonkwo, Lewis & Chadwick, 2002), and due to the nature of ABI was perceived to require constant adaptation (Brereton & Nolan, 2000). The role changes associated with this may impact on their relationship with the person with ABI, other important social relationships, and work commitments (Lynch et al., 2008; Verhaeghe et al., 2005). This means that stress, depression, anxiety and burden are not uncommon experiences that can

impact on the family members' own wellbeing and their ability to support the individual with ABI (Berg, Palomaki, Lonnqvist, Lehtihalme & Kaste, 2005; Han & Haley, 1999; Marsh, Kersel, Havill & Sleigh, 2002). Yet some family members seem more able to cope with these challenges and report higher wellbeing than others, which they attributed to their ability to have hope (Verhaeghe et al., 2005). Thus, understanding the experience and function of hope in family members seems equally pertinent due to their important role in promoting improved recovery outcomes for the individual with ABI.

1.4 Hope in recovery from ABI

Despite the potential importance of hope in the recovery process for individuals who experience ABI and their family members, most research to date has focussed on the consequences of the absence of hope, or hopelessness, of which the core clinical manifestation is depression (Kim et al., 2007; Taylor, Todman & Broomfield, 2011). Hopelessness is defined as a separate but related concept to hope, which “functions as a feeling of despair and discouragement, a thought process that expects nothing, and a behavioural process in which the person attempts little or takes inappropriate actions” (Farran et al., 1995; p 25). Hopelessness impedes recovery, as individuals report it prevents them from taking actions conducive to healing and recovery (Jones, Mandy & Partridge, 2007). However, if hope and hopelessness are seen as dynamic concepts which evolves over time, individuals may experience different levels of hope and hopelessness throughout their recovery (Farran et al., 1995; Snyder, 2000). Out of the two concepts, it is hope that has the potential to be the precursor for engaging in recovery-related activities that help individuals to adjust to and overcome physical, psychological and social consequences of ABI (Collins & Kuehn, 2004; Rochette et al., 2007; Jones et al., 2009; Ylvesaker et al., 2008). This means it is important to understand hope, as well as hopelessness, in recovery from ABI.

Despite the potential important role of hope in recovery from ABI, a very limited amount of research exists on this topic. One review of hope exists in the ABI literature; Bright, Kayes, McCann and McPherson (2011) conducted a construct analysis of hope after stroke. They found preliminary evidence that hope was an inner state, an active process, and as an outcome-oriented process. These three attributes interacted and led to increased participation levels in rehabilitation, increased adjustment and coping, and an overall perception of better quality of life. However, they acknowledged their construct had not reached maturity, due to the dearth of research directly conducted on hope which meant their literature review was predominantly based on research that was not directly intended to investigate hope.

It is possible that due to the incredibly heterogeneous population of people who experience ABI, it has been difficult to conceptualise hope in a unified way. There may be a wide range of experiences that individuals understand as hope, and a wide range of factors that influence why some individuals appear to be able to hold more hope than others. Therefore, it seems important to understand the experience of hope in this population at this stage of the existent literature. This may prove particularly useful for staff working with these populations, as research with clinicians supporting individuals and families with ABI found that they may report different ideas about the role of hope in recovery than the individuals they are supporting (Schutz, Coates, Engelberg, Curtis & Creutzfeldt, 2017; Tutton, Seers, Langstaff & Westwood, 2011). Hope is also currently not included in any clinical guidelines on recovery from ABI (NICE, 2013; SIGN, 2013). A review of this topic may therefore assist clinicians in understanding the contribution of hope to recovery, and offer information about how to support hope in this population, potentially leading improved recovery (Bright et al., 2011).

1.5 Aim of this review

This literature review aims to answer the question: “what is the experience of hope in recovery from ABI for adults who experience an ABI and their families?” The purpose is to integrate all existing knowledge on this topic to create new perspectives that may be particularly pertinent to staff working with these populations. Given that the population of those who experience ABI is very heterogeneous, attention will be paid to any differences between populations, and gaps in knowledge, to accurately review what is known at this point in time.

2. Methodology

2.1 Inclusion and exclusion criteria

This review included both qualitative and quantitative studies published in peer reviewed journals about hope in adults who experienced ABI or their family members. Research studies needed to meet the inclusion and exclusion criteria as displayed in Table 1.

Table 1: Inclusion and exclusion criteria

| Research inclusion criteria | Research exclusion criteria |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> • Studies must be published in a peer-reviewed journal • Studies must be written in English language • Studies must have aimed specifically to investigate hope • Studies must have been completed with either individuals who experienced an acquired brain injury or their family members • Participants must have been adults (age 18 or above) • Studies must have met the minimum data quality deemed acceptable by the quality appraisal tools used. | <ul style="list-style-type: none"> • Studies that used paediatric populations (under the age of 18) • Studies that did not specifically investigate hope • Studies that did not focus on the role of acquired brain injury in recovery (e.g. studies investigating questionnaire validity) |

2.2 Literature search method

A systematic literature search was conducted to identify appropriate research studies according to the inclusion and exclusion criteria. The search process is illustrated in Figure 1.

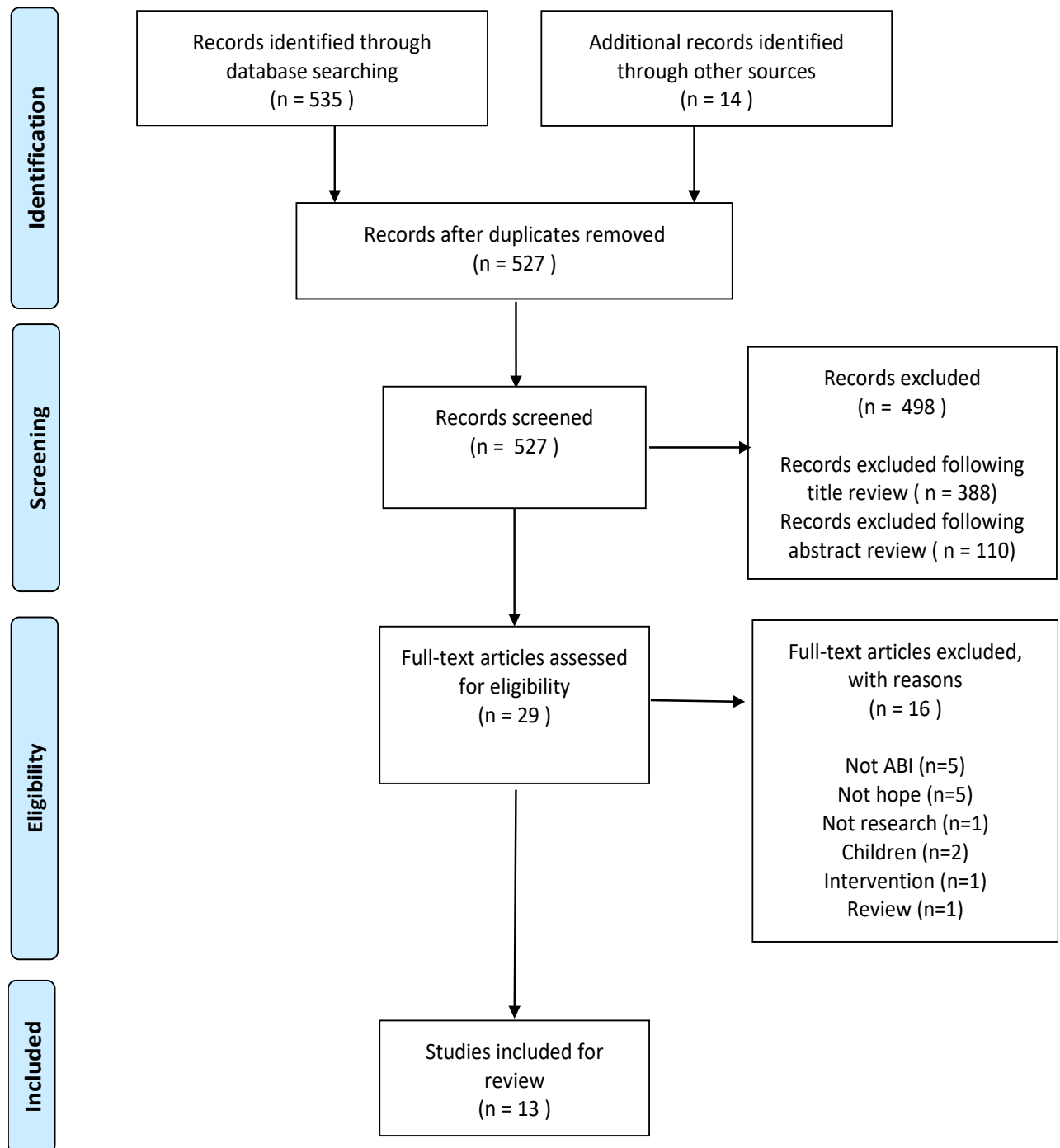


Figure 1: Flowchart with an overview of the literature search process (PRISMA, 2009).

In November 2017, an electronic search was conducted of four research databases; Psychinfo, Medline, Web of Science and the Applied Social Sciences Index and Abstracts (ASSIA). The following search terms were used: Acquired brain injury OR traumatic brain injury OR head injury OR stroke OR cerebro-vascular accident OR cerebral ischaemia OR cerebral haemorrhage OR brain damage OR hypoxia OR anoxia OR brain tumour OR meningitis OR hypoglycaemia AND hope (see Table 2). All terms were auto-expanded to include any other spellings or historical names for these terms. Results were limited to research published in peer-reviewed journals in English language. The time frame was restricted to results from the year 1991 to present, as a preliminary search revealed this was the earliest that relevant research articles began to emerge.

Table 2: Literature Search Terms

| Literature Search Terms | |
|------------------------------------------|-----------------------|
| <i>Terms for Acquired Brain Injuries</i> | <i>Terms for hope</i> |
| Acquired brain injur* OR | AND Hope |
| Traumatic brain injur* OR | |
| Head injur* OR | |
| Stroke* OR | |
| Cerebr* vascular accident* OR | |
| Cerebral ischaemia OR | |
| Cerebral haemorrhag* OR | |
| Brain damage OR | |
| Hypox* OR | |
| Anox* OR | |
| Brain tumour OR | |
| Meningitis OR | |
| Hypoglycaem* | |

Initially, all search results were screened by reviewing the information in the title and abstract against the review inclusion and exclusion criteria. Following this, all search results that appeared to meet the criteria and those from which it remained unclear were subjected to a full text review. The reference lists of all these studies were reviewed to identify further results that could meet the inclusion criteria, of which the results were also subjected to abstract reviews and full text reviews as described above.

Thirteen studies were identified that met the inclusion and exclusion criteria for this review. Nine studies were conducted with individuals who experienced an ABI (stroke n= 8; traumatic brain injury n=1). Three studies were completed with family members of those who experienced an ABI (mixed stroke and traumatic brain injury n=2; traumatic brain injury n=1). One study was completed with both individuals and their family members (stroke n= 1) but reported the results for the two groups of participants separately. Most studies were of qualitative design (n=9), and some used cross-sectional designs (n=4).

Studies were next subjected to a quality appraisal for methodological rigour, assisted by quality appraisal tools. Qualitative studies were assessed using the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (CASP, 2017). Cross-sectional studies were assessed using the “Strengthening the Reporting of Observational Studies in Epidemiology” (STROBE) checklist for cross-sectional studies (STROBE, 2007).

3 Literature Review

This review is structured in four main sections. Firstly, a summary of the thirteen studies reviewed is presented in Table 3. Then, a methodological critique is given. This was presented in this order, as the critical appraisal revealed a significant overlap in the methodological issues across the thirteen studies which impacted on the synthesis of the findings pertaining to the review question. Following this, a synthesis of the available

literature was provided in light of the methodological limitations. This was structured in three sections; the experience of hope for individuals who experienced a stroke, traumatic brain injury, and family members. Finally, the implications for practice and future research were considered.

Table 3: Study summary table

| Study Authors | Population | Aim | Design | Participants | Stage of recovery | Key findings |
|-------------------------------------------------------|----------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Gelling (1999) <i>United Kingdom</i> | Traumatic brain injury Family members | To understand the experience of hope for relatives of people who were in an intensive care unit (ICU) following severe traumatic brain injury. | Qualitative design: semi-structured interviews, analysed using phenomenological analysis. | N= 7 participants whose relative had been in ICU for 48+ hours. <i>Gender:</i> n= 4 female, n= 3 male. <i>Age:</i> Mean age 42 (range: 28-50). <i>Ethnicity:</i> not reported. <i>Relationship:</i> n= 2 mother, n= 2 wife, n= 3 father). | Acute phase – in ICU. Mean time since TBI: 100 hours (range: 64-145 hours) | <ul style="list-style-type: none"> • Hope was present before arriving at ICU. Participants hoped their family member was alive, and that they would get information about what was happening. • Hopes were formulated, achieved and maintained through relationships with others, information and positive progress. Families reported needing to reassess hopes with new information. • Hopes were set in the present (e.g. Hope for person to open eyes) and on the ultimate goal of recovery, but not in between. • Uncertainty developed in absence of information, and this lead to fear, which made it difficult to form hopes. |
| Bays (2001) <i>United States of America</i> | Stroke (age 60+) | To explore patterns of hope and factors associated with these in older adults who experienced stroke | Qualitative design: semi-structured interviews, analysed using descriptive analysis. | N= 9 participants recruited from a stroke survivors support group. <i>Gender:</i> n= 6 male, n= 3 female. <i>Age:</i> mean age =68 (range not reported). <i>Ethnicity:</i> n= 8 Caucasian, n= 1 African American. <i>Type of stroke:</i> n= 7 right hemisphere, n= 2 left hemisphere. <i>Severity:</i> not reported. | Living in the community. Mean time since stroke: 2.5 years (range: 4 months to 4.5 years). | <ul style="list-style-type: none"> • Hope is a life sustaining positive inner strength actively moving the stroke survivor forward toward anticipated future possibilities. • The continuous process of hoping is guided by formulation of personal goals, reflection on previous personal abilities, comparison of current abilities with other stroke survivors, and strong family and spiritual relationships. • Perceptions of progress, supportive family, and spiritual connectedness provided a sense of encouragement, support and belonging • Participants struggled to identify factors that weakened hope. • No one definition of hope fully encompassed the phenomenon of hope as found in this study. |

| | | | | | | |
|---------------------------------------|------------------|---------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Popovich, Fox and Burns (2003) | Stroke (age 50+) | To describe the influence of hope in the recovery process (functional and social recovery) from stroke. | Cross-sectional design: quantitative data. Two time points – time 1 = 10 days post-stroke, time 2 = 3 months post-stroke. | N= 50 participants recruited from 3 hospitals in Midwest USA. <i>Gender:</i> n= 26 male, n= 24 female. <i>Age:</i> mean age= 68 (range: 51-89). <i>Ethnicity:</i> n= 34 African American, n= 16 Caucasian. <i>Type of stroke:</i> not reported. <i>Severity:</i> not reported. | Location during study not explicitly reported. Mean time since stroke: time 1 = 10 days, time 2 = 3-4 months post-stroke. | <ul style="list-style-type: none"> • Self-reported level of hope did not show statistically significant change from time 1 to time 2. However, 46% described less hopefulness at time 2, and 42% described more hopefulness. Those who expressed less hope were male, and described very active pre-stroke lifestyles that became more difficult to achieve after stroke. • Level of hope was not found to be significantly related to functional recovery or social recovery. • Authors wondered whether perhaps not enough time had elapsed to see if those with higher levels of hope experience improved functional and social recovery. |
| <i>United States of America</i> | | | | | | |
| Bluvol and Ford-Gilboe (2004) | Stroke (age 18+) | To examine the relationship among hope, family health work and quality of life in adult couples after one experienced a stroke. | Cross-sectional design: quantitative data. | N= 40 individuals who experienced stroke. <i>Gender:</i> n= 29 male, n= 11 female. <i>Age:</i> Mean age = 69.5 (range: 46-89). <i>Ethnicity:</i> not reported. <i>Type of stroke:</i> n= 25 ischaemic, n= 13 haemorrhagic. <i>Severity:</i> not reported, but most (n= 36) required support at discharge and ongoing support (n= 31). N= 40 family members. <i>Gender:</i> n= 11 male, n= 29 female. <i>Age:</i> mean age = 66.2 (range: 42-89). <i>Ethnicity:</i> not reported. <i>Relationship:</i> n= 40 spouse. | Living in the community. Mean time since stroke 2.5 years (range: 6 months to 5 years). | <ul style="list-style-type: none"> • A moderate positive correlation was found for between level of hope and health work (the active process through which families learn ways of coping that are conducive to healthy living). This finding was at a moderate level for participants who experienced a stroke, and minor for spouses. • A moderate positive correlation was found for participants who experienced a stroke between health work and quality of life. This was not found for spouses. • A positive correlation was found between hope and quality of life. This was at a moderate level for participants who experienced the stroke, and minor for spouses. • The most important predictor of quality of life in stroke survivors was degree of functional independence, followed by level of hope. For spouses, quality of life was most predicted by support available to them, functional independence of their partner, and their employment status. |
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| Arnaert, Filteau and Sourial (2006) | Stroke (age 18+) | To explore perceptions of hope during the acute care phase | Qualitative design: semi-structured interviews analysed using comparative method. | N=8 participants recruited from an acute care stroke ward. <i>Gender:</i> n= 4 male, n= 4 female. <i>Age:</i> mean not reported, age range= 19-90. <i>Ethnicity:</i> not reported. <i>Type of stroke:</i> n= 7 ischaemic, n= 1 haemorrhagic. <i>Severity:</i> n= 5 mild, n= 1 moderate, n= 3 severe. | Acute care – stroke ward. Mean time since stroke: 7 days (range: 2 days – 13 days. One outlier – 50 days). | <ul style="list-style-type: none"> • Participants appeared to identify hope as a life sustaining, positive inner and spiritual strength, which could be influenced by friends and family, and actively influenced progression during the acute care phase. • Their vision of hope was influenced by their appraisal of physical consequences of stroke. • Two types of hope were identified: active and passive. • Passive hope was described as a process where participants had visions of hope but were unable to use that vision as a force for moving forward. They appeared unable to see the future, and were caught up in the present and its associated fears, frustrations and anxieties. • Active hope was described as a process where participants had visions of hope and were able to act upon this hope. They showed acceptance and awareness of their current predicament and, believed adaptation could occur, and started the work of self-healing to achieve new goals. |
| Gum, Snyder and Duncan (2006) | Stroke (50+) | To examine hopeful thinking, depressive symptoms and participation in meaningful activities and roles three months after a stroke. | Cross sectional design: quantitative data. | N= 110 participants recruited from Kansas City Stroke Registry. <i>Gender:</i> n= 46 men, n= 64 women. <i>Age:</i> mean age = 72, range not reported. <i>Ethnicity:</i> 90.1% Caucasian, 9% African American, 0.9% Hispanic. <i>Type of stroke:</i> 91.9% ischaemic, 7.2% haemorrhagic, 0.9% uncertain. <i>Severity:</i> minor 47.3%, moderate 45.5%, severe 7.3%. | Living in the community. Time since stroke 3-4 months. | <ul style="list-style-type: none"> • Level of hopeful thinking was the strongest predictor of depressive symptoms – as hopeful thinking decreased, depressive symptoms increased. Demographic variables and activities did not. • Agency in hopeful thinking was more correlated with depressive symptoms than pathways hopeful thinking (how a person finds ways to pursue their goal). • Participation in meaningful activities was not correlated with depressive symptoms, but physical functioning was. • For the most disabled participants, as hopeful thinking increased, participation in meaningful activity decreased, meaning that this population may strive for unreachable goals, and neglecting more achievable goals. |

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| <p>*Verhaeghe, van Zuuren, Defloor, Duijnste & Grypdonck (2007a)</p> | <p>Stroke and traumatic brain injury</p> <p>Family members</p> | <p>To understand the relationship between hope and information provision by health care professionals for family members of traumatic coma patients in intensive care (ICU).</p> | <p>Qualitative design: semi-structured interviews analysed using grounded theory methodology.</p> | <p>N= 22 participants recruited from 2 hospitals.</p> <p><i>Gender:</i> n= 7 male, n= 15 female.</p> <p><i>Age:</i> mean age = 39 (range: 19-71).</p> <p><i>Ethnicity:</i> not reported, but all native Dutch speaking.</p> <p><i>Relationship:</i> n= 6 parents, n= 5 partners, n= 9 adult children, n= 2 siblings.</p> | <p>Acute phase – in ICU.</p> | <ul style="list-style-type: none"> • Hope and information provision were intertwined. • All family members reported a need for hope • Hope could be defined as keeping a possible positive outcome in mind in an uncertain situation, even if one knows this outcome is unlikely to happen • In general, family members hope for the best for the patient. • Concrete hopes evolved with information and events. Family members wanted honest and clear information about their family member’s condition, to enable them to build realistic hopes. • Hope helped family members to cope, and enabled them to make sure the best care and prospects were maintained for the patient. • Family members did not want to entertain false hope. The consequent negative emotions attached to false hope were perceived as worse than those attached to receiving bad news. |
| <p><i>Belgium</i></p> | | | | | | |
| <p>*Verhaeghe, van Zuuren, Defloor, Duijnste & Grypdonck (2007b)</p> | <p>Stroke and traumatic brain injury</p> <p>Family members</p> | <p>To examine the process of hope that family members experience when their relative is in intensive care due to a traumatic coma.</p> | <p>Qualitative design: semi-structured interviews analysed using grounded theory methodology.</p> | <p>N= 22 participants recruited from 2 hospitals.</p> <p><i>Gender:</i> n= 7 male, n= 15 female.</p> <p><i>Age:</i> mean age = 39 (range: 19-71).</p> <p><i>Ethnicity:</i> not reported, but all native Dutch speaking.</p> <p><i>Relationship:</i> n= 6 parents, n= 5 partners, n= 9 adult children, n= 2 siblings..</p> | <p>Acute phase – in ICU.</p> | <ul style="list-style-type: none"> • The need for hope was expressed by every participant • Hope was described as being constantly present, but what is hoped for changed over time depending on events, information, and how the patient’s condition evolves. • Hope was described as gradually becoming a goal and something that can be aimed for. This gave participants a reason to carry on. • Families where multiple members had the same hopes had a balance that was supporting, understanding and trusting. Families where different hopes were present felt more responsibilities, such as protecting each other. • The loss of hope occurred temporarily, leading to panic and despair in those moments. |
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| Peleg, Barak, Harel, Rochberg and Hoofien (2009) | Traumatic Brain Injury (age 18 to 60) | To investigate the extent to which two coping variables – hope and dispositional optimism – are related to depression severity at least 6 months post-injury. | Cross-sectional design: quantitative data. | N= 65 participants recruited from a neuro-rehabilitation centre. <i>Gender:</i> n= 47 male, n= female. <i>Age:</i> mean age: 28.8 (range: 18-55). <i>Type of TBI:</i> n= 49 road traffic accident, n= 8 war accident, n= 8 fall accident. <i>Severity:</i> n=20 mild, n=5 moderate, n= 40 severe. | During neuro-rehabilitation (not clear if inpatient or outpatient). Mean time since TBI: 2.9 years (range 0.5 years to 9.7 years). | <ul style="list-style-type: none"> • Those with moderate/severe depression had a moderate negative correlation between depressive symptoms and level of hope (both agency and pathways) and dispositional optimism. • Within this group, there was a moderate positive correlation between hope and dispositional optimism. • Those with minimal/mild depression (n= 36) had a moderate correlation with hope (pathways), no correlation with hope (agency) or dispositional optimism. • Hope and optimism contribute distinctly to a person's coping following TBI. Hope was more dominant in predicting depression severity. • The differences in results may mean that for those with minimal/mild depression the main concern is envisioning ways to cope with the trauma (pathways), but for those with moderate/mild depression the concerns are about loss of internal locus of control and positive outlook on life. |
| <i>Israel</i> | | | | | | |
| Cross and Schneider (2010) | Stroke (age 60+) Women | To explore the perceived influence of hope on stroke recovery in women who were at least 6 months post-stroke. | Mixed methods: Qualitative: semi-structured interviews analysed using interpretative phenomenological analysis. Quantitative: two questionnaires and data was compared to interviews to assess consistency in reporting. | N= 10 participants recruited from a medical clinic and a convent. <i>Gender:</i> n= 10 female. <i>Age:</i> mean age = 81 (range 71-100). <i>Ethnicity:</i> not reported. <i>Type of stroke:</i> not reported. <i>Severity:</i> not reported. | Living in the community after receiving neuro-rehabilitation. Mean time since stroke = 5 years (range: 1 year – 13 years). | <ul style="list-style-type: none"> • No discrepancies were found between hope as reported on the two questionnaires and in interviews. • Hope was described as a multi-dimensional concept, which was an unspoken necessity for life, and was the backbone for ultimate recovery. It was a silent motivator that kept individuals fighting and maintained their spirits. • Individuals up to four years post-stroke reported ongoing hope for improvements both generally and in specific domains. • After hope for improvements diminished, participants reported a time of depression, followed by acceptance of their lost abilities and an appreciation of the abilities they had retained. • Hope was influenced by internal, external and personal factors. |
| <i>Canada</i> | | | | | | |

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| Tutton, Seers, Langstaff, and Westwood (2011) | Stroke | To explore the experience of hope for patients and staff at a British stroke unit. | Qualitative design: ethnographic methodology using unstructured interviews and participant observation. | Interviews: N= 10 participants recruited from a stroke unit. <i>Gender:</i> n= 7 male, n= 3 female. <i>Age:</i> mean age not reported, age range 37-72. <i>Ethnicity:</i> not reported. <i>Type of stroke:</i> not reported. <i>Severity:</i> not reported <i>Observations:</i> three shifts of seven hours were observed. Three nurses and their six patients were observed on each shift. | Acute care phase Length of hospital stay ranged from 4 to 19 days. | <ul style="list-style-type: none"> • Participants noticed changes in the way their body functioned, leading to suffering, which was described as emotional and physical distress. • In some participants this lead to descriptions of no hope and despair, which focussed on the closeness of death, leading to low mood (and at times depression), low motivation, and flat affect. Participants wanted to feel hopeful but felt trapped in despair. • For other participants, hope came easily. These participants described believing that life still held much for them if they chose to work at their recovery, even with a heightened awareness of closeness to death. Some hoped to get back to the way things were prior to stroke, and others hoped to find new ways of living or being. Hopes could be general or specific. Participants acknowledged they needed a balanced approach of taking time to recover and striving for hoped for outcomes. • The authors concluded that there was a balance between focus on suffering, no hope and despair, and hope for recovery, mediated through realistic hopefulness. |
| Bright, Kayes, McCann and McPherson (2013) | Stroke Aphasia | To explore how hope is experienced by people with aphasia following stroke during the post-acute period of rehabilitation, and to identify factors that influenced the experience of hope. | Qualitative design: semi-structured interviews were completed, and analysed using an “interpretative description” methodology. Sample: 5 individuals (3 men and 2 women) who experienced left-hemisphere strokes which resulted in aphasia. Mean age =50 (range= 41-62), mean time since | N= 5 participants recruited from two rehabilitation services. <i>Gender:</i> n= 3 male, n= 2 female. <i>Age:</i> mean not reported, age range 41-62. <i>Ethnicity:</i> n= 3 non-indigenous New Zealander, n= 1 Samoan. <i>Type of stroke:</i> n= 5 left hemisphere <i>Severity:</i> not reported | Post-acute (during neuro-rehabilitation) Time since stroke ranged from 2 months to 5 months. | <ul style="list-style-type: none"> • Participants experienced hope in two ways; simply having hope and actively hoping. • Simply having hope was a passive state where participants reported a presence or sense of hope that was reported to be essential for life and recovery. For some this was present constantly since before stroke, for others this was absent. • Actively hoping was described as working toward future hopes. Participants identified hopes for the future that were broad and specific. They took three steps towards achieving hopes; developing a plan, putting in the effort, and taking action. • Hope was influenced by several factors. In times of uncertainty, simply having hope was predominant state. At times of more certainty in the future, active hopes were present. Those who reported increased disruption to identity and engagement in meaningful activities had more difficulty actively engaging with hope. |

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| | | | stroke = 3.6 months (range = 2-5 months). | | <ul style="list-style-type: none"> • Hope could be double sided – if hopes were unfulfilled, participants felt disappointment, failure, and emotional distress, leading to retreat from actively engaging with hopes. |
| Alazewski, and Wilkinson (2015) <i>United Kingdom</i> | Stroke (age 21-60) | To understand the experience of hope by working age adults recovering from stroke over a time period of 18 months post-stroke. | Qualitative design: Longitudinal study – semi-structured interviews at four time points (within 3 months post-stroke, and three further interviews up to 18 months post-stroke). Thematic analysis. | N= 43 participants recruited from three NHS stroke services. <i>Gender:</i> n= 28 male, n= 15 female. <i>Age:</i> mean not reported, age range 30-59. <i>Ethnicity:</i> not reported. <i>Type of stroke:</i> not reported. <i>Severity:</i> not reported. | <ul style="list-style-type: none"> • In hospital, participants reeled under shock of experiencing a stroke. Those who were healthy prior experienced more shock and distress than those who were already chronically ill prior to stroke, who experienced this more as an inconvenience due to disruption of routines. No participants reported any positive thought of hope at this stage. • From discharge home to 18 months post-stroke, participants were consumed with negotiating impairments and ongoing difficulties. • Participants described thinking about the future as threatening and best to be avoided. No positive relationships with hope were described. Particularly those who experienced many setbacks and complications felt any thought of future hope was damaging as it risked too much upset and disappointment. This may have been because this evoked ideal aspirations of their lives before stroke which may no longer have been possible. • Commitment to “realistic hopes” during rehabilitation (short and medium term post-stroke) aggravated existential tensions about what might be hoped for in the long-term. |

3.1 Methodological Critique

The methodological rigour of the studies included in this review was assessed using two critical appraisal tools (CASP, 2017; STROBE, 2007). Scoring of the studies is not included in this review, as both tools did not possess this function. The critical appraisal revealed that all studies clearly stated their aims, and clearly reported appropriate recruitment strategies, data analysis strategies and results in relation to their aim. However, several issues were present across the thirteen studies regarding the definition and measurement of hope, and the measurement of recovery, that impacted on the interpretation of the findings in light of the review question. Additionally, several limitations were evident with regards to the representativeness of the participants used across the studies to the population of individuals who experienced ABI and their family members. These issues are explored in more detail next.

3.1.1 The measurement of hope

3.1.1.1 Exploring the concept of hope in qualitative studies

As might be expected in the context of a lack of consensus on the concept of hope (Snyder, 2000), there were issues in the literature that resulted from difficulty in consistently defining hope. Within the qualitative studies, only Bays (2001) provided a working definition of hope, and all other studies gave multiple definitions of hope and acknowledged the difficulties defining this concept. It is acknowledged that the purpose of the qualitative studies was to subjectively explore hope, which meant a clear definition of a construct was not essential prior to reporting results (Cho & Trent, 2006). However, for results to be considered valid, transparency is required about the questions asked and any potential researcher biases in interpreting results (Whittlemore, Chase & Mandle, 2001). Of the nine qualitative studies, only five gave

clear descriptions of the questions asked to participants, which appeared broad and unbiased towards any model (Arnaert, Filteau & Sourial, 2006; Bays, 2001; Bright, Kayes, McCann & McPherson, 2011; Cross & Schneider, 2010; Tutton et al, 2011). In the context of multiple definitions, none of the studies provided a clear account of how the researchers' understanding of the concept of hope potentially influenced the analysis of results. This is a limitation, as significant dimensions of hope may potentially have been unintentionally omitted or interpreted in different ways depending on the researchers' pre-existing understanding. This loss of transparency in the studies affected the degree of certainty in the validity and relevance of the results. Considering this, there was a significant overlap in the results of these studies that may have meant this was not a large issue, but nonetheless it was not clear whether some of the variance in results happened due to researchers differing concepts of hope.

3.1.1.2 Measurement of hope in cross-sectional studies

Although all four cross-sectional studies (Bluvol & Ford-Gilboe, 2004; Gum, Snyder & Duncan, 2006; Peleg, Barak, Harel, Rochberg & Hoofien, 2009; Popovich, Fox & Burns, 2003) provided clear working definitions of hope, each used a different working definition, and therefore different measures designed specifically to measure those working definitions (see Appendix A). Although the measures used were appropriate to each study aim, only one measure used in one study (Popovich et al., 2003) was validated for use with the ABI population, and therefore the validity of results was not clear. This was impeded further by the use of a different measure in each study, as this meant the results were difficult to compare, making it more challenging to assess the reliability of the results.

3.1.1.3 Capturing the dynamic nature of hope

One further issue was present across both the qualitative and cross-sectional studies related to the measurement of hope. Only four studies used more than one time-point to investigate hope (Bright et al., 2011; Tutton et al., 2011; Verhaeghe, van Zuuren, Defloor, Duijnste & Grypdonck, 2007a; Verhaeghe, van Zuuren, Defloor, Duijnste & Grypdonck, 2007b). As hope is considered a dynamic concept (Farran et al., 1995), the predominant use of only one time point may have meant that the evolving nature of hope was not captured. Only one study (Alazewski & Wilkinson, 2015) used a longitudinal design over 18 months. Participants could have given different responses at different time points in their recovery, as evidenced by differences in results of studies completed at different time points. Therefore, saturation about the full experience and function of hope may not yet have been reached in the data presented, as results were most frequently collected at one time point or over a short period of time.

3.1.2 Measurement of recovery

Recovery from ABI is a similarly ill-defined concept, with no regular definition of recovery in use. This may be due to the unique experience of potential biological, psychological and social impacts (Levack et al., 2010; Pearce et al., 2008). Each individual may have different priorities that encompass recovery for them and may have different markers and time frames for when they perceive recovery to have been achieved. This was not an issue for the qualitative studies, as they provided rich data about the experience of hope in the context of individual's unique experience recovery. However, these were not designed to provide objective information about how hope might lead to improved outcomes for the individual and for the population as a whole (for example, whether it improved recovery outcomes). Reliable and valid

psychometric measures have the potential to provide such evidence, but as of yet there is no psychometric measure that captures the full range of impacts of ABI as described by Bury (1982), and therefore recovery, in this population. This was problematic within the cross-sectional studies, as each study used a unique combination of questionnaires designed to measure specific aspects of recovery, but none collected data on all aspects of recovery for this population (see Appendix B). These studies did also not allow for any inferences about causation, and therefore it was unclear whether any differences in the measured recovery outcomes were experienced due to hope. This limited the review's ability to make conclusions about how the experience of hope may have contributed to recovery outcomes for individuals who experience ABI and their family members.

3.1.3 Gaps in the literature

It was promising that across the studies on individuals with ABI, a wide range of participants of differing ages, genders, ethnicities, type of stroke/traumatic brain injury and severity were used, as this reflected the heterogeneous population of individuals who experience ABI. Particularly it was promising that Bright et al. (2011) used participants who experienced aphasia, as these are more often excluded from research (Dalemans, Wade, van den Heuvel & de Witte, 2009). However, core sub-groups of individuals who experienced ABI were not fully represented in the research available, as most studies were completed with individuals who experienced a stroke (Alazewski & Wilkinson, 2015; Arnaert et al., 2006; Bays, 2001; Bluvol & Ford-Gilboe, 2004; Bright et al., 2011; Cross & Schneider, 2010; Popovich et al., 2003; Tutton et al., 2011). Only one study was completed with individuals who experienced a traumatic brain injury (Peleg et al., 2009). This study was conducted in Israel, which is culturally different to the UK, and therefore the applicability of these

results was questionable. No studies were available that used participants who experienced less frequently occurring types of ABI such as those caused by infections, lack of oxygen, or other toxic/metabolic insults. These absences limited the generalisability of the findings, as core sub-groups of individuals with ABI were not represented in the available literature.

In addition to the omitted populations, further issues were present with the way demographics were reported in the studies available. Across all studies, key demographics were omitted or reported these in ways that did not support comparison (for example, some reported stroke severity, and some reported the location of stroke, some reported neither), which impeded the ability to assess the representativeness of the sample as a whole. This also meant that it was difficult to ascertain whether demographic factors influenced the experience of hope in recovery from ABI.

With regards to family members of individuals who experienced ABI, the representativeness of the samples was unclear. This was due to the small sample sizes and small number of studies available (Bluvol & Ford-Gilboe, 2004; Gelling, 1999; Verhaeghe et al., 2007a; Verhaeghe et al., 2007b), compounded further by the fact that both studies by Verhaeghe et al. (2007) used the same participants. This meant the results were potentially not generalisable to the entire population of family members. Furthermore, due to this limitation, not enough evidence was available about the influences of being of different types of relations to the person with ABI on the experience of hope. Neither was it clear how the experience of hope might have interacted with the individual with ABI's experience of hope.

3.2 Synthesis of the literature

Despite the methodological limitations, there was overlap in the results of the studies related to the experience of hope. Therefore, a synthesis of the literature is provided for each population on which research evidence was available.

3.2.1 Hope in recovery for individuals who experienced stroke

Six qualitative studies (Alazewski & Wilkinson, 2015; Arnaert et al., 2005; Bays, 2001; Bright et al., 2011; Cross & Schneider, 2010; Tutton et al., 2011) and three cross-sectional studies (Bluvol & Ford –Gilboe, 2004; Gum et al., 2006; Popovich et al., 2003) investigated hope in recovery for individuals who experienced a stroke. The studies collected data at differing time points in recovery, spanning from the acute care phase (Arnaert et al., 2006; Tutton et al., 2011), to post-acute care (Alazewski et al., 2015; Bright et al., 2011; Gum et al., 2006; Popovich et al., 2003) to long-term recovery (Alazewski & Wilkinson, 2015; Bays, 2001; Bluvol & Ford-Gilboe, 2004; Cross & Schneider, 2010).

3.2.1.1 The experience of hope for individuals who experienced a stroke

All nine studies found that participants reported experiencing hope throughout the recovery period, with one study (Cross & Schneider, 2010) commenting that hope appeared important to individuals up to around four years post-stroke. Three studies reported that hope arose out of suffering (Alazewski & Wilkinson, 2015; Arnaert et al., 2006; Tutton et al., 2011). Individuals reported feeling intensely shocked and distressed about experiencing a stroke. Arnaert et al. (2006) and Tutton et al. (2011) found this was perceived to be associated with the physical, emotional and social consequences of stroke. Alazewski & Wilkinson (2015) added that the stroke had been experienced as a “traumatic assault on personhood” (p. 179), in which thoughts of hope were absent. However, most other studies provided evidence that hope was

experienced in the context of this suffering, but that the degree of hope reported varied between individuals (Bays, 2001; Popovich et al., 2003; Bluvol & Ford-Gilboe, 2004; Arnaert et al., 2006; Gum et al., 2006; Cross & Schneider, 2010; Tutton et al., 2011; Bright, Kayes & McPherson, 2011).

Hope was most often perceived to be a positive future-oriented, life-sustaining inner strength (Arnaert et al., 2006; Bays, 2001; Bright et al., 2011; Cross & Schneider, 2010; Tutton et al., 2011). Different experiences of hope were perceived to be present, and the degree of hope varied between individuals and fluctuated over time. What was hoped for also varied. Broadly, three differing experiences of hope were discussed; general hope, specific hopes, and loss of hope.

General hope was described as a sense that life still held many things for the individual, and that their lives would get better (Bays, 2011; Bright et al., 2011). For some, this was a hope to return to their pre-stroke life, and for others the aim was to adapt to a new set of conditions for life. This type of hope was sometimes also described as passive; it was just present and did not appear to require engagement or action. This type of hope was present throughout recovery, but appeared particularly important during the acute and post-acute phases (Arnaert et al., 2006; Bright et al., 2011; Tutton et al., 2011). General hope was perceived to enable individuals to manage and tolerate uncertainty and allowed them to picture a future where they survived stroke and adapted or returned to previous life (Arnaert et al., 2006; Bays, 2001; Bright et al., 2011; Tutton et al., 2011) even when these outcomes were still uncertain. Perhaps this occurred because the future-oriented nature of hope offered relief from the distressing circumstances in the present, as well as provided the potential that present suffering was time limited.

Specific hopes were often reported to pertain to individual aspects of the sequelae of stroke that the individual desired to improve, for example, the hope to sip a cup of tea, or dress oneself (Arnaert et al., 2006; Bays, 2001; Bright et al., 2011; Cross & Schneider, 2010). These specific hopes often emerged after the individual had become aware of deficits or received information about their condition (Bays, 2011; Bright et al., 2011; Cross & Schneider, 2010). Hope was experienced as a driver for action to attain the desired improvement, and specific hopes could become goals for recovery. Individuals made plans to action these specific hopes/ goals and monitored their progress (Arnaert et al., 2006; Bays, 2001; Bluvol & Ford-Gilboe, 2004; Cross & Schneider, 2010). Although no evidence was found that this indeed increased recovery outcomes (functional and social) during the acute and post-acute phase (Popovich et al., 2003), there was some evidence that specific hopes did improve recovery in the long-term (Arnaert et al., 2006; Bays, 2001; Bluvol & Ford-Gilboe, 2004; Cross & Schneider, 2010). Bluvol & Ford-Gilboe (2004) reported that in the long-term, hope was associated with increased ability to develop adaptive ways of coping with the consequences of stroke, and increased quality of life. It is possible that hope drives action in the long-term, as individuals have gained more distance from the immediate distressing consequences of stroke and have begun to experience progress in their recovery as a result of support in the acute and post-acute phases. It is also possible that returning hope made the consequences of stroke more apparent, perhaps for some leading to increased motivation to action specific hopes.

Some individuals reported periods of hopelessness, which were experienced as periods of loss of hope, or no hope at all stages of recovery. This was often experienced alongside low mood, increased depressive symptoms, low motivation and reduced participation in meaningful activities (Cross & Schneider, 2010; Gum et al.,

2006; Tutton et al., 2011). It is possible that in these moments, the present distress associated with experiencing a stroke became overwhelming or inescapable (Alazewski & Wilkinson, 2015), and therefore individuals potentially were inhibited from envisioning any kind of more positive future or taking any actions towards changing their current circumstances. Interestingly, individuals who were of working age more frequently reported this as their predominant experience of hope (Alazewski & Wilkinson, 2015; Bright et al., 2011). As a result, they reported preferring to focus on the present, and having hope was experienced as distressing, as they predicted they would go unfulfilled. It is possible that stroke is experienced as more disruptive and threatening to younger individuals, as illness is less expected and they often live longer with the consequences of stroke (Alazewski & Wilkinson, 2015). Therefore, although all individuals potentially experienced times of loss of hope or no hope, younger individuals were likely to report this more frequently. There was some evidence that this led to decreased participation in activities (Gum et al., 2006), however it was not clear whether this led to reduced recovery outcomes for all individuals, as younger individuals who focussed on the present could have still been engaging with behaviours that increased recovery without hoping for the future.

Several factors appeared to influence the degree and type of hope experienced (Arnaert et al., 2006; Bays, 2001; Bright et al., 2011; Cross & Schneider, 2010). These could broadly be grouped into internal and external influences. With regards to external influences, social connectedness with family, friends and staff was most consistently identified by participants as an important positive influence in sustaining hope during recovery. This was particularly important at times when individuals reported loss of hope, as support from others enabled them to develop or regain general and specific hopes (Arnaert et al., 2006; Bays, 2001; Cross & Schneider,

2010). In addition, other stroke survivors were identified as a major positive influence on hope, as they were seen as role-models of the recovery that was possible (Cross & Schneider, 2010). Another important external factor was information provision about the individual's current predicament and future. This helped individuals to set specific hopes which could become goals to work towards, and any progress towards this hope then increased hope further (Bays, 2001; Bright et al., 2011; Cross & Schneider, 2010). Hope could be diminished with lack of progress, which meant some individuals withdrew from specific hopes at these times but retained general hope (Bright et al., 2011). With regards to internal factors, spirituality was experienced as an influencing factor on general and specific hopes, and supported individuals to sustain hope over time (Bays, 2001; Cross & Schneider, 2010). Pre-existing internal traits also influenced the degree of hope individuals reported, such as optimism (Cross & Schneider, 2010; Gum et al., 2006) and determination (Cross & Schneider, 2010). Therefore, although the exact mechanics of influencing factors on hope remain somewhat unclear, it seemed that a range of internal and external factors connected to the individual's pre-existing personality and life, and current environment, were perceived to influence the experience of hope.

3.2.2 Hope in recovery for individuals who experienced traumatic brain injury

Only one study was available (Peleg et al., 2009) that investigated hope in recovery from traumatic brain injury, meaning that a full understanding of the experience of hope could not be established for this population. Although the applicability of the results of this study to UK populations was unclear, the evidence

available seemed to provide initial indications that hope is experienced in different degrees and different ways in this population. Differences were present in the degree to which individuals reported experiencing the ability to form plans to achieve goal directed hopes (pathways hopes) and the inner resources they had to pursue the plans (agency hopes). Individuals who had minimal or mild levels of depression reported higher ability to form plans to achieve goal directed hopes compared to individuals with moderate to severe levels of depression. Individuals who experienced moderate to severe levels of depression reported lower levels of optimism and agency hope. Therefore it is possible that the experience of hope in this population is influenced by internal factors such as optimism and internal resources to pursue plans. Those who experience lower levels of these factors may experience lower levels of hope, which could potentially reduce recovery outcomes as they were more likely to experience depression and therefore perhaps less likely to engage in helpful behaviours associated with improved recovery outcomes.

3.2.3 Hope in recovery for family members of individuals with ABI

Only four studies were conducted with family members of individuals with ABI (Bluvol & Ford-Gilboe, 2004; Gelling, 1999; Verhaeghe et al., 2007a; Verhaeghe et al., 2007b). Three studies were completed with family members (parents, spouses and siblings) of individuals who experienced either a traumatic brain injury or stroke and were receiving acute care in intensive care (Gelling, 1999; Verhaeghe et al., 2007a; Verhaeghe et al., 2007b). No studies were found that were completed during neuro-rehabilitation. One study (Bluvol & Ford-Gilboe, 2004) was completed with family members (spouses only) of individuals in long-term recovery from stroke. No studies were available at this stage with family members of individuals who experienced other types of ABI.

3.2.3.1 The experience of hope in family members

Similar to individuals who experienced a stroke, family members reported experiencing hope as an important part of recovery (Gelling, 1999; Verhaeghe et al., 2007a; Verhaeghe et al., 2007b). One difference was that for this population, hope was reported to arise out of uncertainty, rather than suffering (Gelling, 1999; Verhaeghe et al., 2007a). Hope was predominantly experienced as a continuously present positive driving force for their own wellbeing and recovery of their loved one. Again, the degree of hope and what was hoped for evolved over time and differed between individuals (Gelling, 1999; Verhaeghe et al., 2007a; Verhaeghe et al., 2007b). Four different experiences of hope were described during the acute care phase; general hope, specific hopes, false hope and loss of hope (Gelling, 1999; Verhaeghe et al., 2007a; Verhaeghe et al., 2007b). The experience of hope at other stages of recovery was not clear, but Bluvol and Ford- Gilboe (2004) provided evidence that hope was reported to be present at varying levels for spouses of individuals who experienced a stroke in long-term recovery.

In the acute phase of recovery, general hope was frequently perceived to be constantly present, but what was hoped for varied significantly. Upon arrival to the hospital, some family members hoped the patient was not already dead, and some hoped they only had minor injuries like broken bones (Gelling, 1999; Verhaeghe et al., 2007a). Gelling (1999) suggested this difference might arise out of the family members' past experiences (for example with intensive care). As time passed, this general hope was most often described as a hope for the best for the individual with ABI in the long-term future. Specific hopes were often described in the context of the immediate future during acute care, such as the hope for the patient to wake up or open their eyes (Gelling, 1999; Verhaeghe et al., 2007a). Both of these types of hope

were reportedly experienced as positive by most family members, as it allowed them to function in distressing circumstances (Gelling, 1999; Verhaeghe et al., 2007a; Verhaeghe et al., 2007b). This was because hope was perceived as providing them with a sense of control over a very uncertain situation. This sense of control meant they could take actions to ensure the patient received the best care possible and to support other family members (Gelling, 1999; Verhaeghe et al., 2007a). Hope may therefore have been experienced as a coping strategy that enabled family members to manage their own emotions, as well as drive action to further the recovery of their loved one. Interestingly, both of these types of hopes were orientated to the individual who experienced the ABI, and not hopes for the family members' future.

General and specific hopes were perceived to be influenced by three factors; information provision, social connections with others, and progress of the patient (Gelling, 1999; Verhaeghe et al., 2007a; Verhaeghe et al., 2007b). Family members reported actively seeking and assimilating information in the present and using their relationship with the information provider to assess the value of the information (Verhaeghe et al., 2007b). They talked about using this, in addition with their knowledge of the patient, to set specific hopes for the short-term future and general hopes for the long-term (Gelling, 1999; Verhaeghe et al., 2007b). Milestones in the progress of the patient were used to re-assess and modify hopes regardless of whether it was a positive or a negative milestone, but positive milestones were often seen as significant steps towards achieving hopes and therefore were perceived to increase hope (Gelling, 1999; Verhaeghe et al., 2007a).

Hope was not always perceived as positive. Some family members reported times where they realised that their general or specific hope could never have been attained (Gelling, 1999; Verhaeghe et al., 2007a). They deemed this "false hope".

Realising their hope had been “false” was experienced as intensely distressing, and more distressing than receiving bad news. Family members did not wish to experience false hope. Inaccurate and incomplete information provision by professionals was identified as a cause of developing false hopes.

Family members reported times where they lost hope, which was accompanied by panic, despair and loss of rationality (Gelling, 1999; Verhaeghe et al., 2007a; Verhaeghe et al., 2007b). This was reported to occur when they received medical information that disconfirmed progress (Gelling, 1999; Verhaeghe et al., 2007b). Family members often sought to regain hope in these circumstances through social support from others (such as staff, other family members or friends) who could offer comfort from the distress and encourage adjustment of hope (Gelling, 1999; Verhaeghe et al., 2007a).

No studies were available about the experience of hope for family members whilst the individual with ABI is undertaking neuro-rehabilitation. Only one study investigated the experience of hope during long-term recovery after the individual with ABI had returned to living in the community (Bluvol & Ford-Gilboe, 2004). This study was conducted with spouses of stroke survivors living in the community. They found that hope was reported in varying levels for these individuals, and that as hope increased, reports of behaviours conducive to coping also increased. Hope may therefore continue to be experienced as a driver for action (in this case, adaptive behaviour) in family members during long-term recovery. This suggested that hope may have a role in supporting a family member to adjust to ABI, but it was not yet known if this improved recovery for the individual who experienced the ABI. However, it was equally possible that those who were more able to adapt to the

consequences of stroke had more hope for recovery of their loved one as a result, and that therefore hope was not a causal factor of improved recovery, but a consequence.

4 Discussion

The aim of this review was to develop an understanding of what the experience of hope is for individuals who experienced the ABI and their family members. The thirteen papers included in this review highlighted the complexity of the experience of hope and its consequent influence on recovery.

Similar to other acquired illnesses and injuries (Duggleby et al., 2012; Korner, 1970), hope was reported to be an important part of the recovery experience in ABI. Hope was complex, as it appeared that the specific experience of hope was unique to each individual, but that some broad patterns were evident from the research with individuals who experienced a stroke, and family members of individuals who experienced traumatic brain injury or stroke. As suggested by Dufault and Martocchio (1985) and Farran et al. (1995), hope was perceived to be a future orientated life force that could be present in different degrees and different ways across the full recovery period. Individuals reported moving fluidly and dynamically between these different experiences of hope, with some reporting more fluctuations in the experience of hope and others reporting one more predominant experience of hope. Neither Farran et al.'s (1995) or Snyder's (2000) models of hope were singularly or fully represented in the studies reviewed. Rather, aspects of both these models appeared to be experienced. The descriptions of general hope represented elements of Farran et al.'s (1995) model of hope as an experiential process and a spiritual/transcendent process. The descriptions of specific hope potentially overlapped with Farran et al.'s (1995) rational thought process, and Snyder's (2000) pathways thoughts (plans to achieve the hope). Neither model captured reported experiences of false hope or loss of hope. No

evidence was yet found for the relational process of hope (Farran et al., 1995) or Snyder's (2000) concept of agency thoughts (motivation and willpower that enabled individuals to take action), but this may have been because studies were not designed to capture these elements.

The experience of hope was perceived to be heavily influenced by factors related to the individual's past and present, which could be summarised as internal and external factors. Internal factors included traits such as optimism and determination, as well as spirituality. External factors included previous life experiences, social connectedness with family, friends, staff, and other service users, information about the ABI, and progress in recovery.

Hope appeared to enable individuals to tolerate distress and uncertainty in the present, as it allowed them to envision a future where things were better. This was perceived as "coping". It also seemed to be a precursor to action; participants reported that it enabled them to make plans to attain their hoped-for outcome, regardless of whether this was to obtain improvements related to biological, psychological or social difficulties associated with ABI. It was not yet clear whether this indeed led to improved recovery outcomes, but some individuals reported improved quality of life. These findings were consistent with previous research (Bright et al., 2011; Snyder, 2009).

There were however significant limitations across the reviewed studies that meant the above description of hope was unlikely to be fully comprehensive, and neither representative of the entire population of individuals who experience ABI and their family members. In the context of lack of conceptual clarity of hope (Snyder, 2000), the qualitative studies were not always transparent in the influences of the

different concepts. The cross-sectional studies each used differing measures of hope and recovery. This meant that it was possible that important aspects of the experience of hope could have been omitted, as well as limiting the comparison of results to each other. Hope was also most frequently measured at one time point, which meant that it could not be fully understood how the experience of hope evolved and changed over time, particularly at transition points in recovery.

Recovery was also measured in different ways, and whilst the qualitative studies allowed exploration of this complex experience, the cross-sectional studies used measures which did not capture the full range of outcomes that may be important to individuals with ABI and their family members. This may have meant that important influences of hope on recovery were omitted. The lack of quantitative studies also meant that no objective evidence was available about whether hope lead to improved recovery outcomes.

Significant gaps in the literature were present; only one study had been completed with individuals who experienced traumatic brain injuries, and no studies had been completed with individuals who experienced less frequently occurring types of ABI due to infections, lack of oxygen, or other toxic/metabolic insults. Family members were also underrepresented. Of the studies that were available, some core demographics such as type and severity of stroke were omitted. The cumulative effect of this limitations was that individual variances across the recovery period in the experience of hope could not yet be explained or fully explored, and there is no evidence that the presented findings are generalisable to the entire population of individuals who experienced ABI and their family members.

4.1 Clinical implications

Despite the fact that the full experience of hope may not yet be understood for all individuals with ABI and their family members, given that hope is not considered in any clinical guidelines (NICE, 2013; SIGN, 2013), it seems important based on the evidence available to at least advise that clinicians consider offering individuals the opportunity to talk about hopes during recovery in a supportive and empathic way. This was because it was consistently raised as an important part of the recovery. As part of these conversations, clear and accurate information about the person's condition is important, as this was reported to shape specific hopes which may become goals for recovery.

It may also be helpful to offer emotional support at times when individuals report experiencing loss of hope, or when they have learnt that a hoped-for outcome is unattainable for them or their family member. This is because these times often were reported to provoke emotional distress, which can lead to withdrawal from participating in meaningful activities. Allowing individuals the space to explore these losses may enable them to feel supported and cared for, and may lead to inspiration for new hopes that can be strived for.

4.2 Research implications

Overall, much further research is needed to fully understand the experience of hope in recovery from acquired brain injuries for the individual and their family members. Firstly, more exploratory qualitative studies are needed, particularly with individuals who experienced traumatic brain injuries, infections, lack of oxygen, other toxic/metabolic insults, and family members. These could be conducted at specific stages of recovery, across transitions, and longitudinally, to inform understanding about the dynamic and evolving nature of hope. It may also be beneficial to conduct such

studies with dyads of individuals who experience ABI and their family members, to increase understanding about how hope is influenced and shaped by others.

Secondly, research is needed to assess the validity of existing hope questionnaires for this population. If these cannot be used to validly assess hope, or if further exploratory research reveals they do not fully capture the experience of hope for this population, it may be beneficial to consider development of hope questionnaires. The development of a questionnaire that captures the full experience of recovery as consistently shown in the ABI literature (Levack et al., 2010; Pearce et al., 2008; Salter et al., 2008) is recommended also. In the meantime, further cross-sectional studies may be useful if they use multiple measures of hope to cover the different concepts of hope, and measures that assess as much as possible the full experience of recovery. These could be repeated at different time points in recovery and in different countries to allow for comparison of results. It would also be useful to conduct quasi-experimental studies with individuals who report different levels of hope, to assess whether differing levels of hope are associated with improved or decreased recovery over time.

Finally, more research is needed to assess the influence of other factors on the experience of hope, particularly factors that increase hope. For example, given that other individuals who experienced ABI were reported to have a positive influence on hope, it may be useful to explore whether involvement in support groups or service user involvement groups impacts hope in recovery from ABI.

5 Conclusion

Hope was reported to be experienced as a future orientated life force that was perceived to be present in varying forms and in varying degrees over the course of

recovery from ABI for both the individual and their family members. They reported moving fluidly and dynamically between these different experiences, and this movement appeared to be influenced by a range of internal and external factors. The presence of hope increased their perceived ability to cope with distress and uncertainty, and was reported to be a precursor to engaging with action that, depending on the aimed for outcome, had the potential to lead to improved recovery outcomes across any biological, psychological and social impacts of ABI. However, significant limitations in the measurement of hope and recovery, and the absence of research with important sub-populations of individuals who experienced ABI and their family members meant that the described experience of hope may neither fully represent this experience nor be generalisable to the full population.

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Section B

A qualitative exploration of the experience of service user involvement in the context of personal recovery from acquired brain injuries

Word Count: 7995 (80)

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A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

For submission to the Journal of Qualitative Health Research

APRIL 2018

Abstract

Service user involvement is under-developed with people who experience acquired brain injuries (ABI). Systemic barriers and prejudices may have contributed to this. This study explored the experiences of ten individuals who experienced an ABI and attended a service user involvement group aimed at improving organisational design and governance. Their experiences were explored in the context of their personal recovery from ABI. Semi-structured interviews were conducted and analysed using Interpretative Phenomenological Analysis. The results suggested that service user involvement was predominantly a positive experience. SUI enabled participants to re-connect with pre-ABI life. It enhanced their agency in their recovery via empowerment. It also provided opportunities for developing valued peer relationships. However, not all participants experienced each of these effects, which highlighted barriers to meaningful involvement. Increased awareness of these experiences could support health care professionals to initiate opportunities for meaningful SUI that may enhance services delivered.

Key words: Acquired brain injury, service user involvement, recovery, personal recovery, neurorehabilitation

Introduction

Service user involvement (SUI) is recognised as essential to ensure health services are shaped to the needs of those accessing them, and therefore forms a central component of UK national policy (Department of Health, 2012; NHS England, 2012). SUI is defined as “involvement in decision making and active participation in a range of activities (e.g. service planning, service evaluation, delivery of care, research, training, recruitment) starting from the expertise by experience of the person, in collaboration with and as equal partners of professionals” (Tambuyzer, Pieters & Van Audenhove, 2011). SUI is said to occur at three levels; individual care, organisational design and governance, and policy making (Carman et al., 2013). It may take the form of consultation, involvement or partnership, with the latter representing the highest level of shared power and responsibility (Carman et al., 2013). This research pertains to SUI in the form of involvement at the level of organisational design and governance and is here forth referred to as SUI.

Despite limited evidence about the impact of SUI (Mockford, Staniszewska, Griffiths & Herron-Marx, 2012), the extant literature suggested that SUI underpinned by mutual respect and value can lead to benefits for services, health care professionals and involved service users themselves (Doyle, Lennox & Bell, 2013; Omeni, Barnes, MacDonald, Crawford & Rose, 2014). Yet many groups of individuals are still under-represented or excluded from participation (Ocloo & Matthews, 2016). One of these groups is people with acquired brain injuries (ABI) (Clare & Cox, 2003). To contextualise the present study, the nature of ABI and the recovery process are summarised, followed by a review of evidence regarding SUI for this population.

The nature of ABI and the recovery process

ABI is an umbrella term for non-progressive sudden-onset injuries to the brain that occurred after birth and the neo-natal period (Royal College of Physicians, 2003). The main causes of ABI include stroke, traumatic brain injury, and brain injuries due to infection, lack of oxygen and other toxic/metabolic insults (Royal College of Physicians, 2003). Individuals may experience any range of physical, cognitive, emotional and behavioural changes (Turner-Stokes, Nair, Sedki, Disler & Wade, 2005) as a direct consequence of the ABI. These require extensive multi-disciplinary input from health services aimed at regaining functioning, usually including acute care, in-patient neurorehabilitation, and ongoing support in the community (NICE, 2013; SIGN, 2013). Despite this support, individuals commonly experience long-term impairments. Therefore, ABI is recognised as one of the leading causes of disability in the UK (Headway, 2015; Public Health England, 2017).

The consequences of ABI are not limited to the direct biological impairments, but also include a wide range of psychological and social impacts (Ellis-Hill, Payne & Ward, 2008; Williams & Evans, 2003). Bury's (1982) theory of biographical disruption is the most widely accepted biopsychosocial theory of the impact of ABI (Levack et al., 2008; Pearce et al., 2015; Salter, Hellings, Foley & Teasell, 2008). Bury (1982) suggested that the sudden onset of long-term illness drastically disrupts an individual's life as it creates new and qualitatively different conditions. This disruption challenges everyday physical, emotional and social lives, and leaves a person in a state of uncertainty about the future. Recovery, therefore, becomes more than regaining functioning. Individuals must reconstruct their identity, personhood, and place in the world to either reconcile with pre-ABI life or adapt to the qualitatively new conditions (Levack et al., 2008; Salter et al., 2008). Internal factors such as hope and determination are important influences on this process, as well as external factors such as support and guidance from health care professionals and family members (Levack et al.,

2008; Salter et al., 2008). Interestingly, there is no definition of recovery in health populations that reflects the psychosocial aspects of this process, and therefore Anthony's definition of personal recovery is adopted. Anthony (1993) defined personal recovery as the unique process of developing meaning and purpose through which one comes to lead a satisfying and contributing life, even with limitations caused by the illness.

The need for SUI with people who experience ABI

The development of SUI initiatives with people with ABI has been incredibly limited despite a need for such involvement at service level. Research showed that people with ABI have different priorities for their recovery from health care professionals; they were mostly concerned with resuming previous personal roles and social activities (personal recovery). In contrast, professionals were often focussed only on the regaining physical functioning (Burton, 2001; Salter et al. 2008). This variance may mean that current services do not meet the full needs of people with ABI. Indeed, approximately half of people with ABI report experiencing ongoing unmet needs in relation to the care they received (McKevitt et al., 2011; Pickelsimer, Selassi, Sample, Heinemann & Veldheer, 2007). At the level of individual care, SUI via sharing experiential knowledge to inform decision making about care was associated with an increase in the individual's health care needs being met (Kristensen, Tistad, von Koch & Ytterberg, 2016). Providing a platform for increased narratives of experiential knowledge at the service level could therefore potentially support the development of increasingly responsive services to the needs of the populations they serve.

Current barriers to SUI with people with ABI

There are several barriers that have potentially contributed to the scarcity of SUI for people who experience ABI. Firstly, implementation of meaningful SUI is often described as complex, with little clarity on how to achieve and measure change (Brett et al., 2012). The

only study in this area for the population of ABI was conducted in two stroke services, and found that impact of SUI on services was difficult to measure due to different understandings of SUI between professionals and service users (Fudge, Wolffe & McKeivitt, 2008). In the absence of clear evidence of the benefits of SUI, there are concerns from professionals that SUI may actually lead to adverse impacts on the individuals, such as further disempowerment and burden (Slomic, Christianssen, Soberg & Sveen, 2016). This may be further compounded by a commonly held assumption by health care professionals that individuals who experience cognitive and communicative impairments are unlikely to be able to engage in SUI in a meaningful way (Clare & Cox, 2003). In this context, professionals perceived facilitating meaningful SUI as a labour-intensive and time-consuming process (Ocloo & Matthews, 2016), which could be perceived to be a waste of ever increasingly limited resources without clear evidence of effectiveness in improving services delivered.

The present study

Differences have been identified in how people with ABI perceive their experience of recovery and SUI from health care professionals. To facilitate the development of meaningful SUI for this population, it appears necessary to investigate experiences of SUI within the context in which they are experienced (recovery). This may highlight benefits and barriers to taking part. Fudge et al. (2008) identified that people with stroke reported their experiences of SUI in terms of their personal gains related to their recovery (eg. feeling heard and increased social opportunity via peer relationships). Therefore, the concept of personal recovery was selected from which to explore the experiences of SUI involvement. This research thus aims to address the question: How do people with ABI experience SUI in the context of their process of personal recovery?

Method

Design

This qualitative study uses an interpretative phenomenological design (IPA) using Smith, Flowers and Larkin's (2009) methodology. This design was selected to enable an in-depth exploration of how one type of experience (in this case, SUI) was experienced in the wider context of personal recovery from ABI. A critical realist stance was adopted in all stages of the research, as IPA posits that objects and phenomena exist in relation to the person's current position, but that the way in which these become measurable is through the relationship with the researcher (Larkin, Watts & Clifton, 2006). To acknowledge the researcher's lens, a statement of position is provided in section 2.5.

Data were collected using one-off semi-structured interviews. Participants were recruited using purposive sampling from one SUI group, and interviewed retrospectively about their participation in SUI in the context of ongoing personal recovery. The interview schedule (Appendix I) was developed under supervision from the research supervisors. The schedule consisted of broad open-ended questions to allow participants maximum opportunity to express their experiences in their terms (Smith et al., 2009). Topics covered included the impact of ABI, recovery process, experience of SUI, and perceived interaction with the recovery process.

Ethical approval

Ethical approval was obtained from the Bromley NHS Research Ethics Committee (see Appendix C) and the NHS trust Research and Development Department (see Appendix E). The British Psychological Society Code of Conduct (BPS, 2009) was adhered to.

Participants

Context.

Participants were recruited from one trans-diagnostic SUI group embedded within a secondary care inpatient neurorehabilitation ward in South East England. Inpatients were invited to attend the open, user led group meetings occurring once every 3-4 weeks. The group was facilitated by a clinical psychologist and an occupational therapist. Topics of discussion included issues related to the practical experience of the ward environment, and wider service organisational issues. Action plans were developed collaboratively and were implemented by the multi-disciplinary neurorehabilitation team. Progress was fed back to the SUI group.

Inclusion and exclusion criteria.

Potential participants were identified according to the inclusion and exclusion criteria displayed in Table 1.

Table 1: Summary of inclusion and exclusion criteria

| Inclusion criteria | Exclusion criteria |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> • Participants must be age 18+ (adult) • Participants must have experienced a first episode of ABI • Participants must have attended at least 2 SUI meetings • Participants must be able to provide informed consent | <ul style="list-style-type: none"> • Participants must not have any physical, cognitive or psychological difficulties that would prevent them from participating in an interview without causing high levels of distress • Participants who did not have capacity to provide informed consent |

Sampling strategy.

A purpose sampling strategy was used to recruit participants who reflected the population of individuals who experience ABI (differing types and ages). Homogeneity of the sample was according to SUI experience.

Participant characteristics.

Eleven individuals were eligible for participation in this study. Ten provided written informed consent and participated (n = 10). One could not be contacted. Participant demographics are displayed in Table 2. Most participants were male (n = 7). Participants ranged in age from 19 to 80 (median = 58 years). ABI related demographics are displayed in Table 3. Participants experienced differing types of ABI, including stroke (n = 5), traumatic brain injury (n = 3), meningitis (n = 1) and hypoxic brain injury (n = 1). The length of stay in neurorehabilitation was on average 3.3 months (range: 2 months to 4.5 months), with participants attending on average 2.8 SUI group meetings (range: 2 to 6). All participants' SUI had ended upon discharge from neurorehabilitation. Two participants were interviewed as inpatients within one week of discharge. Eight participants were interviewed post-discharge from neurorehabilitation (average: 4.6 months, range: 1 month to 12 months).

Table 2: Participant demographics

| <i>Gender</i> | | <i>Age</i> | | <i>Ethnicity</i> | |
|-----------------------|-------|------------------------------------|-------|---------------------------|--------|
| Male | n = 7 | 18-24 | n = 2 | White | n = 10 |
| Female | n = 3 | 25-44 | n = 1 | British | |
| | | 45-64 | n = 2 | <i>First</i> | |
| | | 65-84 | n = 5 | <i>language</i> | |
| | | | | English | n = 10 |
| <i>Marital status</i> | | <i>Highest level qualification</i> | | <i>Employment pre-ABI</i> | |
| Single | n = 4 | None | n = 2 | Full-time | n = 3 |
| Married | n = 3 | GCSE | n = 4 | Retired | n = 5 |
| Divorced | n = 3 | A-level | n = 1 | Student | n = 1 |
| | | Undergraduate degree | n = 2 | Carer | n = 1 |

Table 3: Demographics related to ABI and neurorehabilitation

| <i>Type of ABI</i> | | <i>Time in neurorehabilitation</i> | | <i>Number of SUI group meetings attended</i> | |
|------------------------------------------|---------|-------------------------------------------------------------------------|-------|----------------------------------------------|-------|
| Stroke | n = 5 | 0-2 months | n = 1 | 2 | n = 6 |
| (Ischaemic) | (n = 1) | 2-4 months | n = 7 | 3 | n = 2 |
| (Haemorrhagic) | (n = 4) | 4-6 months | n = 2 | 4 | n = 1 |
| Traumatic Brain Injury | n = 3 | | | 5 | n = 0 |
| Meningitis | n = 1 | | | 6 | n = 1 |
| Hypoxic Brain Injury | n = 1 | | | | |
| <i>Total time since ABI to interview</i> | | <i>Total time since discharge from neurorehabilitation to interview</i> | | | |
| 0-6 months | n = 3 | Inpatient at interview | n = 2 | | |
| 7-12 months | n = 3 | | | | |
| 13-18 months | n = 2 | 0-3 months | n = 3 | | |
| 18-24 months | n = 2 | 4-6 months | n = 3 | | |
| | | 7-9 months | n = 1 | | |
| | | 9-12 months | n = 1 | | |

Procedure

Participant recruitment.

Eligible participants were identified from a list of SUI group attendees who had consented to being contacted about research. Initial contact was made by a member of their care team, and with consent the potential participants were contacted by the lead researcher to inform them of the study. Participants were provided with the Participant Information Sheet (Appendix F), and copies of the Consent Form (Appendix G). Participants indicated their intent to take part by returning a signed consent form by post. A £10 voucher reward was offered to each participant.

Data collection.

Prior to commencing interviews, participants were reminded of the study information (Appendix F & G) and were invited to ask questions. Given that all participants had some degree of cognitive impairment, the lead researcher informally assessed capacity to consent to participation in the study and participants provided written informed consent before the interview was conducted. Participants completed the Participant Demographic Questionnaire (Appendix H). An audio-recorded semi-structured interview (Appendix I) was then completed. Interviews lasted on average 54 minutes (range: 18 to 100 minutes), and 9.5 hours of data were recorded.

Given the potential sensitive nature of the interview topics, and the potential vulnerability of individuals who experience ABI, measures were in place to protect participants from undue distress during the interview, such as opportunity for breaks and early termination of interviews without any reason. Participants were verbally debriefed at the end of the interview, and their wellbeing was checked. None reported experiencing distress as a result of the interview or need for support.

Data analysis.

Interviews were transcribed verbatim. The data analysis was completed according to Smith et al.'s (2009) methodology. This was selected for its provision of a clear analytic framework with flexibility to present results in a way that fitted the data collected. The framework consisted of six stages. First, individual transcripts were read multiple times for immersion, followed by initial noting of descriptive, linguistic and conceptual comments. Emergent themes were developed next by mapping connections, relationships and patterns between initial notes. Then the emergent themes were grouped into themes (Appendix L). Each of these steps were repeated per participant. The themes of each individual participant were collated at group level to reflect patterns of themes across participants via subsumption, abstraction and polarisation (Smith et al., 2009). These sub-themes were then organised into superordinate themes (see Appendix M).

Statement of position

I am a white British female who identifies as heterosexual. I have previous experience of working in an Older Adult Mental Health and Memory Assessment Service where there was a culture that valued SUI. I am training to be a clinical psychologist where SUI perspectives are shared through lectures. I believe that experiential knowledge enriches my practice, and my beliefs lead to me wondering whether SUI had any effect on service users themselves.

Quality assurance

The guidelines for qualitative research by Elliot, Fisher and Rennie (1999) were utilised to ensure quality. "Owning one's perspective" was achieved in three ways. Firstly, the researcher provided a statement of position. A bracketing interview was completed prior to commencing data collection, and a reflective diary was kept throughout the process of the

research (Appendix O). “Providing a credibility check” was achieved by including a verification step within the data analysis by continuously comparing developing ideas against quotes and excerpts and discussing theme development with research supervisors. To support transparency of the analysis, appendices illustrating theme development have been included (see Appendices J, K, L & M). “Grounding in examples” was evidenced by including multiple quotations for each theme within the results section and providing an extended list of quotations (Appendix N).

Results

This study aimed to explore the experience of SUI in the context of the process of personal recovery from ABI. Consistent with the concept of personal recovery, each participant’s experiences were unique. However, three superordinate themes of the influence of SUI on this process were identified. The first theme described the perceived mediating effect of SUI on biographical disruption whilst in neurorehabilitation. The second theme described the sense of belonging SUI was reported to provide at a time when participants felt socially isolated. Participants reported that this occurred via the development of peer relationships. Thirdly, the perceived empowering effect of SUI is described. Participants felt this supported their ability to take an active role in their recovery both during neurorehabilitation and in the present. The subthemes of each of these themes and an overview of illustrative quotations can be viewed in Table 4. Pseudonyms have been given to each participant to protect their anonymity.

Table 4: Superordinate themes and subthemes

| Superordinate Theme | Subtheme |
|---------------------------------------------------------------------------------------|--------------------------------------------------------------------|
| SUI as a mediator for biographical disruption during neuro-rehabilitation | ABI as a cause of biographical disruption |
| | Engaging in an ongoing meaning-making process |
| | SUI as a provider of temporary biographical continuity |
| Peer relationships developed via SUI as a source of belonging in neuro-rehabilitation | Social isolation during neuro-rehabilitation |
| | SUI as a provider of valuable peer relationships |
| SUI as a source of empowerment in recovery | Agency as vital to recovering from impairments associated with ABI |
| | SUI as a source of personal empowerment in recovery |
| | The shared voice as a source of empowerment |

SUI as a mediator for biographical disruption during neurorehabilitation

This theme summarises the perceived effect of SUI as a provider of a sense of biographical continuity in the context of reports of total loss of pre-ABI life. It consists of three subthemes; ABI as a cause of biographical disruption, engaging in an on-going meaning-making process, and SUI as a provider of temporary biographical continuity.

ABI as a cause of biographical disruption.

This theme summarises the devastating losses participants reported experiencing as a consequence of ABI. The eight participants living in the community described both physical and cognitive impairments that had impacted on their ability to engage in all activities, from basic self-care to enjoyed work and hobbies. They had experienced this as a total disruption of life as they knew it.

“But that’s my, my life is, completely upheaved. Pretty topsy turvy. I’ve gone from doing everything, to nothing.” (David)

The impact of these losses was that participants felt they were no longer the same person, particularly in the early stages of recovery during neuro-rehabilitation.

“It’s really weird, like it kind of makes you think like that can’t have been me. I must be looking back on someone else. But then it’s like, I’m not at all, I’m not looking back at someone else, I’m looking back at myself. So it’s just really, it’s really bizarre.” (Richard)

The two participants who were still inpatients at the time of interview reported a partial disruption of their lives at present that was associated with anticipation of the losses they would experience upon discharge.

“I should be able to go to (supported living)... It’s a good thing, I mean it gets me out of here. So yeah, yeah. I mean, I’d rather go back to my mum’s.” (Florence)

Five participants reflected on neurorehabilitation as a time where their “being” was obscured from others as a result of the consequences of ABI. They found health care staff related to them as they appeared at that time, which led to a sense that they had lost their personhood in addition to losing their sense of life coherence.

“They can’t be perfect, can they? Nobody can. Some are a lot better than others, the girls are more cheerful, more happy. But I’ve seen ones where you could be, haha, smile, and then the next, without you, not really looking. You’ve got to look actually at me, but they are looking like they’re talking to a moron again, you know.” (Robert)

In the context of these wide-ranging losses and changes, participants reported feeling significantly distressed. They reported feeling intensely shocked, despairing, depressed, and angry. Some also experienced fear as a result of becoming aware of their mortality, and what ABI might mean for their future.

“Yeah it is like upsetting, because it’s just like, it was just like a moment’s blip, that my whole life was changed. (Richard)

“It was very scary, because I’m a nurse and I know about strokes. And he said I was lucky to get to hospital, because they said, she will, if she makes it to hospital, but I probably wouldn’t make it there.” (Stephanie)

Engaging in an ongoing meaning-making process.

As a consequence of biographical disruption, nine participants appeared actively engaged in an ongoing process of meaning making. The purpose of this process seemed to be to integrate their pre-ABI life and current experience to regain a coherent life narrative. This supported participants to reduce their experience of distress and begin to orient themselves to achieving their desired future recovery. Participants reported an initial absence of meaning.

“My sister was there at one point, and a doctor came through to say to her that um, after the scan I’d had, because I seemed to have scans all the time, um, it was meningitis. And that’s when I first heard the word meningitis. Do you know it didn’t mean a thing to me at all? It just didn’t mean anything.” (Catherine)

The need for meaning making appeared to be prompted upon beginning to develop an awareness of the diagnosis and losses in physical and cognitive functioning. Participants then reported setting out to assimilate information from family, friends and health care professionals to begin to understand what happened to them, often during neurorehabilitation. The meaning formed evolved constantly with the receipt of new information and new experiences. This process was often lengthy, and appeared ongoing for most participants.

“I had various leaflets showing drawings and things, you know, where it had been and how long you’ve had it, and what’s the results and all that sort of thing. So everybody’s, where they came from I can’t remember, but I remember seeing things like that over the last 7 to 8 months. Throughout the last year.”(John)

Ongoing memory difficulties impeded the meaning making process, as this made it difficult for participants to integrate experiences and information into a coherent life narrative. This was perceived to limit their ability to actively engage with their recovery.

“I think I must have been in an induced coma. I don’t know. [It’s] horrible. Because I want to know. If I know then I can try and improve certain things, can’t I?” (Liam)

One participant did not yet appear engaged in this process as they were still assimilating an understanding of the impacts of ABI on their life.

SUI as a potential provider of temporary biographical continuity.

In the context of biographical disruption, and for some the loss of personhood, seven participants reported experiencing SUI as personally meaningful whilst in neurorehabilitation. Often participants did not have extensive memory of the content of SUI, but instead seemed to have one or two memories of SUI that held particular emotional salience to them personally. For example, Stephanie, who was a health care professional prior to ABI, had an overriding memory of a discussion in which other service users highlighted an issue that she had not been aware of in her practice.

“And that’s what stood out, and that’s why I can remember it, I think, because I thought, what a wonderful [idea].” (Stephanie)

This suggested that these participants engaged with SUI from their pre-ABI frame of reference. This was further evidenced by the experience of the other three participants, who reported that SUI held no meaning for them as it did not connect with anything personally meaningful.

“But that’s the things, because in the patient forum, there’s nothing, it’s not personal.” (Oliver).

It was not clear why participants approached SUI from their pre-existing frame of reference, or whether indeed this was unique to the experience of SUI. However, this appeared to hold a clear function of providing connection (and therefore continuity) with pre-ABI life at a time point in recovery when participants had very little connection with this. This connection with pre-ABI life had a positive impact on most participants during neurorehabilitation, as they consequently reported feeling good about themselves. For example, Liam re-connected with his sense of self as a kind and helpful person to others upon making a well-received suggestion for improvements to the service.

“Yeah, well, everyone else, everyone else said yeah it was good, well done. So it was nice for other people to recognise it as well.” (Liam)

“Well it made me feel proud, because everybody wanted the same. So it was a good idea.” (Liam)

Participants reported that these moments of continuity with pre-ABI life did not continue to hold this meaning upon return to the community, and instead held no meaning in their current lives. This suggested that the influence of SUI was temporary and limited to the setting in which it occurred. This was perhaps because upon return to the community, SUI was not sustained. It is possible that in the context of continuing struggle and suffering due to ABI participants lost connection with this experience, as it was not subsumed into the meaning-making processes at present.

“In the overall part of my, um, recovery, it doesn't mean anything to me, because I'm trying to remember what he said, you know, last night or something.” (Stephanie)

It is also possible that returning home provided an increased sense of connection to pre-ABI life, which meant these moments of connection held reduced meaning as recovery

progressed. Therefore, it appeared that SUI provided a temporary effect of continuity with pre-ABI life which provided relief from distress caused by ABI whilst in neurorehabilitation.

Peer relationships developed via SUI as a source of belonging in neurorehabilitation

This theme described the reported need for peer support whilst in neuro-rehabilitation, and how participants obtained this by attending SUI. Two subthemes were identified; social isolation during neuro-rehabilitation, and SUI as a provider of valuable peer relationships. Through these peer relationships, participants reported gaining a sense of belonging and enhanced wellbeing.

Social isolation during neurorehabilitation.

Participants reported experiencing an unmet social need during neurorehabilitation. Eight participants reported feeling isolated at times when their family and friends were absent. It seemed that in the context of the shock of experiencing all-encompassing losses due to ABI, the participants had a heightened need for connection with family and friends as this provided them with comfort and belonging. The physical separation from these was therefore perhaps more deeply felt whilst being an inpatient. It is possible that as a consequence participants reported seeking relationships with peers who were also inpatients, in the hope that this would provide them with this comfort and belonging. However, participants often only had access to maximally three other peers for social contact, due to the lay out of the medical unit. Sometimes these peers were unable to interact due to their own experience of ABI, and other times participants reported that the peers in their bay were more insular. This left the participants who sought social contact reporting feeling isolated and lonely.

“But they [other patients] can’t really communicate. Um, (patient) can hardly talk. Um. (patient) sort of keeps herself to herself, and (patient) is quite young, and keeps herself to herself really as well, so yeah.” (Florence)

Some participants (Richard, Stephanie and John) talked about initially withdrawing into themselves whilst they were inpatients in neuro-rehabilitation, due to feeling unsettled, uncertain and distressed about the losses associated with ABI. For example, Stephanie talked about being a very social person, but in the context of distress and word finding difficulties found herself withdrawing from speaking with others.

“I can remember being stuck in a corner in a chair and looking around the ward but realising that a lot of them didn’t, I thought they wouldn’t understand. And I was quite quiet, and I wouldn’t talk to anybody, because I couldn’t really talk.”

(Stephanie)

Despite the difference between feeling isolated and withdrawing, this meant all eight participants felt their need for social contact was perhaps not met during their time in neuro-rehabilitation.

SUI as a provider of valuable peer relationships.

Eight participants discussed their social relationships with peers in the context of SUI. Six participants reported being motivated to attend SUI as a means of meeting peers. For some, this was motivated mostly by limited social interaction or dislike of peers who resided in the same medical bay as them. Two participants said they had already established peer relationships with individuals who attended SUI and were motivated to continue these relationships by attending SUI together.

All eight participants talked about gaining valuable peer relations from attending SUI. It appeared the effect of these peer relationships was that participants gained a sense of belonging at a time of isolation. This improved participants’ perceived sense of wellbeing. Furthermore, participants reported finding comfort within these relationships at times of distress, as talking with peers enabled them to feel more able to cope with the impact of ABI.

“They started to, they started to do things [as a result of SUI], we had evenings as well... They had er, quizzes, in the evenings, and er, film nights, things like this. That was quite good... and they got popcorn and cakes and different things like that, and then they had going away parties for the people that were leaving and things like this. Things that would not normally happen on the hospital ward. It was only our ward. It gave us pleasure.”(Bill)

It seemed the effect of gaining a sense of belonging from peers was limited to the context of neurorehabilitation, as most participants reported these relationships ended upon discharge. Only one participant reported having continued friendships with peers whilst living in the community and continued to find these a source of belonging and comfort. Therefore, it was possible that these relationships predominantly served a function as an inpatient of providing belonging at a time of isolation, but that this function became redundant upon returning home.

It is important to note that not all people who participants met at SUI became a source of friendship and comfort. Four participants described dislike for some of the other attendees of SUI. These attendees tended to be individuals who were perceived to dominate group discussions with problems that were only relevant to them. They were experienced as aggravating and were consequently avoided by the participants.

“[SUI], it was quite nice because I saw people from other wards. And I was always curious about other people, and interesting, but when the ladies came in that I hadn't seen before, I'm very naughty, I thought, I'm glad I'm not on your ward. I have to be honest and say that is how I felt. There was just something, perhaps, er, they irritated me. (Catherine)

Another barrier was that three participants described that belonging was inhibited by the perception that they had a visible difference from all other SUI attendees. Two participants acted to resolve their perceived difference, which enabled them to feel belonging.

“In the chair I was, not anonymous, but I was one of the group.” (Catherine)

In contrast, one participant found that seeing differences, in this case more impaired others, an upsetting experience. Despite gaining one valued peer relationship, he at times reported wanting to withdraw from SUI, suggesting that belonging to this group might have been threatening.

The sad people in there that were never happy... It made me want to get out there like quicker, in a certain sense.” (Oliver)

Therefore, SUI was predominantly reported to enable participants to develop valuable peer relationships that provided belonging and coping during neuro-rehabilitation. However, some peers were disliked, and some participants found that visible differences from the majority of SUI attendees inhibited their sense of belonging.

SUI as a source of empowerment in recovery

This theme described the experience of SUI as an empowering influence on personal recovery. The need for empowerment is contextualised with a description of the recovery process in the first sub-theme. This is followed by the descriptions of two distinct experiences of empowerment, at the personal level and at group level.

Agency as vital to recovering from impairments associated with ABI.

The meaning-making process that participants engaged in occurred alongside another process of striving for return to a satisfying life. This process summarised the way participants experienced the process of recovery from the impairments in functioning caused by ABI. All participants reported aiming to return to their pre-ABI life. Participants engaged in a process of setting interim goals, taking action, and reviewing progress, to constantly strive to recover, with the overall aim of achieving their satisfying pre-ABI life. The approach participants took appeared heavily influenced by the meaning they ascribed to their ABI, and evolved as the meaning made evolved with new information and experiences. At the time of interview, none of the participants felt they had completed this process.

“So yes, and I am setting myself goals. Now my next goal, a big one for me, was, er, ordering taxis, which I did, I went to lace-making and I did that.... I’ve done that three times. So I, the first time I was very nervous about it, but now it’s just easy. And then um, the next thing is to take the dog for a walk.” (Catherine)

Nine participants felt that being an active agent in this recovery process was the most crucial driving force for achieving their overall goal.

“I’d like to think it was all me. I was determined, and I still am, I’m still determined to go that step further. But they send me a report they say, if you’re going to get any recovery, you’ll notice it in the first few months of having the operation, and then it peters out. But that hasn’t been the case. Nor will I let it be the case. I’m going to continue to fight it, as best as I can, and that’s it.” (John)

One participant felt unable to assume this active position as they felt they had not yet understood the meaning of their ABI. This meant they complied with professionals without knowing the purpose of interventions.

“Ok really. Um. I don’t know really [what I am recovering from].” (Florence)

In the context of neurorehabilitation, participants often reported that they felt limited in their ability to take an active approach to recovery. Many participants were bed-bound, and often were unable to engage in stimulating activities such as reading due to cognitive impairment caused by ABI. Their only relief from this was when they were engaged in rehabilitation activities with health care professionals. This meant the predominant experience was of reduced agency at this time, due to dependency on others.

“I couldn’t sit up. I couldn’t get out of bed. I couldn’t control bodily functions. So physically, it was really hard.” (Bill)

Despite this, eight participants described inventive ways in which they developed the beginnings of agency in their recovery during neuro-rehabilitation. They began to make plans for their recovery. Some began to practice impaired skills within the resources they had available to them. Once agency developed, it continued throughout the process of recovery (it was not lost at any stage).

“I remember one of the patients said to me... oh what have you been doing today? And I would be like, what’s she talking, but then I realised the more I started talking out, the more it was coming.” (Stephanie)

SUI as a source of personal empowerment in recovery.

Eight participants reported being motivated to attend SUI as a means of seeking stimulation. Five of these participants described raising issues they were experiencing whilst in neurorehabilitation and engaged actively in discussions by problem solving issues others had raised. These participants reported feeling listened to, and this enabled them to feel their voice mattered. This was perceived as empowering, as it increased their perceptions of equality with health care professionals.

“I found it helpful that each patient could say or suggest certain ideas and people listened to them. Because, it is, they are there most of the time.” (Richard)

Well it’s good because you feel like you’re being listened to. About your ideas, yeah, you feel like you’re being listened to. Obviously you are always being listened to, but you don’t always feel like it.” (Liam)

Making plans to address issues provided participants with a sense of control over their recovery process. In turn they felt this boosted their ability to take an active role in their recovery. Two participants felt that this sense of boosted agency continued beyond the setting of neurorehabilitation, and was still influencing their recovery approach at present. These participants reported witnessing change as a result of SUI.

“It probably did give me a bit of confidence back, yeah.” (Richard)

“I suppose it must have helped in a way. It certainly helped in dealing with the doctors. Because we all had an opinion.” (Bill)

For the other three participants, the increased sense of agency appeared limited to the neurorehabilitation setting. This was perhaps because these participants were discharged before being able to see any change on their neurorehabilitation ward as a result of their suggestions.

“It’s a nice meeting, and it was, it was interesting too. Because, but I felt as though people were coming and going, and like myself, I didn’t get to see any follow through. (Catherine)

Five participants reported that SUI had no effect on their process of recovery, and therefore that they did not experience empowerment. These participants’ experiences highlighted several important potential barriers to experiencing SUI as empowering. Oliver,

Stephanie and Florence suggested that their central motivation to attend SUI was related to seeking increased social interaction, rather than to enhance care received. This indicated that engaging with the process of seeking change was important to developing empowerment.

“I didn’t really have any problems, so I didn’t feel the need to share.” (Oliver)

“I don’t know if it helped, or if it didn’t, but either way, I’ve made whatever recovery I’ve made.” (Oliver)

Robert suggested that his experience of cognitive impairments left him feeling unable to keep up with conversations and understand discussions. Although he did not experience this as distressing, he suggested this meant that SUI had no impact on his recovery.

“I can’t honestly say to myself that this has been a good effort, whatever it is, you know, because half the time I don’t know what the hell they’re talking about.”

David reported that memory difficulties impeded his ability to remember even attending SUI, which meant this had no effect on his recovery.

“I didn’t join it. I didn’t join it. Or if I did, I don’t remember, haha!” (David)

For four of these participants, the absence of empowerment via SUI did not inhibit them from developing agency in recovery. This perhaps suggests that the role of SUI boosts agency for some, rather than it being the sole source of development of agency in recovery.

The shared voice as a source of empowerment.

Seven participants described experiencing empowerment at a group level. This mainly came from their perception of having influence and power by using their shared voices to drive improvements in their experience of the neuro-rehabilitation setting. The function of this empowerment was subtly different from personal empowerment. It focussed on the

perception of having an important role in shaping the experience of future other patients, by using one's own experience to enhance care for the benefit of others.

“Like, obviously I knew I wasn't going to be there forever, um, but obviously if anyone else my age happened to be in there, they would get some kind of similar, hopefully, experience.” (Richard)

It seemed participants felt this responsibility was shared and drew upon each other to heighten the strength of their message.

“Well we did our part on the ward, all of us, because I told them when I went back [to SUI], because I brought it up, and I said, I think when we have our visitors we must ask them if they would take their chairs away. And they did just that.” (Catherine)

This empowerment at group level appeared to further enhance agency in recovery as it supported participants as a group to feel equal to staff; they felt as though their experiences and needs mattered. The importance of this was summed up by John.

“It takes over the running of your life really, when you're stuck there in hospital. So you want to get it as near perfect as you possibly can. You can never get it completely right, it's not your home, is it. But if you can get, go some way of getting there, and bring up certain things that could be, need to be tidied and trimmed up, you know what – (smiles).” (John)

Discussion

This is the first study that has completed an in depth qualitative analysis of the experience of SUI for people with ABI. It is novel in its use of the framework of personal recovery as the anchor point from which to understand the experience of SUI. The findings regarding the process of personal recovery were consistent with previous findings that people with ABI experience a sense of biographical disruption (Bury, 1982). Participants appeared

actively engaged in a process of meaning making and adaptation in order to regain a sense of continuity in personhood, identity and place in the world (Levack et al., 2010; Salter et al., 2008). This seemed connected to their sense of life satisfaction (Anthony, 1993). It therefore appeared that personal recovery (Anthony, 1993) was an appropriate theoretical framework from which to elucidate this process.

This study added to the extant literature via the three novel findings which illustrated the interaction between the process of personal recovery and SUI. Firstly, SUI appeared to be experienced in the context of individuals' pre-existing frame of references. This included participant's reported experience of their pre-ABI life (such as identity, social roles, occupation) and their present surroundings. Kelly's (1977) theory of personal constructs suggested that individuals engage in a process of evaluating the world around them to understand its present relationship to themselves. It is possible that SUI allowed for the testing and verifying of hypotheses that the participants were inherently still "themselves" despite the drastic change in their life circumstances. This resulted in a perceived sense of continuity with pre-ABI life at a time of apparent total disconnect, and alleviated the experience of distress. This elaborated on Fudge et al.'s (2008) finding that people with ABI identify the influence of SUI in terms of personal gains. This finding directly challenges the common perception of health care professionals that people with ABI cannot engage in meaningful SUI (Clare and Cox, 2003). Instead, it highlighted that what was meaningful at the time of SUI was likely unique to the person and their way of constructing their life and the world around them.

A second core finding was that even a relatively small amount of SUI (eg. two meetings) was reported to have an empowering effect on individual's experience of agency in recovery. Theory of psychological empowerment (Zimmerman, 1990) suggests that developing an understanding of social and political environments via participation supports

individuals to identify and utilise resources to achieve goals. In this case, SUI may have supported some participants to develop increased understanding of the complex care systems in which they were embedded, and had an experience of influencing these, which increased their perceived knowledge and confidence in navigating these (Fudge et al., 2008). However, some participants did not report experiencing empowerment, but neither did they report further disempowerment (Slomic et al., 2016). It appeared that the level of engagement with the purpose of SUI (to enhance care) influenced this experience. Particularly important was the identification of common barriers to participation such as cognitive impairments and memory difficulties (Ocloo & Matthews, 2016). In addition, systemic barriers such as slow progress in change in complex health care systems were also perceived to inhibit further empowerment, as witnessing change was identified as an important component of this.

The experience of empowerment at group level appeared synonymous with collective empowerment (Castro, van Regenmortel, Vanhaeght, Sermeus & van Hecke, 2016), although in this case within the microcosm of the neurorehabilitation ward. This appeared to increase perceptions of equality with health care professionals, which in turn positively influenced the process of psychological empowerment in recovery (Zimmerman, 1990). This theme raised interesting questions about the role of health care staff in facilitating SUI. In this study, participants valued the role of the facilitators in enabling SUI. However, it is also possible that the limitations placed on the SUI group (pertaining to the particular setting) may have limited further development of collective empowerment beyond the setting (Clare & Cox, 2003). This highlighted the systemic challenges in achieving true collaboration in facilitated SUI (Carman et al., 2013).

The reported experience of social isolation as a result of ABI is a common theme within the wider literature on the impact of ABI (Levack et al., 2010; Salter et al., 2008). It appeared participants' narratives of isolation overlapped with wider narratives about

marginalisation in the context of sudden onset of disability, as they reported awareness of dependency on others, impairments, and segregation from family (Yates, 2003). This perceived sudden change of social identity in the eyes of others may have led to the desire to connect with similar others, as these had the potential to provide a sense of belonging (Tajfel, 1982). SUI appeared to provide a platform and a purpose for such interactions. However, meeting peers in reality did not always automatically provide this sense of belonging. Some talked about disliking other peers, and others talked about visible differences inhibiting a sense of belonging. Difference is commonly found to be a barrier to group cohesion, which appeared to occur at both task-level (dislike due to differences in beliefs about the purpose of SUI), and at personal-level (lack of perceived similarity with group members) (McLeod & Von Truer, 2013). Therefore, the reported level of need for social interaction, and the perceived desirability of belonging to the available social group, may have influenced the level of belonging experienced with peers.

Limitations

The sample size was appropriate for an IPA study (Smith et al., 2009), but overall represented a very small subsection of the ABI population, with no involvement from black and minority ethnic populations. Participants were recruited from only one site. With this being the first study in this research area, the relevance of the findings to the wider ABI population were unclear (Mays & Pope, 2000).

Recovery was an evolving process, and the meaning ascribed to experiences such as SUI may therefore also evolve over time. Retrospective data collection at one time point may not have captured the full experience of SUI.

Finally, this research only pertained to one type of SUI, at the level of participation in service governance and development (Carman et al., 2013). Results may therefore not be transferable to other types of SUI.

Research implications

Much further research is needed. Replication of the above research in other settings with increased diversity of participants would enable an assessment of the validity and relevance of the results. Further research is needed with other types of SUI, including both longer term involvement and SUI at partnership and policy development levels. These could provide additional insights into the influence of SUI on identity, social relationships and agency in recovery.

It is also strongly suggested that studies are completed with health care professionals and stakeholders, both who are and aren't yet involved in SUI, to understand their perspectives and experiences. It is only by researching both perspectives that a full understanding of how to support meaningful SUI can be achieved. Studies that focus on the relationships between professionals, stakeholders and involved service users may be particularly useful.

Clinical implications

The experiences of participants in this study suggested that common assumptions that people with ABI cannot participate in meaningful SUI (Clare & Cox, 2003) were unfounded. No evidence was found that SUI resulted in increased disempowerment or burden (Slomic et al., 2016). With this in mind, it is recommended that increased opportunities for SUI with people with ABI are developed.

Although the reported experiences of SUI were predominantly positive, several areas of complexity in implementing SUI were identified. The results of this study suggested that

people with ABI may not only have different ideas about the meaning of SUI from staff (Fudge et al., 2008), but may also have different ideas between each other. It may be beneficial to consider these to negotiate the purpose of SUI. Providing an environment where individuals feel listened to and valued appeared crucial to empowerment, which could be increased by ensuring the visibility of change. Finally, although peer relationships were a source of comfort and belonging, facilitators of SUI may have a role in promoting group cohesion, perhaps by focussing on shared purpose and goals in the context of visible (and perhaps invisible) differences between SUI group members.

Conclusion

The results of this study highlight the many ways in which people with ABI may experience SUI in the context of personal recovery. Each of these unique experiences were reported to hold individual meaning to the person. Consequently, SUI appeared to provide a welcomed opportunity for connection with pre-ABI life at a time of complete disconnect from this. This refutes common assumptions that people with ABI cannot engage with the process of SUI.

The process of asking individuals about their experiences also allowed unmet needs to become apparent. Participants reported feeling socially isolated whilst in neurorehabilitation at a time of increased need for comfort and support from others. It seemed participants felt SUI offered a purpose and a platform for increased interaction with peers.

SUI was also perceived to increase agency in recovery for individuals who actively engaged with the purpose of SUI. Several important barriers such as accessibility of SUI for individuals with cognitive impairments were also highlighted by participants.

The small sample used in this study meant that the above findings may not be relevant to the entire population of individuals with ABI. However, the depth of experiential

knowledge expressed in this research supports the call for increased SUI with people with ABI. Providing opportunities to engage with service users in ways that are meaningful to them has significant potential to enhance care and practice. Over time, this may support increased recovery and wellbeing amongst individuals who experience ABI. Further research may support the development of SUI by providing an evidence base from which increasingly effective ways of collaboration can be established.

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EMMA HART BSc Hons

SECTION C: APPENDICES AND SUPPORTING INFORMATION

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

APRIL 2018

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

Appendix A – Hope measures used in cross-sectional studies

| Measure | Description of measure | Validated with ABI? | Studies used by |
|------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------|---------------------------------------------------------------------------------|
| Hopefulness Scale 1 (Mercier, Fawcett & Clark, 1984) | This scale is a modification of the Beck Hopelessness Scale (Beck, 1974), which was designed for use with individuals who attempted suicide. This self-report questionnaire asks the same 20 questions about negative expectancies, attitudes about the future and feelings of pessimism, but instead of true or false responses, responses are given on a 5-point Likert scale ranging from “never” to “almost always”. | NO | Popovich, Fox & Burns (2003). |
| Modified Stoner Hope Scale (Farran, 1985) | This self-report scale consists of 20 items asking about interpersonal and intrapersonal hopes, using a 4-point Likert scale ranging from “cannot possibly be realised” to “definitely will be realised”. | NO | Popovich, Fox & Burns (2003). |
| Adult Hope Scale (Snyder et al., 1991) | This scale is a 12 item self- report measure of hope according to Snyder’s cognitive model of the concept. The scale is divided into two subscales, agency and pathways. Each item is answered using an 8-point Likert-type scale ranging from “definitely false” to “definitely true”. | NO | Gum, Snyder & Duncan (2006). Peleg, Barak, Harel, Rochberg & Hoofien (2009). |
| Hope and Coping Questionnaire (Popovich, 1991) | This self-report measure asks 15 questions about how individuals perceive their predicament and cope with this and asks about general and specific hopes. Developed based on interviews conducted with stroke patients during acute and neurorehabilitation phases of recovery. | YES (stroke) | Popovich, Fox & Burns (2003). |
| Herth Hope Index (Herth, 1992) | This self-report scale is a shorter version of the 30 item Herth Hope Scale (Herth, 1991). The scale consists of 12 items, and is based on Dufault & Martocchio’s (1985) multi-dimensional concept of hope. Responses are given on a 4-point Likert scale ranging from “strongly disagree” to “strongly agree”. | NO | Bluvol & Ford-Gilboe (2004). |

Appendix B: Measures of recovery used in cross-sectional studies

| Measure | Aspect of recovery | Description of measure | Validated with ABI? | Studies used by |
|------------------------------------------------------------------------------------|-----------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------|------------------------------|
| Health Options Scale (Ford-Gilboe, 1997) | Family health work | This questionnaire measures the way through which families learn ways of coping that lead to healthy living over time. It consists of 21 self-report items, with responses given on a 4-point Likert scale (from “strongly disagree” to “strongly agree”). A higher score indicates higher levels of family health work leading to healthy living over time. | Not clear | Bluvol & Ford-Gilboe (2004) |
| Reintegration to Normal Living Scale (Wood-Dauphinee & Williams, 1987) | Everyday living (physical, social, emotional) | This questionnaire measures the impact of disease or disability on an individual’s ability to resume normal patterns of everyday living. It consists of 11 self-report items, which individuals rate on 0 (does not describe my situation) to a 100 (fully describes my situation) visual analogue scales. According to the authors it is considered a proxy measure for quality of life, and a higher score indicates higher reintegration into everyday living. | YES | Bluvol & Ford-Gilboe (2004). |
| Level of Rehabilitation Scale (Carey & Posavac, 1978) | Functional outcomes in neurorehabilitation | This questionnaire measures functional outcomes during neurorehabilitation in activities of daily living and cognition. Outcomes are scored 0 (does not do) to 4 (attempts to do independently). A higher score indicates better functional outcomes. | YES | Popovich, Fox & Burns (2003) |
| Barthel Index (Mahoney & Barthel, 1965) | Physical functioning | This clinician-rated questionnaire measures the functional independence of individuals who experienced a stroke. It consists of 15 items which are scored from 0 (dependent) to 10 (independent). A higher score indicates more independence in physical functioning. | YES | Popovich, Fox & Burns (2003) |
| Modified Rankin Scale (van Swieten, Koudstaal, Visser, Schouten & van Gigin, 1988) | Disability in daily activities | This clinician rated tool is used to assess degree of disability in daily activities. It is rated from 0 (no disability) to 5 (severe disability requiring constant nursing care). Each score has specific behaviour descriptions associated with them. A higher score indicates higher levels of disability | Yes | Gum, Snyder & Duncan (2006) |

| | | | | |
|-------------------------------------------------------------------|-------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|------------------------------------------------|
| Mini Mental State Examination (Folstein, Folstein & McHugh, 1975) | Cognitive functioning | This questionnaire, administered by a clinician, is a brief screening tool of cognitive functioning. It is used to indicate the presence of cognitive impairment. The questionnaire is scored out of 30, with a higher score indicating better cognitive functioning (scores under 21 indicate impairment). | Yes | Gum, Snyder & Duncan (2006) |
| Orpington Prognostic Scale (Kalra & Crome, 1993) | Severity of stroke | This clinician rated tool involves a physical examination to measure movement and cognition. A higher score indicates greater severity. | YES | Gum, Snyder & Duncan (2006) |
| Stroke Impact Scale – Version 2 (Duncan et al., 1999) | Disability after stroke | This self-report questionnaire measures disability after stroke on five factors; physical, memory and thinking, communication, participation and emotion. It consists of 64 questions rated on a 5-point Likert scale. A higher score indicates better functioning. | YES | Gum, Snyder & Duncan (2006) |
| Beck Depression Inventory (Beck, Steer & Garbin, 1988) | Depression | This self-report questionnaire measures depressive symptoms occurring over the past week. It consists of 21 self-report items which individuals rate on a 4-point Likert scale. A higher score indicates more depressive symptoms. | Yes | Peleg, Barak, Harel, Rochberg & Hoofien (2009) |
| Life Orientation Test Revised (Scheier, Carver & Bridges, 1994) | Dispositional optimism | This self-report questionnaire measures dispositional optimism (trait optimism). It consists of 10 self-report items rated on a 5-point Likert Scale. A higher score indicates higher levels of optimism. | Yes | Peleg, Barak, Harel, Rochberg & Hoofien (2009) |

Appendix C: Research Ethics Committee Approval

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Appendix D: Health Research Authority Approval

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Appendix E: Local NHS trust Research and Development Department Approval

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Appendix F: Participant Information Sheet

V4 18/04/2017
IRAS No: 217552



Salomons Centre for Applied Psychology

Participant Information Sheet

Research study: An investigation into the effect of service user involvement on personal recovery from acquired brain injury.



My name is Emma Hart and I am a Trainee Clinical Psychologist. I study at Canterbury Christ Church University. I am doing a research study. I have two supervisors to help me with the research, Dr Edyta Monika Hunter and Dr Leigh Emery.

The study is to find out what it is like to take part in a service user involvement group. I'd like to know whether this has any effect on your recovery from an acquired brain injury.



This information sheet will tell you about why the research is being done, and what taking part will involve. Please take time to read this information before you decide if you would like to take part. If you have any questions, please do get in touch with me.

Part 1: This part tells you about the reason for doing the study, and what is involved if you decide to take part.

What is the purpose of this study?

The government asks the NHS to meet with service users, so they can have a say about how their services are run. This is known as "service user involvement". In some services, NHS staff meet with service user involvement groups, where you can share your views with these professionals.

We don't know very much about what it is like for people who have had an acquired brain injury to take part in these groups. This study aims to find out what it is like for you to take part in a service user involvement group. We'd like to find out what the effects are on your ability to lead a satisfying, hopeful and meaningful life, even with any limitations caused by the brain injury.

What does taking part in this study involve?

I will ask you to come to one meeting with me. This meeting lasts up to 90 minutes. The meeting will be at the Tower Ward in Canterbury. If you have any problems getting there, just let me know and we might be able to find a different place to meet.

At this meeting, I will ask you some questions about you and your life, some questions about your brain injury, and some questions about the service user group you went to. You can answer in as little or as much detail as you feel able to. I will record our conversation using an audio recording device.

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Are there any benefits to taking part in the study?

Some people find it a rewarding experience to talk about their life experiences. Some people may also find it rewarding to know that what they tell us could encourage professionals to run more groups, and encourage other people to get involved.

Are there any risks or disadvantages to taking part?

Talking about your life after having an acquired brain injury can be a sensitive topic. It is possible you might find some of the questions difficult or upsetting to answer. I will make every effort to make you feel at ease. It is unlikely you will find the interview very upsetting, but if you do, I can provide information about how to get support.

Do I have to take part?

It is completely your decision whether you decide to take part. You do not have to if you don't want to. You don't have to give us a reason if you don't want to take part. Your care will not be affected in any way if you take part in this study, or decide not to.

Do I get anything for taking part?

As compensation for your time, we can offer you a £10 voucher of choice.

Who do I contact for further information?

There may be some things you would like me to explain more. If you have any questions before you decide whether you would like to take part, you can contact me (Emma Hart) on 07917063228. I'd be very happy to hear from you to answer any questions you might have.

If you are currently staying on the East Kent Neurorehabilitation Unit at Kent and Canterbury Hospital, you can also ask to speak to Dr Leigh Emery (Clinical Psychologist) who will be able to help with any questions you might have.

What do I do now if I want to take part?

If you are currently staying on Harvey Ward: You can let me know you want to take part by filling in the "Consent Form" and giving this to Dr Leigh Emery. With your permission, he will provide me with your name and telephone number so I can contact you to arrange a time to meet.

If you have been discharged from Harvey Ward: You can contact me by phone (on 07917063228) or by returning the "Consent Form" by post (FAO Emma Hart, Salomons Centre for Applied Psychology, Canterbury Christ Church University, 1 Meadow Road, Tunbridge Wells, TN1 2YG). I will then contact you to arrange a time to meet for the interview. Please make sure to leave your name and telephone number so I can contact you.

Part 2: This section contains more detailed information about how the study is run.

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Who is supervising this research?

As I am a trainee, my research is supervised by two academic supervisors. Dr Edyta Monika Hunter is a Lecturer in Applied Psychology at my university. Dr Leigh Emery is a Clinical Psychologist that works on the East Kent Neuro-Rehabilitation Unit.

Confidentiality

All the information that is collected about you during the course of the research will be kept strictly confidential within the research team (me, Monika and Leigh). Anything you tell us will be anonymized. We will follow ethical and legal practices set by the NHS Research and Development departments and Canterbury Christ Church University.

The only exception to confidentiality is if you tell me something that means I am concerned about your safety, or the safety of others around you. If this happens, I may need to tell someone who is involved in your care about my concerns. This would usually be your lead clinician. I will always tell you first if I need to talk to them, and I will only tell them what they need to know that has made me concerned.

The interview will be recorded using an audio-recorder, and what we both say will be typed up. This is known as an interview transcript. After this, the voice recording will be destroyed. Any identifying information will be removed from the transcript, which is then kept by the university for 10 years.

What will happen to the results of this research study?



The results of this study will be written up as part of my university course, the Doctorate in Clinical Psychology at Canterbury Christ Church University. I also intend to publish my results in a scientific journal, which are magazines for other researchers to keep up to date.

We will make sure that anything you tell us is anonymised, which means that we will make sure you can't be recognised. We do this by removing your personal information. We will ask your permission to use quotes from things that you have told us in the written reports.

What if I wish to complain about the way the research study has been conducted?

I will make every effort to make sure that the interview process is respectful and sensitive. However, if you have any concerns or complaints about anything related to the study, we will take these seriously and address them immediately.

You can contact me on 07917063228. You may prefer to speak to my supervisors, Dr Monika Hunter on 0333 011 7117, or Dr Leigh Emery on 01227 864261 (ext. 722 4261).

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If you remain unhappy, or wish to make a formal complaint, you contact Prof. Paul Camic (Research Co-ordinator at the Department of Applied Psychology) at Canterbury Christ Church University on 0333 011 7114.

You can also contact the East Kent Hospitals Trust Patient Advice and Liason Service (PALS) on 01227 783145 or by e-mailing ekh-tr.pals@nhs.net.

Contact Details

If you would like to talk to me or my supervisors about this research, you can contact us on the details below:

Researcher: Emma Hart (Trainee Clinical Psychologist)
Salomons Centre for Applied Psychology, 1 Meadow Road, Tunbridge Wells, Kent, TN1 2YG
Tel: 07917063228

Supervisor: Dr Edyta Monika Hunter (Lecturer in Applied Psychology)
Salomons Centre for Applied Psychology, 1 Meadow Road, Tunbridge Wells, Kent, TN1 2YG
Tel: 0333 011 7117

Supervisor: Dr Leigh Emery (Clinical Psychologist)
East Kent Neurorehabilitation Unit (EKNRU), Tower Ward, Kent and Canterbury Hospital, Ethelbert Road, Canterbury, CT1 3NG
Tel: 01227 864261 (ext. 722 4261)

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Appendix G: Consent Form



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Consent form

Title of Project: An investigation into the contribution of service user involvement to personal recovery from acquired brain injury.

Name of researcher: Emma Hart (Trainee Clinical Psychologist)

Please initial box

| | |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|
| I confirm that I have read the Participant Information Sheet for this study. I have had time to consider this information. I have been able to ask questions and confirm these have been answered satisfactorily. | |
| I understand that my participation is voluntary. I am free to withdraw my participation at any time without giving any reason. My medical care or legal rights will not be affected if I withdraw. | |
| I agree to take part in this study. | |
| I give permission for my interview to be audio-recorded by the researcher. | |
| I agree that anonymised quotes from my interview may be used in published reports of the study findings. | |
| In the unlikely event that I become very upset during the interview, I give the researcher permission to contact my care team so I can access support. I understand that the researcher will discuss this with me first. | |

| | | |
|---------------------------------------------------------------------|-----------|-------|
| _____ | _____ | _____ |
| Name of Participant | Signature | Date |
| _____ | _____ | _____ |
| Name of Person taking consent (if different from the researcher) | Signature | Date |
| _____ | _____ | _____ |
| Name of Researcher | Signature | Date |

*When completed, 1 copy for participant, 1 for researcher, and 1 to be kept in medical notes

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Appendix H: Participant Demographic Questionnaire

Participant Number:



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Participant Demographic Sheet

Information about you:

1. **Gender:** Male Female Other: _____

2. **Age:** _____

3. **Ethnicity:**

White:

English
Scottish
Welsh
Irish
Other: _____

Mixed ethnic group:

White and black Caribbean
White and black African
White and Asian
Other: _____

Asian:

Indian
Pakistani
Bangladeshi
Chinese
Other: _____

Black:

African
Caribbean
Other: _____

Any other ethnic group: _____

4. **What is your first language?** _____

5. **How many years did you spend in education?** _____

6. **What type of qualification did you obtain:**

Up to age of 16 (GSCE, O levels)

Up to age of 18 (A levels)

Undergraduate university degree

Masters level university degree

PhD level university degree

Other: _____

7. **What is your occupation?** _____

8. **What is your marriage status?** _____

Please turn over

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Participant Number:



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Questions about your illness

1. Type of acquired brain injury (eg. Stroke, traumatic brain injury):

2. Date that you experienced the acquired brain injury (please write the exact date if you know, or the month and year)

3. Do you know in what area of your brain you experienced the acquired brain injury? If yes, please write down the area below.

4. How long did you stay on Harvey Ward (East Kent Neurorehabilitation Unit)? Please write the amount of weeks or months you stayed.

5. Medical conditions you experienced before the acquired brain injury (please list):

6. Have you been diagnosed with any new medical conditions since the acquired brain injury? If yes, please list these.

7. How many service user involvement groups did you attend whilst you were on the ward? Please circle:

1 2 3 4 5 6

Other: _____

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Appendix I: Interview Schedule

Interview Schedule

Introduction:

I am interested to hear about you and your experiences, in as much detail as you want to give. I have a few questions I'd like to ask you, but as we talk, I might occasionally ask you to tell me a bit more about something you were talking about. There are no right or wrong answers, I really want to hear what you have to say.

If at any point you feel uncomfortable, or you do not want to answer a question, you can let me know and that is absolutely fine. If you begin to feel a bit tired, or would like a comfort break, we can pause the interview and take a short break. Just let me know if you would like this to happen.

Would you like to ask me any questions or check anything at this point?

Question 1: To start with, can you tell me a bit about yourself?

Prompt: what was your life like before having an acquired brain injury, what was important to you, what kind of person are you, how would others describe you?

Question 2: Can you tell me about how you learnt you had experienced an acquired brain injury?

Prompt: what type of acquired brain injury, what happened, who was around you, what did others tell you, how did you make sense of this?

Question 3: What was the impact of the acquired brain injury on your life?

Prompt: physical/cognitive impairment?, relationships? Psychological wellbeing? Activities? Sense of who you are? Life goals?

Question 4: How are you recovering from any changes/impacts?

Prompt: what are your goals, how are you working towards these, how are you evaluating your progress?

Question 5: Can you tell me about how you came to be part of the service user involvement group?

Prompts: when, why, how, what did it mean, what was the purpose?

Question 6: Can you tell me about your involvement in the group?

Prompts: what did you do, how did it work, what did you think/feel, how did you relate to other group members?

Question 7: Are there any ways in which service user involvement has helped you to recover? If yes, how?

what did you gain from taking part, how did this help you to recover, how did this fit with your goals? Think CHIME – connectedness, hope for the future, identity, meaning in life, empowerment)

Question 8: Are there any ways in which service user involvement has not helped your recovery? How?

Were there any costs to taking part, how did this interact with your recovery, how did this impact on your goals? Think CHIME- connectedness, hope for the future, identity, meaning in life, empowerment)

Thank you very much for your time today. We really appreciate you taking part in this research. Would you like to ask me any questions before we finish the interview today?

Appendix J: Exemplar coded transcript

TRANSCRIPT OF PARTICIPANT

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Appendix K: Full list of emergent themes

Distress
Unrecognisable self post-ABI
Fear of mortality
Loss of ability to complete ADL's
Loss of ambitions (temporary)
Seeking understanding (pre-ABI symptoms)
Devastating loss due to ABI
Loss of verbal expression
Difficulty with verbal expression
Shame
Relief at being spared from further disability
Feeling like a burden
Frustration
Embarrassment at difficulty remembering people
Loss of writing
Loss of physical functioning
Memory difficulties
Despair at losses
Loss of reading
Loss of dancing
Fatigue
Pre-ABI life as normal
Loss of mobility
Uncontrollable vomiting
Low mood/depression
Loss of basic self-care
Loss of independence
Stress
Fear
Anger
Pre-ABI high life satisfaction
Resentment of losses
Absence of purpose
Betrayal/deceit by friend
Loss of aspired for future
Loss of income
I was strong and invincible
Survival guilt (in the context of death of friends)
Total loss of enjoyed activities
Deep appreciation of care staff
Conflict with care staff
Loss of personhood
Dependence on staff
Hospital as unsafe
Independence as important for life satisfaction
Distrust of medical team
SUI increased personhood (neurorehabilitation)
I'm fighting to be seen as me
Feeling unheard

Feeling rejected by staff
Feeling vulnerable
Disorientation
Neuro-rehabilitation as home now
Friends and family as advocates for “me”
Ruptured coherence of life story
Absence of memory of neurorehabilitation
Absence of memory of SUI
Loss of identity
Work as a source of self-esteem
Assimilation of information to form understanding
Withdrawing from meaning-making in the context of distress
Cognitive fog (disjointedness)
Shock
Disbelief
Continuous process of meaning-making
Meaning-making as a lengthy process
Understanding informs recovery
Conflict in care team regarding treatment
Memory void post-ABI
Post-ABI increased appreciation of life
Post-ABI increased self-reflection
Meaning making impeded by memory difficulties
Uncertainty
Initial absence of meaning
Evaluating information with own experience to develop meaning
Struggling to form understanding
Reflecting causes distress
ABI as incomprehensible
Seeking understanding
Caring identity
SUI memory focussed on emotional salience
SUI experienced from existing frame of reference
Attaining coherence in self takes effort
SUI as providing connection with pre-ABI identity
Identity as a nurse
SUI as a temporary means to connect with self
SUI feeling heard
SUI seeking stimulation
SUI time passage: content memory faded
Independence as important to life satisfaction
SUI held no meaning
SUI cognitive difficulties impeded participation
SUI dominated by cognitively able
SUI – dangerous to bring up relationship with staff
Loss of social identity
Withdrawing in neurorehabilitation
Pre-ABI social life important
Isolation in neurorehabilitation
Social withdrawal
Abandoned by friends due to ABI

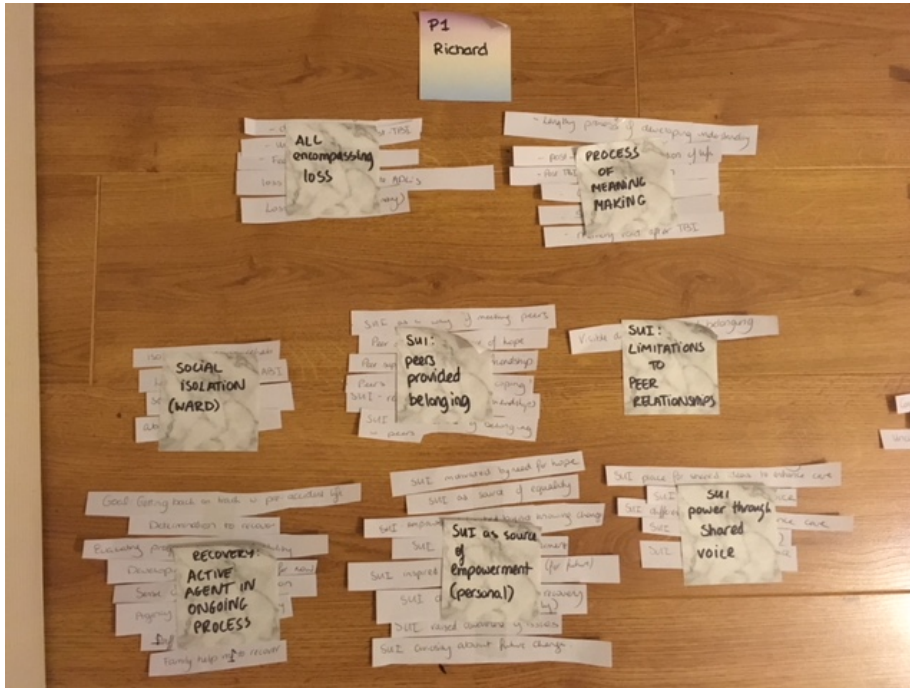
Challenge of negotiating shared living
Family important source of belonging
Maintaining friendships via social media (pre-ABI)
Reassessing value of friendships
ABI as a cause of changing friendship dynamics
ABI as a cause of changing relationships dynamics
Loss of valued family role
SUI supporting others to cope
Dislike of some patients
SUI as a way of meeting peers
SUI as a source of belonging with peers
Understanding peers using past experiences
Camaraderie with peers (belonging)
Peers as a source of coping
Friendships give self-worth
Friendships give belonging
SUI as a way of continuing peer relationships
SUI desire to withdraw
Peers as a source of ongoing coping (SUI)
Changes in family dynamics
Family provide belonging
Peers as a source of friendship
Witnessing suffering in others in SUI made me want to withdraw
SUI difference inhibited involvement
SUI dislike of some group members
Existing patient dynamics replicated in SUI
Peers as a source of understanding
Visible difference inhibited belonging
Peer support as a source of hope
SUI - reassessing value of friendships
Goal to leave neurorehabilitation
I comply with professionals
Tolerating grievances (powerless)
Recovery goal: return to pre-ABI life
Pride at achieving progress
Developing coping strategies for now
Determination to recover
Hope for progression
Progress evaluated via comparison to pre-ABI life
Humour helps to cope
Practice leads to progress (agency)
Family help me to recover
initial hope
Goal to regain mobility (to access pre-ABI life)
Evaluating progress via ability to do ADL's
Sense of gradual progression
Agency as vital to recovery
Staff help me to recover
Planning for reaching goals
Exerting effort to reach goals (action)
Progress just happens

Goal: to return home independently
 Past recovery from illness gives me hope
 I will learn to cope
 Stepwise goal setting
 Oscillating process in recovery
 Medicines help me to cope
 Future-oriented approach
 Family as a source of coping
 I'm in charge of decision making in recovery
 Seeking cognitive stimulation
 Progress increases confidence to set next goals
 Monitoring success of coping strategies
 Negotiating with staff to aid recovery
 Analysing body to inform coping strategies
 Evaluating progress via comparison with peers
 Others as a safe base for practice
 Future is uncertain
 Fear about future
 Setbacks due to ongoing complications
 Questioning ability to cope
 Recovery as intensely effortful
 Frustration
 Body remains unreliable
 Continuing struggle with verbal expression
 ADL's a significant struggle
 Apprehension/anxiety to practice goals
 Withdrawing from recovery due to pain
 Withdrawing from recovery due to fatigue
 Setbacks due to other health problems
 Continued dependency on others
 Transitioning home: reality dawned
 Shrivelling world- marooned at home
 Distress at not returning home
 I resent the losses I have experienced
 Uncertainty impedes agency
 Recovery process as distressing
 I exist, but I do not live, in the present
 No hope for recovery (at times)
 I grieve for my pre-ABI life
 SUI – satisfied with care so no need for change
 SUI uncertain if helped recovery
 SUI no influence on recovery
 SUI relief from boredom
 SUI curiosity about change
 SUI limit to empowerment due to not seeing change
 Boredom in neurorehabilitation
 SUI as giving purpose
 SUI visible change as source of self-esteem
 SUI as valued experience
 SUI relief from boredom
 SUI as a way of giving back

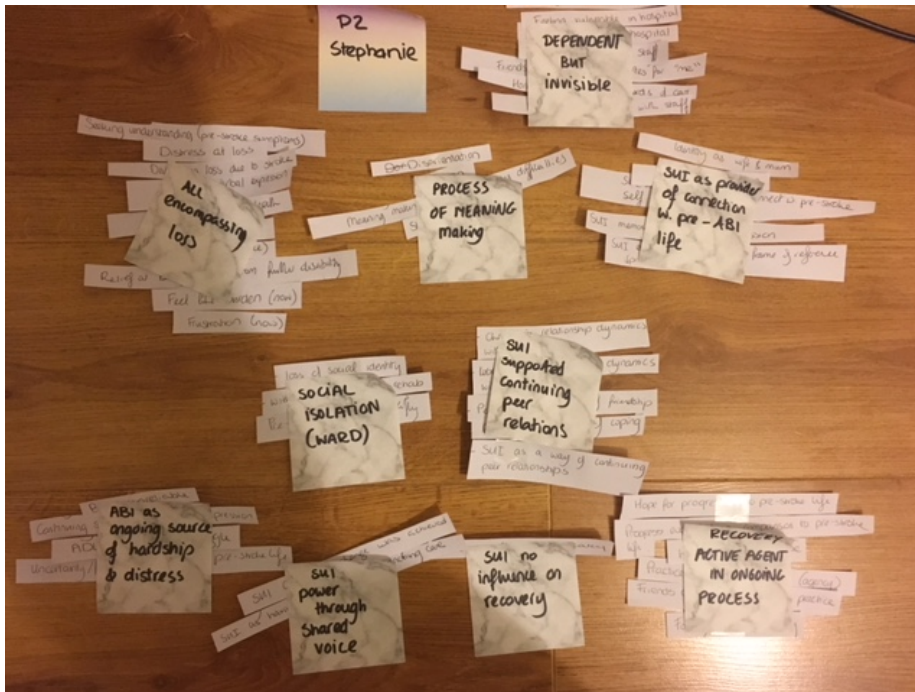
SUI empowerment from change
SUI feeling heard was empowering
SUI challenge maintaining change
SUI resolving conflict
SUI feeling valued
SUI as source of empowerment
SUI facilitators enabled empowerment
SUI increased ability to navigate complex medical system
SUI pride at achievement
SUI facilitators support equality
SUI pride at helping others
SUI motivated by the need for hope
SUI as a source of equality
SUI inspired ongoing empowerment for future
SUI changes benefitted my recovery (neurorehabilitation only)
SUI raised awareness of issues
SUI place for shared ideas to enhance care
SUI power through shared voice
SUI difference as asset to enhance care
SUI enhanced future care
SUI achieved change – shared power
SUI group equality with staff source of change
SUI source of equality with staff
SUI group (nature) as an asset to enhance care
SUI valuable for those who can engage
SUI opportunity for change via access to decision makers
SUI as enhancing care

Appendix L: Emergent themes and themes per participant

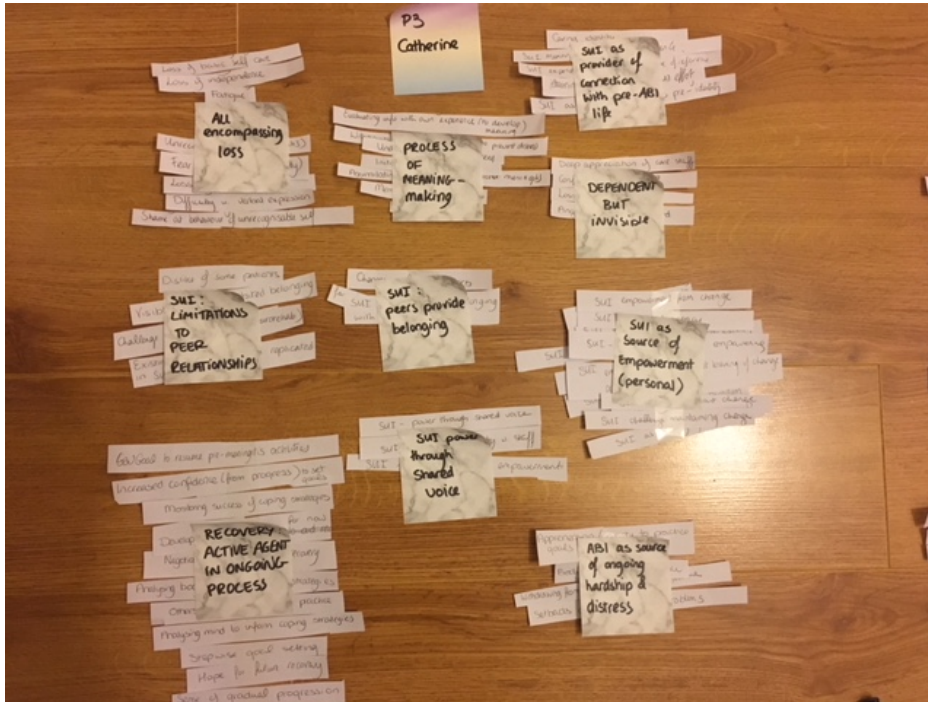
Participant 1: Richard



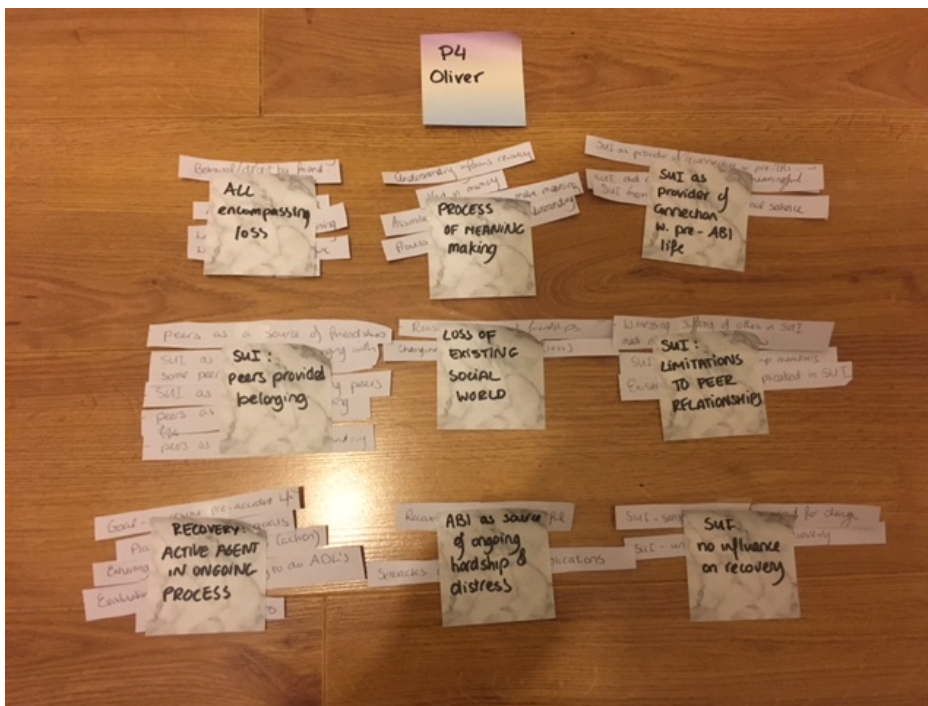
Participant 2: Stephanie



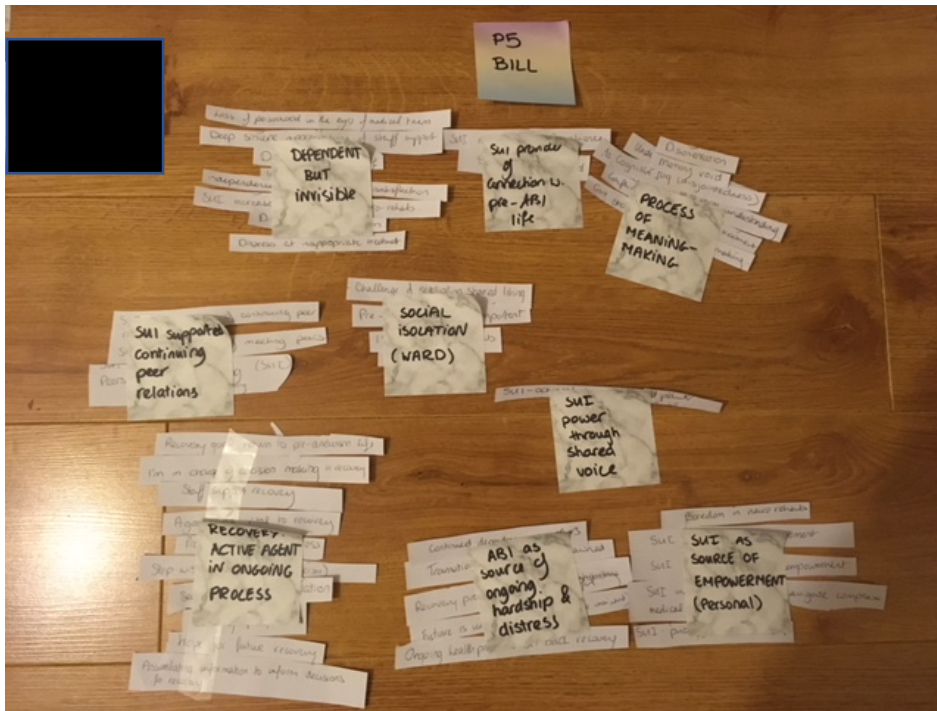
Participant 3: Catherine



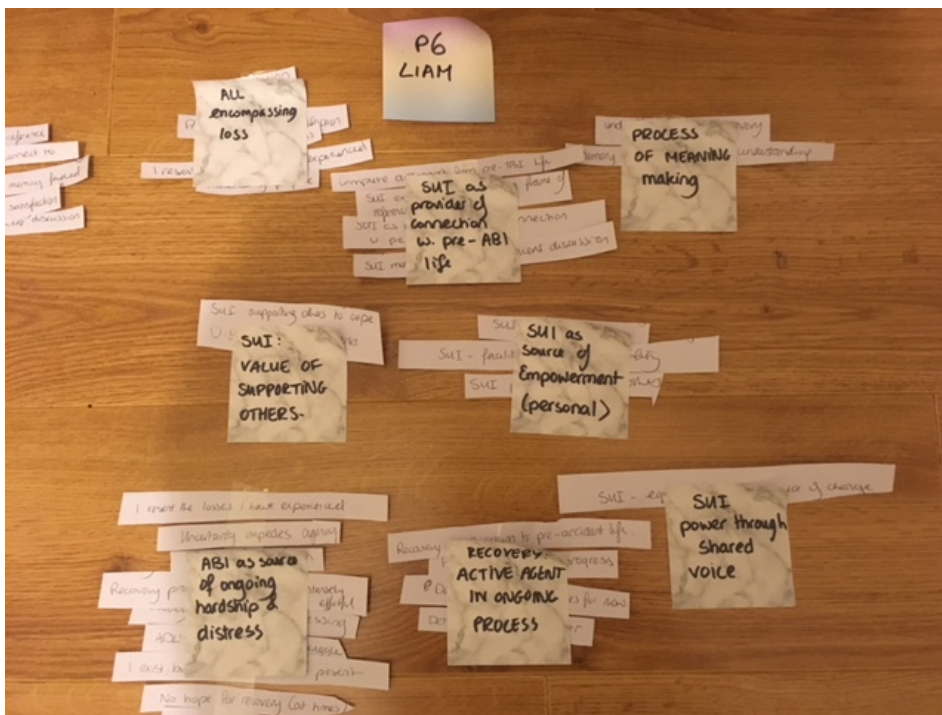
Participant 4: Oliver



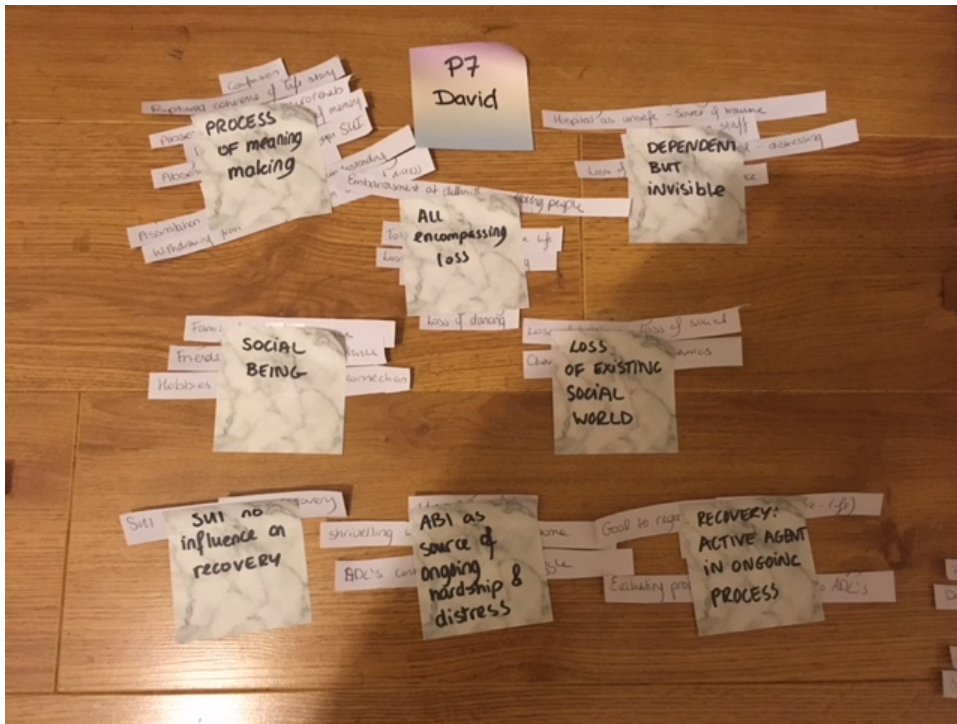
Participant 5: Bill



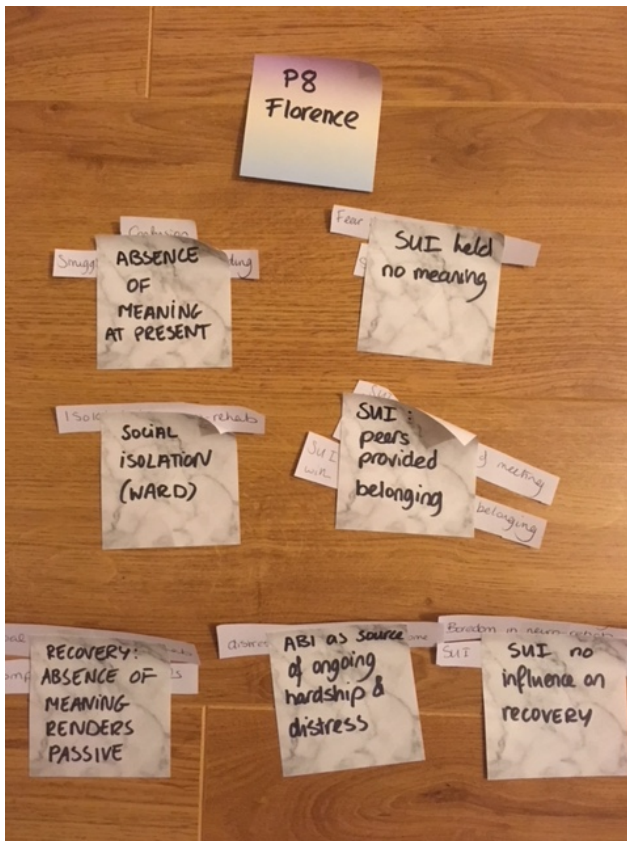
Participant 6: Liam



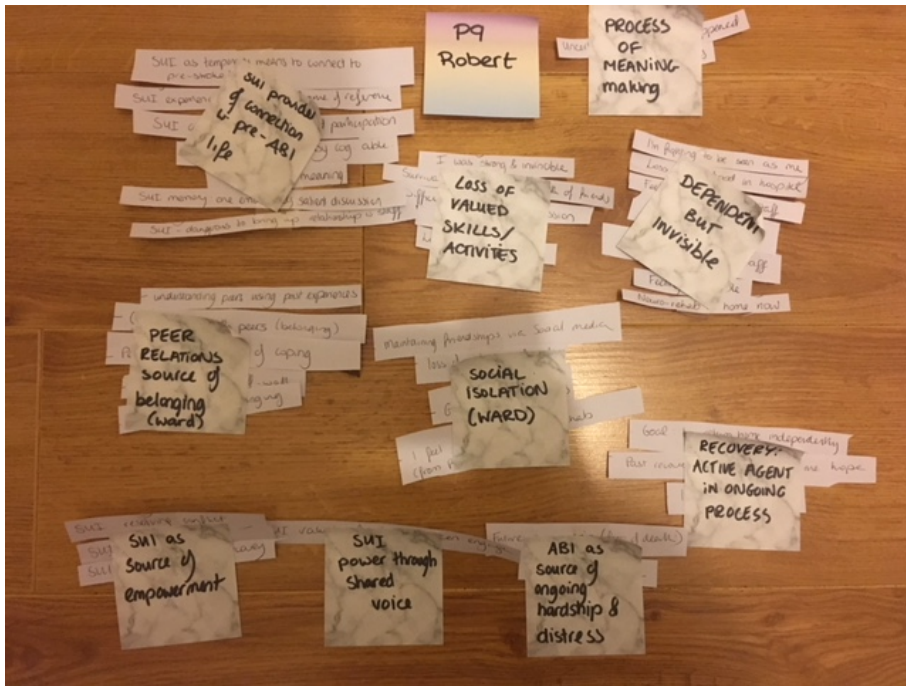
Participant 7: David



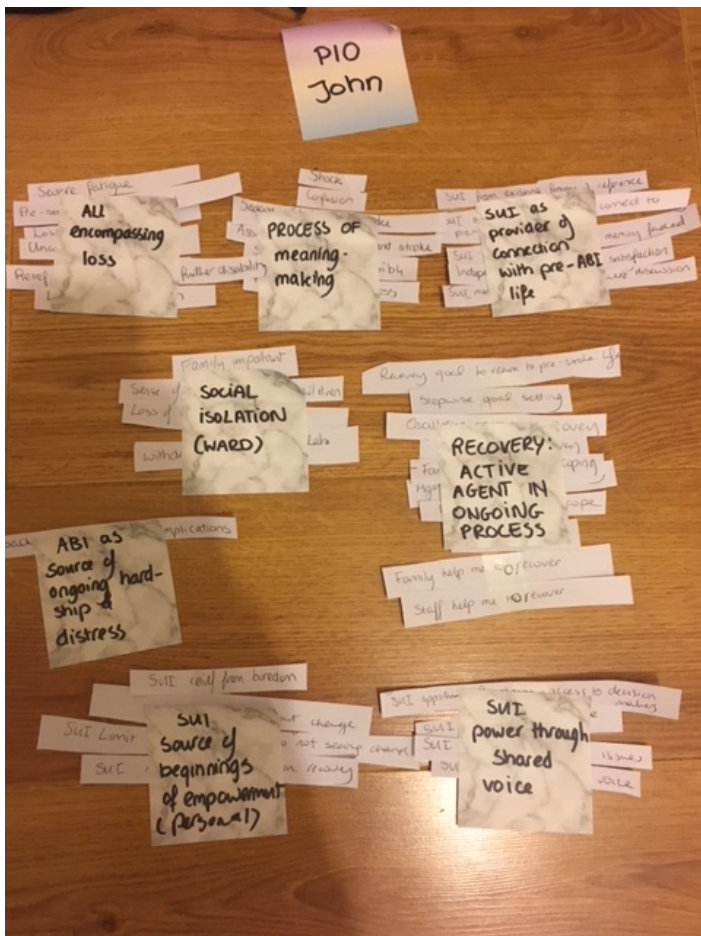
Participant 8: Florence



Participant 9: Robert



Participant 10: John

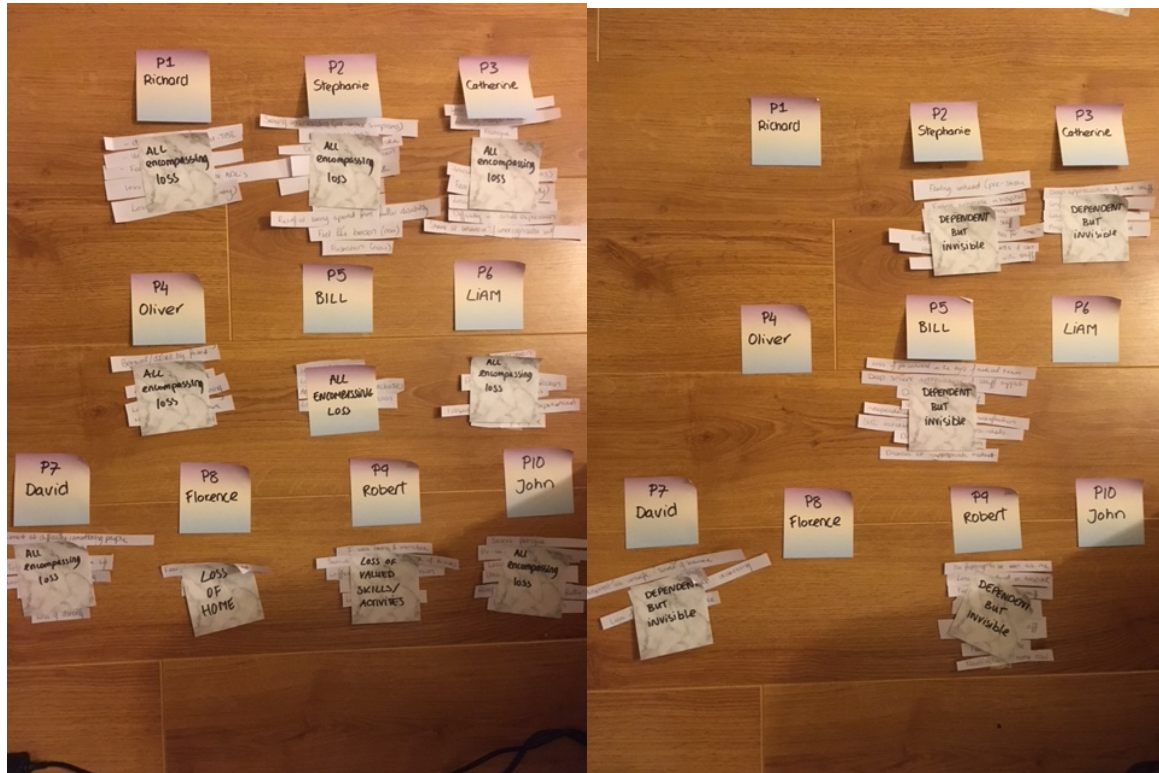


Appendix M: Themes and superordinate themes

Superordinate theme 1: SUI as a mediator for biographical disruption during neuro-rehabilitation

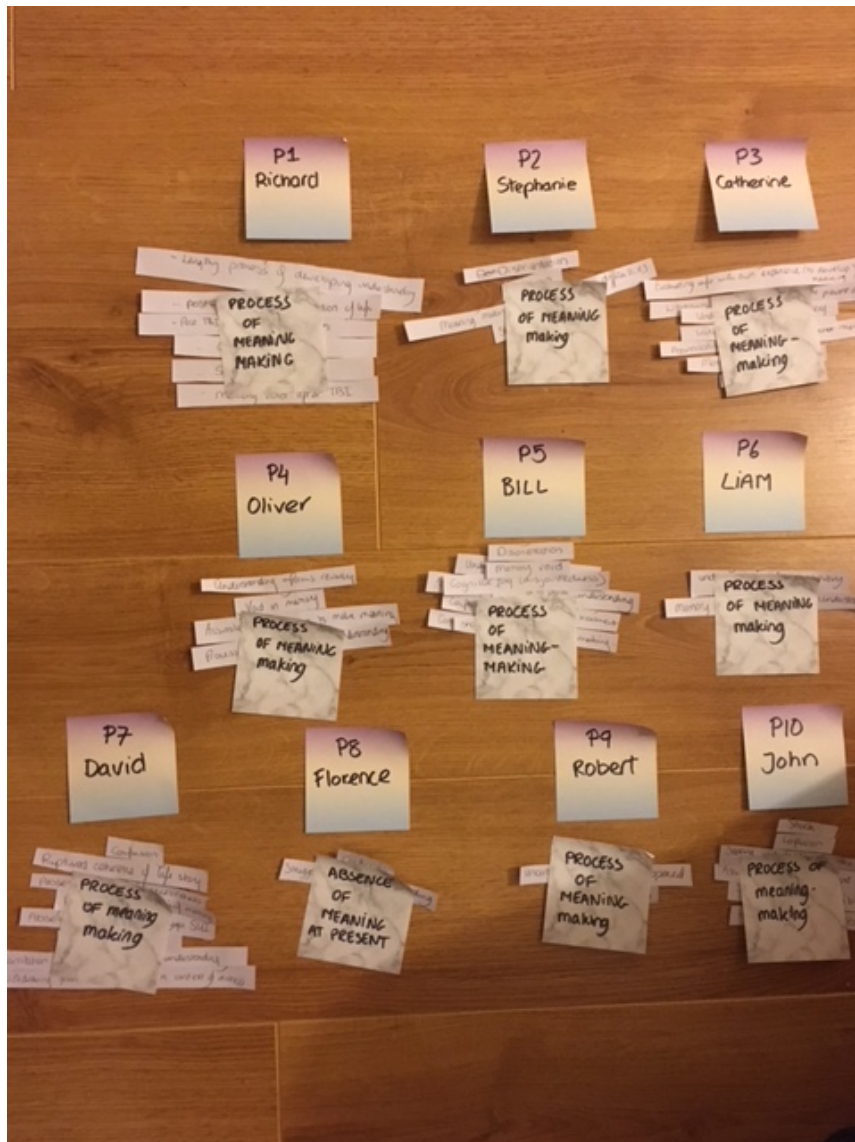
Subtheme: ABI as a cause of biographical disruption

Note – this theme was developed using subsumption



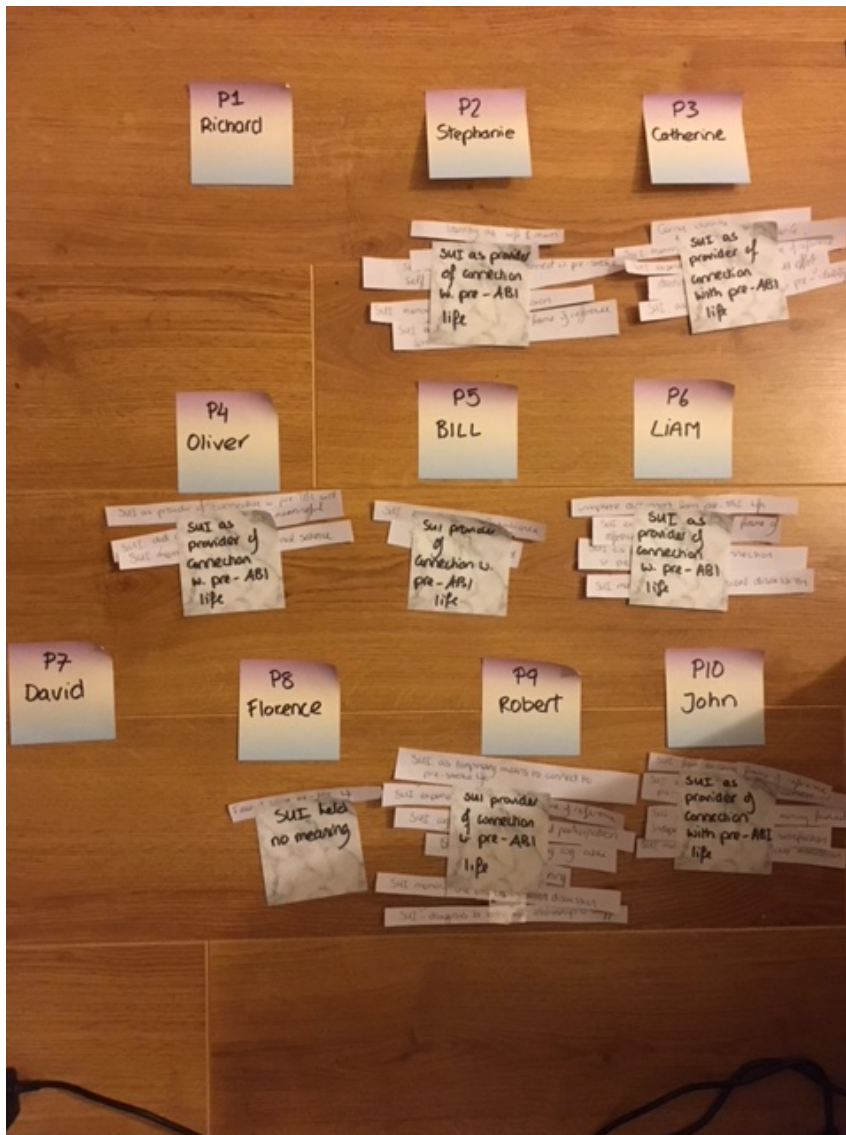
Subtheme: Engaging in an ongoing meaning-making process

Note: this theme was developed using abstraction



Subtheme: SUI as a potential provider of temporary biographical continuity

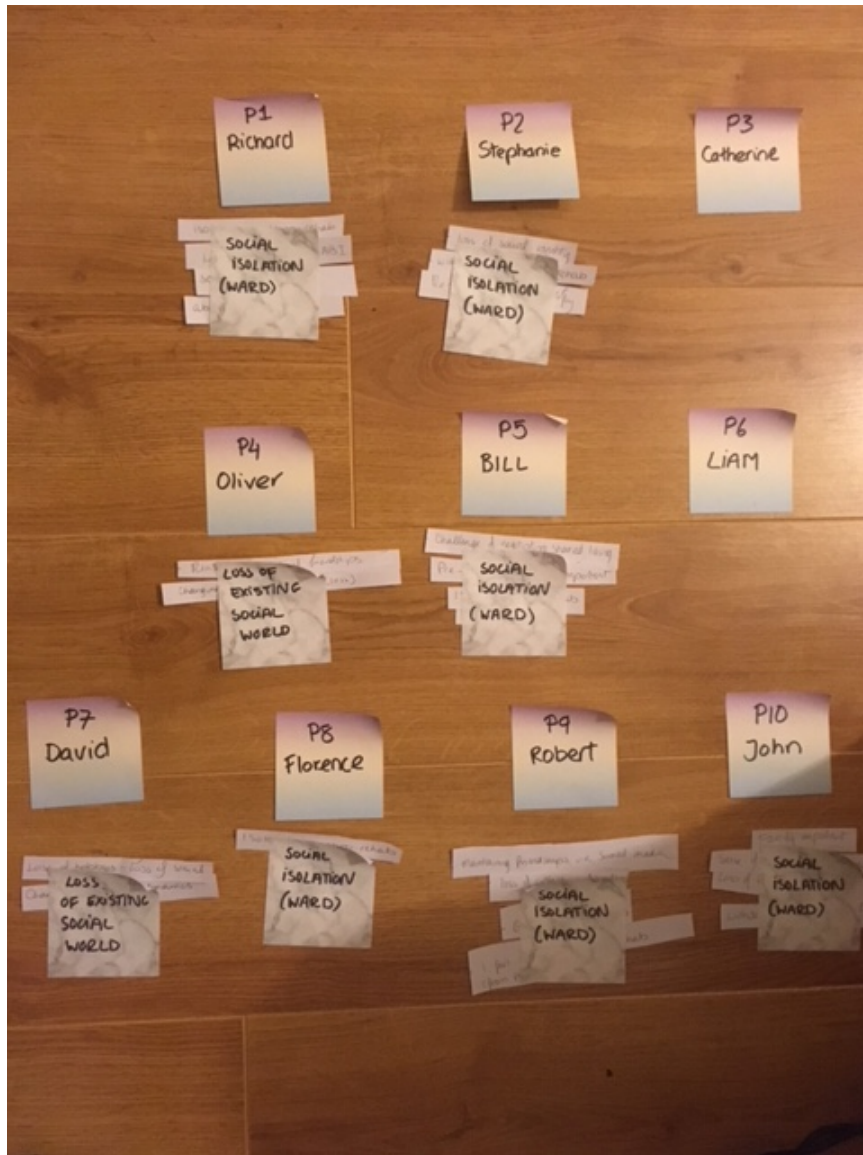
Note: this theme was developed using abstraction



Superordinate theme 2: Peer relationships developed via SUI as a source of belonging in neuro-rehabilitation

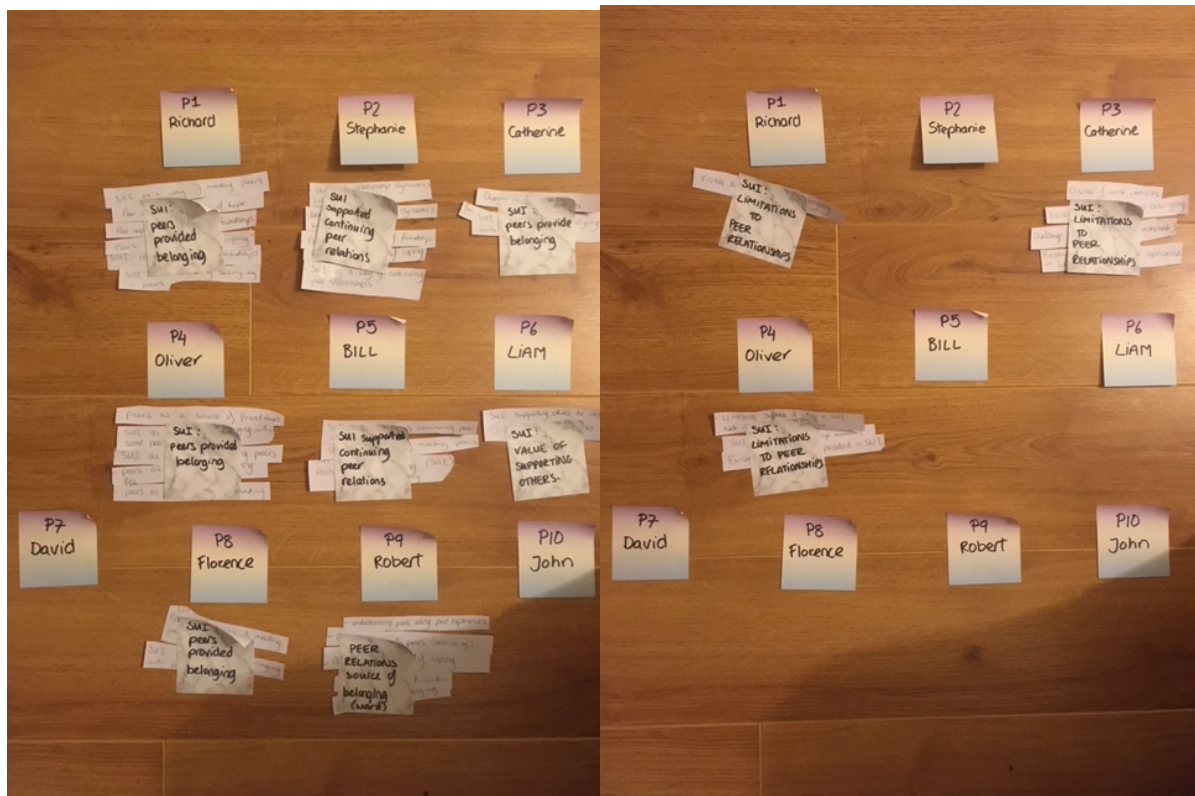
Subtheme: Social isolation during neuro-rehabilitation

Note: this theme was developed using abstraction



Subtheme: SUI as a provider of valuable peer relationships

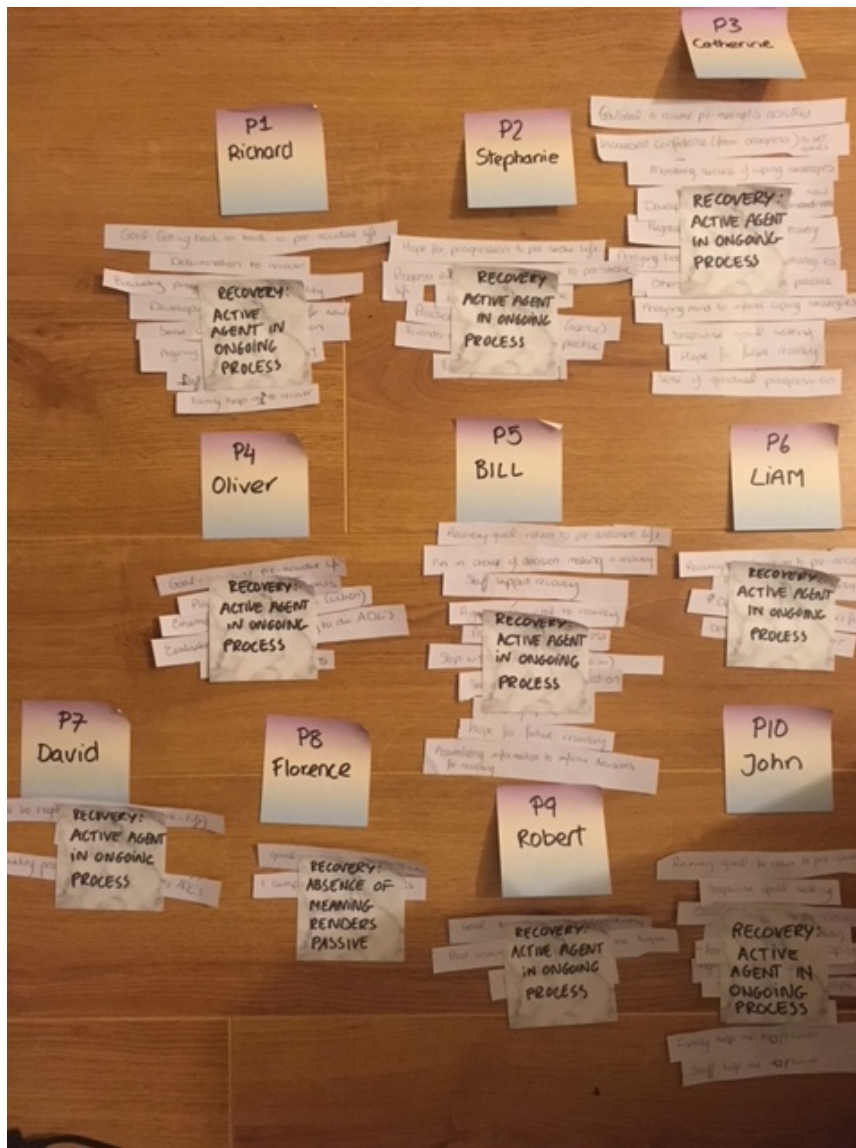
Note: this theme was developed using polarisation



Superordinate theme 3: SUI as a source of empowerment in recovery

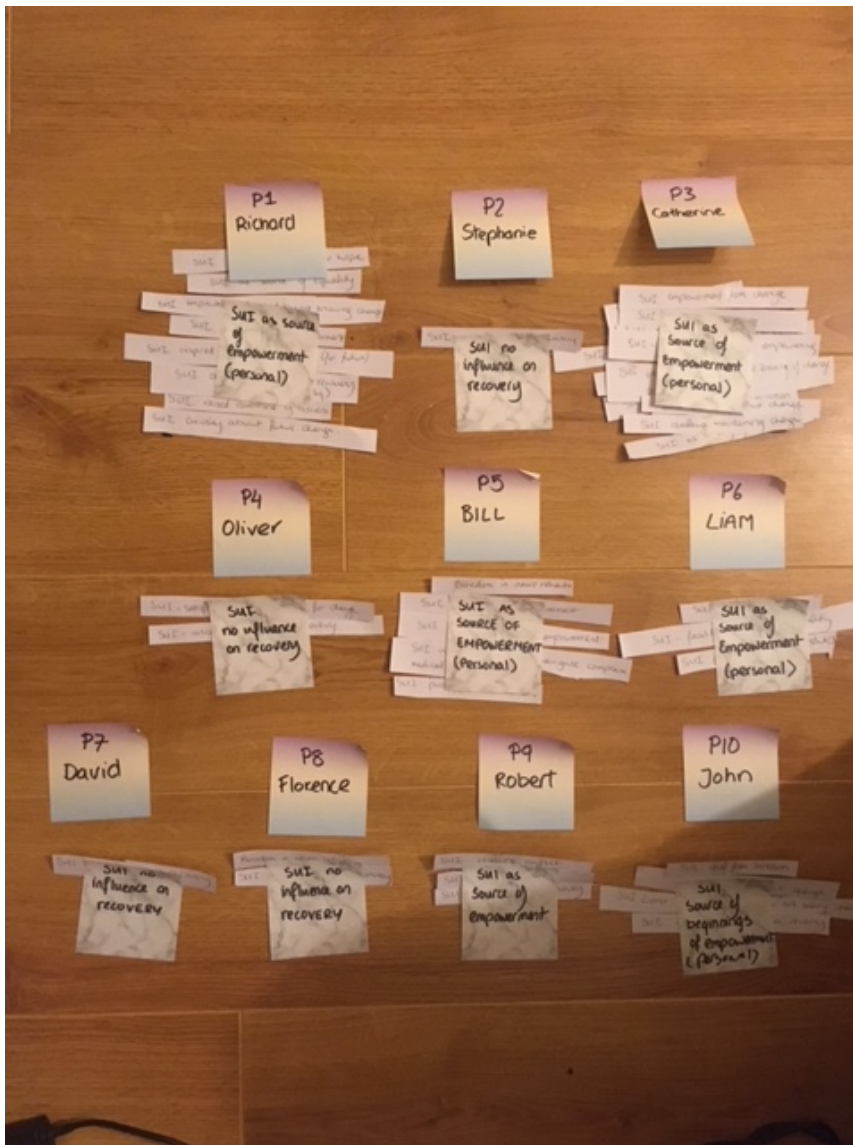
Subtheme: Agency as vital to recovery from impairments associated with ABI

Note: this theme was developed through abstraction



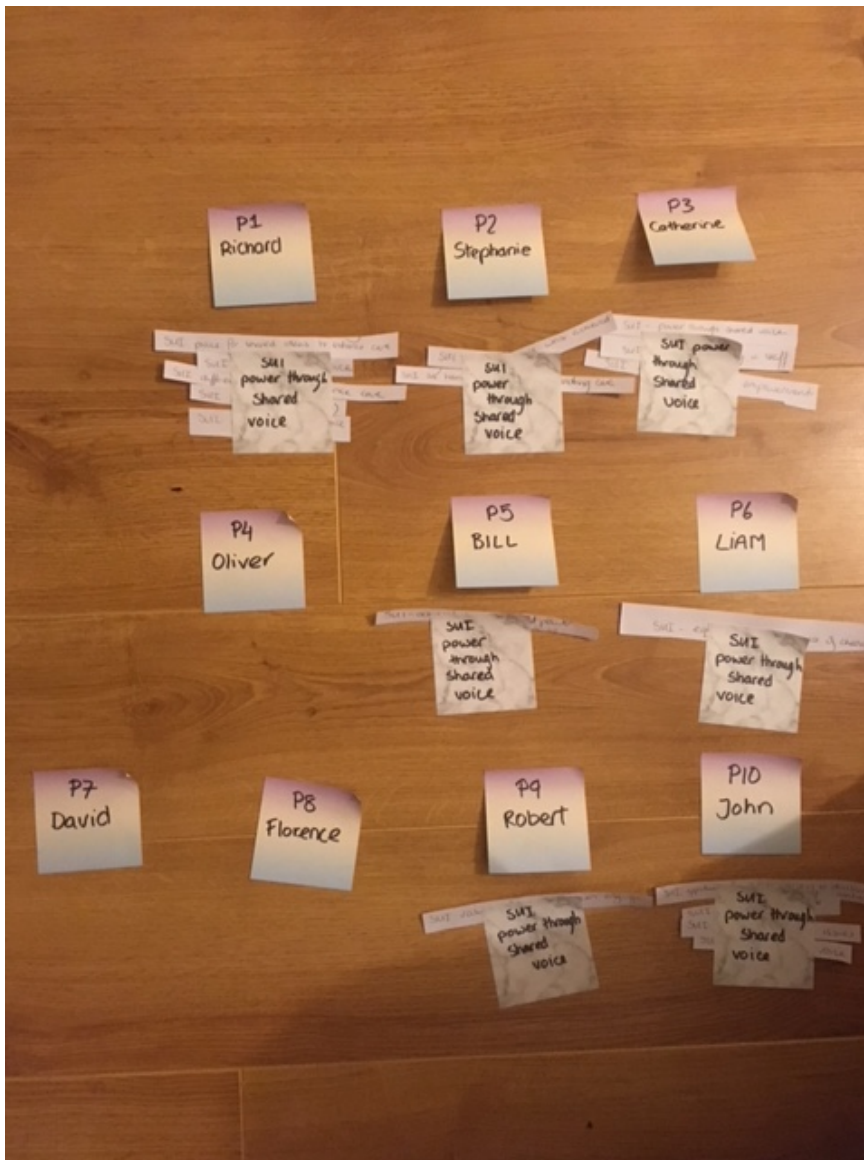
Subtheme: SUI as a source of empowerment in recovery

Note: this theme was developed through abstraction

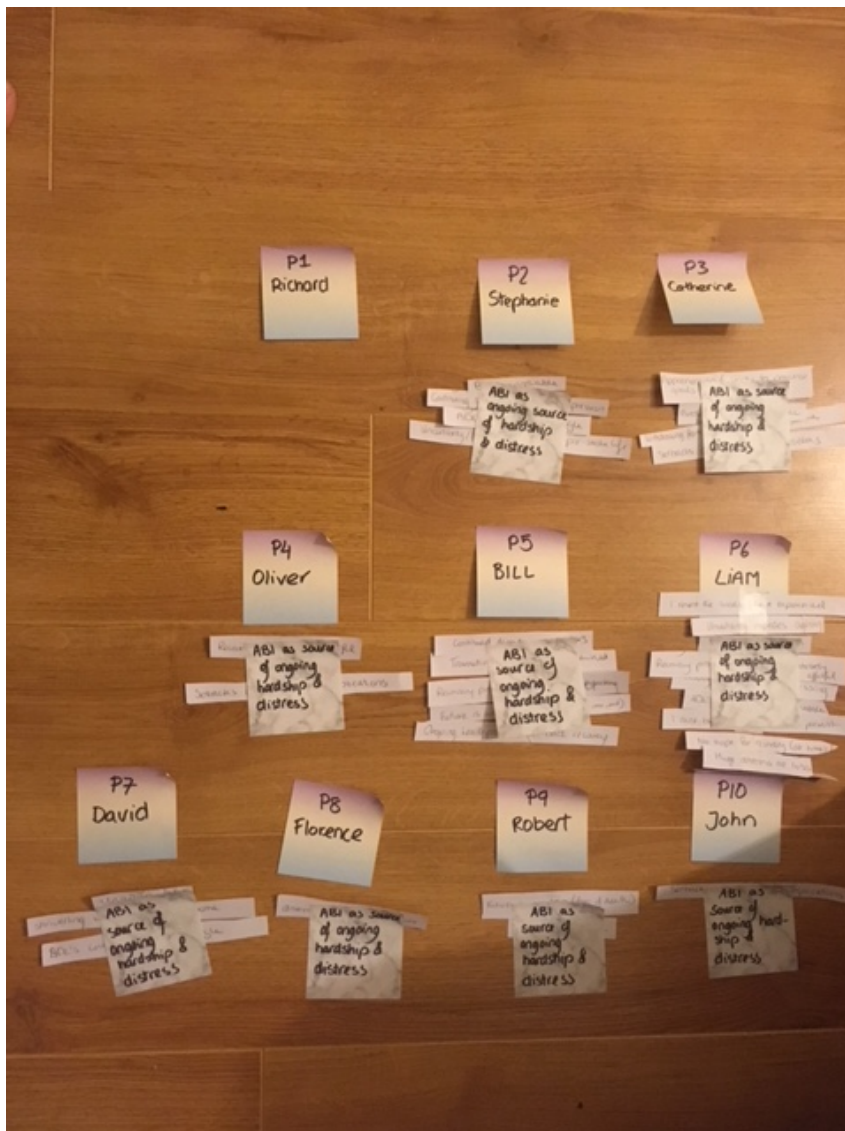


Subtheme: The shared voice as a source of empowerment

Note: This theme was developed using abstraction



Discarded theme: ABI as a source of ongoing hardship and distress



This theme represented the participant's present context. Rather than representing this theme as a separate entity in the research results, this theme was used to inform the interpretation of the effect of SUI on personal recovery of all the above themes, and therefore became infused in the results. This was because IPA methodology seeks to understand participant's understanding of phenomena within their current context.

Appendix N: Extended list of example quotations per theme

Superordinate theme 1: SUI as a mediator for biographical disruption during neurorehabilitation

| Subtheme: | Participant | Quotation |
|--------------------------------------------------|--------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| ABI as a cause of biographical disruption | Richard | <p>“It’s really weird, like it kind of makes you think like that can’t have been me. I must be looking back on someone else. But then it’s like, I’m not at all, I’m not looking back at someone else, I’m looking back at myself. So it’s just really, it’s really bizarre.”</p> <p>“Yeah it is like upsetting, because it is just like, it was just like a moment’s blip, that my whole life was changed.”</p> |
| | Stephanie | <p>“[ABI], it’s just had a really bad effect on everything.”</p> <p>“Anyway, she gives me my tablets, and didn’t even look to see who I was, didn’t even ask me who it was, this was another nurse who had never met me before. Didn’t even ask me, just put the pills in front of me, didn’t ask me who I was, didn’t look at my band, nothing.”</p> |
| | Catherine | <p>“My mum and dad were not very well people. And I’d come home weekends to be with them. And I spent my time, really, looking after them, and I never regretted it.”</p> <p>“I could get up but when I started to get down again, because the edge of the bed was catching that part of my leg, and I said, I can’t stand it, I can’t stand it, and I did say to the consultant on the ward, I don’t want to go home and take this pain with me. So I thought that I was – afterwards I thought that was rude of me. But I just wanted people to listen to me. They weren’t listening. They were telling me I’d been very ill, but they weren’t listening.”</p> |
| | Oliver | <p>“There was all the physical parts of it. Then there was the fact that I couldn’t eat, couldn’t talk. That’s when I had the tracheotomy in, you know. You can’t talk with that in.</p> <p>“It was a pretty big shock.”</p> |
| | Bill | <p>“Well, I was busy. I had quite a few friends, and I did my gardening, did shopping, did cooking, did all, did all the things, normal things, went to the concerts. I used to go to the theatre quite a bit, used to go out. Can’t do any of those things now.”</p> <p>“Oh terrible, I couldn’t sit up, I couldn’t get out of bed. I couldn’t control body functions.”</p> |
| | Liam | <p>“Life was fantastic. I had a very good job. Very good money... Yeah I done lots of construction jobs, but real big ones, big ones, that are hundreds of millions, yeah hundreds and hundreds of millions of pounds”</p> <p>“My life right now, it’s a nightmare. My life is hell. Horrible.”</p> |

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| | David | <p>“Well, you cannot compare it to what you’re doing before, because it’s nothing like what you done before.”</p> <p>“And as soon as I tried to walk, my legs gave way on me. I had been in bed for god knows how many weeks, so I lost all my use of my legs... And uh, I heard some, I heard someone walking up side the corridor, and I, where am I? And people walking up the side. At it was at night time. And they said. They was talking and what have you. And I said, help me, help me, please. And nobody came. And I was scrambling around on the floor. And I couldn’t get across it. And I was exhausted by this time. And I thought, oh blow it, I’m going to lay here. I’ll probably die here, but never mind.”</p> <p>“Nobody mentioned it in the morning.”</p> |
| | Florence | <p>“I should be able to go to (supported living).... It’s a good thing, I mean, it gets me out of here. So yeah, yeah. I mean, I’d rather go back to my mum’s.”</p> <p>Interviewer: “What would you say is really important to you?” Florence: “Well getting back to my mum’s really.”</p> |
| | Robert | <p>“I couldn’t remember people talking as much, like me talking to you, or anybody I suppose. Talking, like I can’t still to, remember what a medicine is or things like that.”</p> <p>“But I, I know why they’re like that, it’s because they think you’re not as smart as you think, if you like. And I am, smarter than they think I am.”</p> |
| | John | <p>“I did encounter a lot of fatigue. I was ready to, I could stay in bed all day and night and not want to get up. I was absolutely wacked.”</p> <p>“I tell you what, if I uh, had to go back to those past few months, uhm. Put your hands up tell you to go back and do it again. I really don’t think I could.”</p> |
| Subtheme: | Participant | Quotation |
| Engaging in an ongoing meaning-making process | Richard | <p>“At the beginning I was quite confused as to why I was in hospital... It was around mid-march, around then, I kind of realised the severity and everything.”</p> <p>“It was hard for me to understand, because I didn’t have like, a real physical injury. I think it just gradually happened, as like the months went by. So at first it wasn’t going to happen at all, but then it happened a little, bit, bit by bit. To kind of like, to the point that I am now.”</p> |
| | Stephanie | <p>“But they told me I was a patient, and I’d had a stroke, and well, I don’t think I really took, I don’t remember, I can’t remember them telling me.”</p> <p>“I said to like my, friend, not my friends, my parents, or him, or my in-laws, I can’t, I can’t believe how I am. Because I had all the, you know, this side wouldn’t work at all. Um, my speech wasn’t very good at all, I couldn’t write. I can’t, I can’t think. But that was just awful.</p> |

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| | Catherine | <p>“and I, um, thinking back on that time, I was so run down I must have picked up his infection, and I was very low. That day was the most awful day of my life, that I think that’s how the meningitis started. I don’t know, this is just my thinking about it.”</p> <p>“But I do want to know, I say to myself. And a lot of the time I just sort of shrug and say, well I don’t really want to know, but then there’s another time something’s maybe said and I, oh I wish I knew exactly what had been going on.”</p> <p>“But none of it, and I, I don’t think I’ve still made sense of it, interviewer, because it’s sort of at least six weeks of my life when I – I mean my brother tells me tales, bless him.”</p> |
| | Oliver | <p>“It’s just like, trying to make sense of certain things.”</p> <p>“All I know is what people have told me.”</p> |
| | Bill | <p>“Yes, it’s just things that people have told me that have happened, but you have no recollection of them whatsoever.”</p> <p>“I mean, I don’t know what’s caused the aneurysm, but I believe in my mind what caused it was my friend dying.”</p> |
| | Liam | <p>“I’ve forgotten everything, everything about my ward, everything, I forgot it all. Everything. But that might be my choice in my mind to forget these things, but I don’t even know.”</p> <p>“I’d help everybody all the time, I always helped people. That’s why I found it really frustrating for this to happen to me... But I happen to be the one that got hurt, not all the toe rags that are going out in the world that are going out and getting hurt, you know. I feel a bit begrudged about that.”</p> |
| | David | <p>“But I don’t remember anything about anybody in hospital, all the nurses. And I’ve been up there again to, for, uh to be check up on, after about three weeks, to have a check-up. And went back to the same doctors, I didn’t remember any of them, either the nurses.”</p> <p>“Doctors did tell me. In fact, I said to them, I said to them, what happened to me? They said, you don’t want to know dad. I said, fair enough. And that was it. They never told me.”</p> |
| | Florence | <p>Interviewer: “How did you come to find out you’d had a hypoglycaemic attack?”</p> <p>Florence: “Don’t know really, no.”</p> |
| | Robert | <p>“I don’t know if I’m going to get any better, or only worse, to be quite honest.”</p> <p>“That’s the only one I remember, the black man, who was, er, talked to me at the time there, but I don’t know what he was talking about. Uh, he just said, all right (participant name), and they went and my folks came to see me, everybody came to see, er, it’s never been the same since.”</p> |

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| | John | <p>"I wasn't aware of it. I wasn't aware of it happening. I wasn't aware of the first month at hospital. It was only until I got back in neuro-rehabilitation again that I was aware, more or less, what had gone wrong."</p> <p>"Well, it's upsetting to say the least... Um, well, something like that could cause so many other problems and injure yourself. You know, and, uh, it might never have disentangled itself. Um, and you could still have it today, you know, I wouldn't have known any better. Obviously I wasn't aware of having it at all."</p> |
| Subtheme: | Participant | Quotation |
| SUI as a provider of temporary biographical continuity | Richard | N/A |
| | Stephanie | <p>"But the only one I can really remember is about the bins. Yeah, because there was a lot of disabled people there in wheelchairs, they couldn't use their legs, so how were they supposed to put their, put their paper towels in the bin, and rubbish in the bin, because they couldn't do that to the bins."</p> <p>"I can't remember for the life of me what else was brought up. I just remember that because I thought, what a bloody good idea that is!"</p> |
| | Catherine | <p>"But when I got back to the ward, no, in fact the particular nurse she came to take me back, move the bed back, and I said I brought it up, I brought it up about the chairs. Thank you, she said!"</p> <p>"That made me feel good that I could do that for this particular lady."</p> <p>"I don't think it told me anything as a person, it just made me feel good that I had done something good and not grumbled at somebody." (Catherine)</p> |
| | Oliver | <p>"But that's the thing, because the patient forum, there's nothing, it's not personal."</p> <p>"I can't really remember what was, what specific things were being brought up in the patient forum."</p> |
| | Bill | <p>"I used to listen, and then voice my opinion afterwards."</p> <p>"Yes, yes, that's how I- I want to hear what everybody's got to say and then make up my own mind."</p> |
| | Liam | <p>"Yeah, you know I put forward for the patient forum to get a computer for the patients, so that the patients could still use a computer and search the internet for themselves. That was my suggestion."</p> <p>"Yeah well everyone else, everyone else said yeah it was good [my idea], well done. So it was nice for other people to recognise it as well."</p> |
| | David | <p>"I cannot remember anything about it."</p> <p>"I couldn't remember the ward... Is it still running?"</p> |
| | Florence | N/A |

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| | Robert | <p>Pre-ABI: "I said, I've never done anything for anything. I said, only even, never been to rob anybody, I'd rather give it to people than have them take it from me. And that's how it's been always in my life, I said."</p> <p>During SUI: "And I said, I said to the girl, I said, oh, so it was bullshit as usual, I said. I said, it's a load of bull. I thought you were an honest lady, telling me the truth about me, I said. I said I'm not perfect, but I'll never lie openly to, to plain lie to people."</p> |
| | John | <p>"See that was the trouble, the sandwiches were dry."</p> <p>"See, evening time, it was never a hot meal. It was always lunch time, and there were some people who wanted a hot meal in the evening."</p> <p>"It's trouble remembering now. But uh, I should remember this because it's not that long ago, isn't it, in comparative terms."</p> |

Superordinate theme 2: Peer relationships developed via SUI as a source of belonging in neurorehabilitation

| Subtheme: | Participant | Quote |
|----------------------------------------------|-------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Social isolation during neuro-rehabilitation | Richard | “The people who I would have thought would have come down and see me, haven’t come down. It just like, kind of makes you realise who your true friends are.” |
| | Stephanie | <p>“It’s being really difficult, because I was like, the one out of all our, you know, friends, who we’d all be, you know, I’d be the one, biggest, well, but you know, talk with all my friends and laugh all the time.”</p> <p>“I can remember being stuck in a corner in a chair and looking around the ward but realising that a lot of them didn’t, I thought they wouldn’t understand. And I was quite quiet, and I wouldn’t talk to anybody, because I couldn’t really talk.</p> |
| | Catherine | “Er, but as for the forum, no, it was quite nice, because I saw other people from other wards. And I was always curious about other people.” |
| | Oliver | <p>“Just to meet people that weren’t in my bay. That was literally, that was the main reason.”</p> <p>“[other patient], he had a friend who was in a different bed, like right down the other end... and yeah, so in a way I wanted to meet him.”</p> |
| | Bill | <p>“I have family, but I don’t see them very often.”</p> <p>“Yeah we talked about it before the date, amongst several of the patients, and we say yes we’d go have a look. We saw who the people were that were going, and who the people were going to be, and that’s how we decided yes we’d go and take part in it.</p> <p>“I mean when you’re stuck in a hospital bed for months, I mean the only time we got out of the bed was to go to the, what do you call it? Not the gymnasium, but that’s basically what it is... Of course we didn’t, there was no socialising on the gymnasium, that was all men and same sex... so only the forum was mixed [genders].”</p> |
| | Liam | <p>“It takes people a long time to get to know me, because I’m a very at arms length person... I have to become friends with them to let them know about my life.”</p> <p>“I got to talk to the guys in my bay. They rung me, a good one called (name). He was a really good, really clever.”</p> |
| | David | N/A |

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| | Florence | “Um, ok really. But they [other patients in bay] can’t really communicate. Um. (Name) can hardly talk. Um, (name) sort of keeps herself to herself, and (name), um, is quite young, and keeps herself to herself really as well. So yeah... you get used to it.” |
| | Robert | “I don’t know why they [nurses] come back and say he’s [brother] not phoned. She’d already been and phoned her to talk to me, but they were too busy. All it was, all it was the girl was too busy, it seems to me, fussing with their little ticky bits that they’re- there’s a girl doctor, probably didn’t want to get up, and then you get anger, you know, that sort of thing, you know.” |
| | John | “I just went into my own self, because at the beginning, I was, I, in my bed, turned up in a little corner being sick everyday all the time.” “Plus I’m lucky I’ve got my family around me. They were, there were plenty of people in hospital who were single. All on their own with no one to turn to. I think that’s been really a great difference. Even with the support, with the uh, hospital, clinical staff around you, it’s not quite the same as family is it.” |
| Subtheme: | Participant | Quote |
| SUI as a provider of valuable peer relationships | Richard | “I’m so far removed from what they are, and same them for me. But obviously you have this bond of the patient forum.” “It made me feel more, one of the community. Even though I was in hospital, I still felt like I was part of a community.” |
| | Stephanie | “Um, I’ve made like five friends on there, and we used to go for coffees and come back to the ward.” “So he (patient) couldn’t really drink or anything, and he was saying about, you know, a couple of pints of lager would be nice, and things like that... I thought it was quite funny, because he couldn’t have none anyway, you know.” |
| | Catherine | “I was glad to go, and I was glad that I was going in my chair and not a bed. I didn’t really like being on the bed. I was the only one on the bed, because I just felt, you know, that, I think I felt a little bit inadequate... but in the chair I was, not anonymous, but I was one of the group.” |

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| | Oliver | <p>“There was a particular person I got on with who was rather intellectual, so you could say something that might be true, might not be, and he’ll, if you’re wrong, he’ll be able to argue it and then make you realise why it’s wrong... and because being in hospital for like the nearly 7 months that I had been in, it was rare you would get intellect. Especially bear in mind I was in the sixth form before then.”</p> <p>“Yeah, he was the leader of it (SUI)”.</p> |
| | Bill | <p>“And then I talked to another friend of mine that was here for many months as well... Name was (name), living in (place). I still go and see him now and again.”</p> <p>“Well we were all together at one time, we were all stuck.”</p> <p>“They started to, they started to do things, we had evenings as well. We arranged evening so that we could, er, break up the monotony of just staying in bed in the evenings. They had er, quizzes, in the evenings, and er, film nights, things like this. That was quite good... and they got popcorn and cakes and different things like that, and then they had going away parties for the people that were leaving and things like this. Things that would not normally happen on the hospital ward. It was only our ward. It gave us pleasure.”</p> |
| | Liam | <p>“Uh, well a lot of people, they’re not interested in them sort of things [SUI]. But I mean, you put 20 people in a swimming pool and just paddling around, they’ll talk a lot more than they would just sitting at a classroom desk. See what I mean? Because they’re already relaxed, they’ve dropped their guard already. Instead of sitting at a desk and then that’s it. You instantly think of teacher.”</p> |
| | David | N/A |
| | Florence | <p>“I just thought, I’d, I’d, I hadn’t taken part in anything yet, really.”</p> <p>Interviewer: “Was it a good thing, or a not so good thing [to meet others at the forum]?” Florence: “Uh, good thing.”</p> |
| | Robert | <p>“Er, like my chap I’ve got in here now... He’s a very funny chap, but he reminds me of the days of the army, when I was in the, er, (country), when I had hospital with this leg, my right leg.”</p> <p>“He was one of my favourite one’s there, my friend there. And we were good friends together [in hospital].”</p> |
| | John | N/A |

Superordinate theme 3: SUI as a source of empowerment in recovery

| Subtheme: | Participant | Quotations |
|---------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Agency as vital to recovering from impairments associated with ABI | Richard | <p>"I would say it's probably about 85%. I'm not there 100%, and I never will be, but I'm not like as far as I can get."</p> <p>"Some of it's like, self-taught."</p> |
| | Stephanie | <p>"But then I realised, the more I started talking, the more it was coming."</p> <p>"But what, but, I'm hoping that, I mean it's only been 10 months since I've had the stroke, so I'm hoping, well no this is about the 11th month, and believe me I've been moving on, moving on, so I'm hoping that I'm just going to move on that little bit more and little bit more."</p> |
| | Catherine | <p>"So yes, and I am setting myself goals. Now my next goal, a big one for me, was, er, ordering taxis, which I did, I went to lace-making and I did that.... I've done that three times. So I, the first time I was very nervous about it, but now it's just easy. And then um, the next thing is to take the dog for a walk."</p> <p>"Because I wouldn't go in a hoist, I was able to transfer from the bed on to the, er, wheelchair. Everybody was amazed that I managed to do it, but I was dead chuffed that I could do it."</p> |
| | Oliver | <p>"Originally it was just learning to like, walk again, like physically... because I had a lot of like, relaxed muscle, because, you know, I couldn't do much."</p> <p>"Well I can't, that's the thing, because in terms of like gym and that, I can't go to the gym until they fit the titanium plate (in my skull). Um, but yeah, as soon as they fit the titanium plate I will wait a couple of weeks or whatever, then start going back to the gym."</p> |
| | Bill | <p>"[my aim is] to get back to normal."</p> <p>"You, you just got to believe what you've been told. It's like, if I tell you if you put your hand in the fire, it's going to hurt. You've just got to trust that, yes."</p> <p>"You've always got a choice. You don't have to follow the professionals, just because they say, we want to do a shunt, you can, you don't have to, you don't have to agree with them."</p> |
| Liam | <p>"It's just me, my self-determination. Because I'm like that. I don't let things beat me. And that's what I've done. That's how I've tackled everything in my life since the accident."</p> <p>"I won't settle for being in a wheelchair. I want to walk. And if I walk, I want to fly, sort of thing."</p> <p>"Exercising your brain and getting better, is actually you yourself getting better. So you've got to exercise yourself to become better."</p> | |

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|------------------------------------------------------------|--------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | David | <p>“I pressed the button, but nobody came to me, so, oh blow it, I’ll do it myself. So I went out on myself, pushed myself back to the ward, which is only across the way, and I started to fly, I started to get dressed. And uh, they, the nurses come and sort of said, oh. I said yeah, I said I couldn’t wait for you. And I was part dressed by then. And uh she said, you alright, and I said I can get dressed myself thank you.”</p> <p>“It got better, and it was great. I thought, oh lovely, I’d soon be walking, walking down to (place) and everything else. But, the last month or so, my walking, well, it’s got non-existent. I have a job to walk with a, with me actual, uh, well this little wheelie thing I’ve got.”</p> |
| | Florence | <p>Interviewer: and what sort of things are you recovering from? How’s your recovery going?” Florence: Ok really. Um. I don’t know really.”</p> <p>Interviewer: Right, ah, so do you know why they’re doing that [physiotherapy]?” Florence: “Not really, no, no, no.”</p> |
| | Robert | <p>“Because I can’t, as long as I can get out, as long as I can get home at my house where I live and I can get my tv on again and have a nice bed to lie down, in bed, and go to sleep and clean everything up again, make myself clean.”</p> <p>“And I’m trying my best with (OT) to do the stuff, to get... I went to get this stuff but it’s the wrong time of day because I’ve got to go today to take my dinner out the microwave, and learn how to do that, but I don’t know whether I’ll be able to do it now.”</p> |
| | John | <p>“I’d like to think it was all me. I was determined, and I still am, I’m still determined to go that step further. But they send me a report they say, if you’re going to get any recovery, you’ll notice it in the first few months of having the operation, and then it peters out. But that hasn’t been the case. Nor will I let it be the case. I’m going to continue to fight it, as best as I can, and that’s it.”</p> <p>“Mhm, [recovery goes] forwards in a way, but it goes backwards and forwards.”</p> |
| Subtheme: | Participant | Quote |
| SUI as a source of personal empowerment in recovery | Richard | <p>“When I first went it, I was a bit like, I used to just come down to the ward. I was still quite new, and I wanted to see what everyone was doing. So it’s nice to see that progression, from there to the end... Definitely at the end I was like, that’s a good idea.”</p> <p>“I found it helpful that each patient could say or suggest certain ideas and people listened to them. Because, it is, they are there most of the time.”</p> <p>“It probably did give me a bit of confidence back, yeah.”</p> |

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| | Stephanie | <p>“In the overall part of my um, recovery, it doesn’t mean anything to me, because I’m trying to remember what he said, you know, last night or something.”</p> <p>“I don’t know if they got them. Do you know if they got them?... I mean, it would be nice to know if they got them bins, because of them being, everyone being so, you know, disabled.”</p> |
| | Catherine | <p>“I think it was also getting away from the, the chitchat that we had on the ward, which wasn’t always, you know, inspiring.”</p> <p>“I thought it must be a friendly meeting, it’s a nice meeting, and it was. It was interesting too, because, but I felt as though people were coming and going, and like myself, I didn’t see any follow through with anything.”</p> |
| | Oliver | <p>“I don’t know if it helped, or if it didn’t, but you know, either way I’ve made whatever recovery I have made.”</p> <p>“I had nothing better to do.”</p> <p>“Well I didn’t really have any problems, so I didn’t feel the need to share.”</p> |
| | Bill | <p>“I suppose it must have helped in a way. It certainly helped in dealing with the doctors. Because we all had an opinion.”</p> <p>“Some things did change, but I can’t be specific because I just don’t remember now, it was so long ago. Although it’s only a year, for me a year is a long time.”</p> <p>“It was pretty good. The questions came up, and it was people like (facilitator) who arranged the people to come in and answer the questions. It was him that got the people into the hot seat.”</p> |
| | Liam | <p>“Well it’s good because you feel like you’re being listened to. About your ideas, yeah, you feel like you’re being listened to. Obviously you’re always being listened to, but you don’t always feel like it.”</p> <p>“Well it made me feel proud, because everybody wanted the same. So it was a good idea. Hah.”</p> |
| | David | <p>No [influence of the forum on recovery], because, because, I didn’t join it. I didn’t join it. Or if I did I don’t remember, haha.”</p> |
| | Florence | <p>Interviewer: “and so do you think, go to that, the patient forum, has had any impact on your recovery?” Florence: Not really, no, no, no.”</p> |
| | Robert | <p>“Er, to be quite honest, er, a bit boring, I suppose. You know, apart from these two, because the ones who spoke most were people who all had normal brains, but I haven’t got that.”</p> |

| | | |
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| | | <p>"I can't er, honestly say to myself that this has been a good effort, whatever it is, you know, because half the time I don't know what the hell they're talking about."</p> |
| | John | <p>"I said, yeah, I'd, it was something to do. I've got nothing else to do. I'm not a great reader, so uh, that was one of the reasons I just, joined in."</p> <p>"But uh, by someone else bringing it up, you could say that's good that's bad. If it was something that was being done wrongly, then you'd sort of think, I'd ought to look out for that, out for that too."</p> <p>"Hopefully it's still done. I don't know, do they still have it there? Is it still done?"</p> |
| Subtheme: | Participant | Quote |
| The shared voice as a source of empowerment | Richard | <p>"Like, obviously I knew I wasn't going to be there forever, um, but obviously if anyone else my age or similar age happened to be in there, they would get some kind of similar, hopefully, experience."</p> <p>"Hopefully, they will listen to some of the things that have been said, and the patient forum will make some more changes."</p> |
| | Stephanie | "I think they're helpful, if they can be, if patients bring up the ideas, if they can be changed, if they are ok to be changed." |
| | Catherine | "And er, she said, when I brought it up at the meeting, oh good, she said. I said, it wasn't just me, most of the people in the meeting agreed with it. Oh, perhaps we'll get something done now, she said, and people will take their chairs away. Well we did our part on the ward, all of us, because I told them when I went back, because I brought it up, and I said, I think when we have our visitors we must ask them if they would take their chairs away. And they did that." |
| | Oliver | N/A |
| | Bill | <p>"So they had, er, the catering staff come in, the manager, or manageress as she was then, catering, to answer questions on the food and the menus and things. And that was helpful"</p> <p>"Yes it did [make a difference], because it gave us, it gave us some insights as to how the menus were done, and why things couldn't change. And things like this."</p> |
| | Liam | <p>"I mean, you don't want someone whose taking the patient forum and kissing everyone's butt. Just straight honest answers, but in a positive way, in a positive manner, that's enough."</p> <p>"Yeah, I mean, making people laugh is important, because that is when they're happy, and that is when they're positive. And if you make someone smile, you can bring something positive in the mix, and it makes someone keep achieving and keep attending [SUI] as well."</p> |

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| | David | "Strange. No, I can't remember anything." |
| | Florence | N/A |
| | Robert | "It's obviously good for their questions, each ones asking individual, if you could cover all, for my, an expert, or a good brain that's working right to listen to people talking sense, I would say it was mostly a useful object of doing what they were doing. You know, it would be better to do that than not to do one. You're more likely to learn something from it, than if you're not to, you know." |
| | John | <p>"The only thing you know is you brought it into the light, uhm, to the powers that be, That's what it was there for, highlight it from there, it can rise from there, right to the top."</p> <p>"It did clash sometimes. Well, the patient forum, as you tell me, is once a month. Now that don't take up a great deal of time. I'm sure if you check on, if you check on that round, from there point of view, if that was the real reason, I don't know. If that was a reason, then I'm sure that the powers that be, can do appointments for various physio's and things, you juggle themselves around that."</p> |

Appendix O: Abridged reflective diary

Initial question development

Jan 2016

Neuropsychology has been an interest of mine ever since I started pursuing psychology, so I knew I would want to do an MRP in this area. I've always been more interested in people's experiences of injuries and illnesses that affect the brain (mostly), rather than the technical stuff like brain scans and testing (although I do enjoy testing in a clinical setting). I saw a proposal about doing research within the neurorehabilitation setting looking at SUI, and it instantly reminded me of the work I'd done in Older Adult Services and the talks I'd attended by service users who had gotten involved in sharing their experiences on both a local and national level. I wondered if this might be the same for people with brain injuries, and to my absolute surprise I found... nothing. Nothing! Maybe I'm not very good at internet searching. But I suppose this lit a bit of a fire of wanting to find out more.

I met with the external supervisor and they told me they were in the process of setting up a service user involvement group on the neuro-rehabilitation ward where they worked. their research ideas were:

1. How might experiences of being a part of patient involvement activity (e.g. patient forums, training) influence individuals' narrative identities? 2. What possible role does patient involvement have in individuals' rehabilitation from neurological conditions? 3. What is the experience of patient involvement in a neurorehabilitation setting in the context the immense personal change that patients are making sense of?

I think all of these could be feasible so I'm going to review the literature to see if this helps direct the research more.

Deciding the question

June 2016

Meeting with supervisor: I've met with both Monika and Leigh now on a couple of occasions to discuss the research question. We talked about the participants for the study, and I was advised it would be allow for more conceptual clarity if I chose one clinical sub-population of individuals who were in neurorehabilitation. We decided on people who had experienced a stroke as this is a relatively large sub-population which would give me optimal chances for recruitment. In terms of the question, I've decided to focus on the area of personal recovery after looking at other topics like identity, social relationships, hope etc. It seems too narrow to pick one of these because it seems to me SUI could have an impact on any of these. So we've chosen personal recovery to encompass all these potential areas.

It feels somewhat uncomfortable doing a study on SUI without consulting service users and "picking" an area like this. I've reflected on this some time now, but as the SUI group has only just met once and nobody seemed to know of any other initiatives running, there simply weren't any service users to consult with (that fit with the university deadlines). I'm hoping with the broad area we've chosen to study this

will compensate for this by allowing the service users the freedom to express what was important to them, rather than confining this too early on.

Ethics application:

December 2016

Writing the NHS ethics application has been in full swing for some time now. But while I've been writing it I've become more and more concerned about whether I will be able to recruit enough participants if it is just focussed on individuals who experienced a stroke. My external supervisor has also raised the possibility that not enough participants could be available now the SUI group has been running for a few months, as most have experienced traumatic brain injury so far. I'm thinking of changing my ethics form to broaden out the participant group, but I wasn't really sure how I could do this. I've spoken with both my supervisors on the phone, and they've suggested broadening out my research to a wider population of "individuals who experienced an acquired brain injury". They said this includes people who have had traumatic brain injuries as well, and people who have had meningitis or lack of oxygen to the brain from diabetes and things like that. My external supervisor said this will significantly increase the pool of participants who could take part in my study, because most participants of the patient forum have been people who have had traumatic brain injuries thus far. I've decided to amend my ethics form from people who experienced a stroke to people who experienced acquired brain injuries. I think even though it is a bit more work now, getting the approval for all these potential participants makes me feel much more confident that I will be able to recruit enough participants, and it also seems more representative of the people who are actually attending the patient forum. I was already feeling awkward about inviting people to take part in the research whilst knowingly excluding large groups of people who were attending the patient forum solely on the basis of their type of brain injury, and this makes me feel that it is a much more representative project of the individuals who might take part in service user involvement.

Ethics amendments

March 2017

The ethics panel want me to amend my participant information sheet to have symbols like leaflets for people with learning disabilities have. I'm not sure I'm entirely comfortable with this. The problem is that some participants may have quite significant cognitive impairments, and some might not at all, such is the diversity of the population. It's a hard balance to keep it accessible without it being oversimplified for some. I've decided to put a few pictures in but not illustrate every point with a picture to try and strike this balance.

Data collection:

June 2017

I've met with my external supervisor about participant recruitment, now the full ethics approval has been given. We've reviewed potential participants against the eligibility criteria, and there's only two people currently eligible who've had a stroke, but there are 7 potential participants if we broaden out to acquired brain injuries, the contingency plan, from now. I've discussed this with Monika, and we're all in agreement to put the contingency plan into action. So my study is now looking at people with acquired brain injuries. I feel comfortable with this, because luckily in

doing the ethics application I've already reviewed the literature and the general design of the research and conceptual background still fit.

Bracketing interview

June 2017

A bracketing interview was completed to develop awareness of potential assumptions and biases in this research. I drew a spider diagram with all the words and phrases I could think of associated with "ABI", "SUI" and "recovery". Then a few days later a colleague asked me questions about each of the written words and phrases like "what does this word mean to you, why did you choose that word and not this word". Afterwards, I tried to think of the opposite of what someone might say to what I said. It was a really helpful process. I realised that I held three main assumptions that I would need to hold in mind during both the data collection and data analysis phases.

- 1) People with ABI are older – retired, not working, have adult children, etc. (I think I was still thinking mainly of stroke, and now we're using ABI I need to be aware that participants could really be any age, they may have been working, they may have children, they may have financial worries from not working at present, etc.) Must be aware hold this in mind when asking questions.
- 2) Recovery is probably going well – I think I have a slightly optimistic view of recovery in that I hold assumptions that this will be a forward moving process for everyone, and that they will be "getting better". I have to remember that this may not be the case, and that people may be really suffering from the losses and changes to their lives. I must hold this in mind to make sure I do not shut people down from talking about suffering.
- 3) SUI is really rewarding and great – I think again I have a slightly optimistic view of SUI based on my own experiences. The literature suggests individuals might also have negative experiences like feeling even further devalued and disempowered if they are not heard. I must remain neutral and explore both sides of the coin in as much rigour.

Reflections on interviewing

August 2017

I've now done five interviews, and in moments during some of these the participants have said they cannot remember details about SUI. After exploring what they did remember, I decided to then follow this with exploring what not remembering is like for participants. I had my external supervisors comments in my head after a couple of months ago I said I was worried no one would remember anything, and he said that not remembering was also valuable data that holds meaning. But the issue more recently is that one participant then asked me directly what the group was about, and I gave a short synopsis of the patient forum; that people who are staying on the ward go there to talk about things they'd like to see improved, and that it is run a bit like a business meeting where they have an agenda and then work through the things people want to talk about. This seemed to prompt recall about the group, which could then be explored more. Although this felt surprising in the moment, it made me think after how this was similar when I was doing cognitive assessments for people who thought they might have dementia; often in Alzheimer's disease people's recognition memory was much stronger than free recall. I was wondering whether

this might be the same for some people who have had brain injuries and experience memory problems. I've spent quite a bit of time thinking about this now, as this wasn't something that I'd considered when I designed the project. I didn't want to prompt people, as I thought this might influence their responses, maybe particularly towards reporting positive experiences. For example, if they repeatedly said they couldn't remember but then I provided a summary it might seem like I was pressing for particular responses, which might change how they respond to me. But at the same time, the participant who was prompted after directly asking was able to provide really useful insights that would not have been captured without. I've decided to take the following approach from here forward. If participants say they can't remember, but explicitly ask me for information about the patient forum, I will give a short summary as close to the one given before. If they appear to be able to spontaneously recall the group, I will not give any prompts unless specifically asked, as before. If they can't recall at all, and don't ask me for information, I will ask whether it would be helpful to give a short summary of the patient forum. If they say yes, I will give this, and wait to see how they respond to this. I will keep an eye on this issue to see if the above approach seems helpful without biasing participants' responses. It will probably be useful to think about this further for future research, to have a pre-considered strategy about how to respond to memory issues, and whether a summary is given to everyone in the same standardised way at the beginning of data collection, or whether this is dealt with on a participant by participant basis.

Reflections after interview 6

September 2017

Half way through the interview, p6 made a disclosure related to risk – suicidal ideation. Halted the interview (sensitively) to do risk assessment. Not a new experience, managing, no plans to act, but had made plans in the past and only minimal protective factors – one care worker who feels able to talk to. That care worker currently on leave. Lived in assisted living with daily staff presence but said would not talk to staff about feelings. Had crisis phone numbers displayed in large print and said felt able to call for help if they started to become concerned for their safety. I decided this needed sharing with care team, participant was happy with this and consented to me sharing with Leigh, the second supervisor and part of participant's care team – said they had very good relationship with him and would be happy to talk to him. Participant wanted to continue the interview- I re-checked all the consent to be sure as I wasn't sure about what to do for the best. I decided to tell them the questions left (only about service user involvement left) and see how they felt about this. They said they wanted to go through the questions so we recommenced the interview with full informed consent.

I left the participant in good spirits; we ended the interview and they showed me their positive affirmations they use to help manage, and showed me different photos of their children. Rang Leigh immediately and informed of risk information including my concern about minimal protective factors (particularly absence of trusted care worker). Leigh rang participant. Leigh rang me back and shared that participant had not shared any new information to me that was unknown to the care team and that a care plan was in place to support them with their experience.

I was glad to hear that a good care plan was in place and that the participant had support. I did feel quite sad after the interview. I thought about how my interview style may have been affected in the second half, and I definitely asked fewer follow up questions. I think this was because I did not want to push the participant into anything that might have been distressing or uncomfortable for them. This may have meant that their version of experience of SUI may appear more positive than others (as I didn't ask many follow up questions about the negatives). Must balance this in the analysis and use information from present circumstances of struggles with losses to help this balancing.

Data analysis

February 2018

I'm half way through going through the transcripts now (5 down, yay!) and each one I do the more and more motivated I feel to do this project. I had anticipated that I would find this part of the research tedious, as many discussions with past students had revolved around the frustrating and lengthy nature of the analysis process. I don't know if it's the analysis method, IPA, that allows me to feel connected to the participants' inside worlds, which feels like an immensely privileged position. The stories of loss and sometimes trauma at the experience of an acquired brain injury has been at times painful to submerge into. The participants have been extremely skilled at imparting what their daily life is like, and how they are making sense of their injuries and losses, which I feel has added real depth to the analysis, but at the same time has taken its emotional toll. I can't imagine what it is like to live that everyday, as even submerging into it from an outside perspective a few hours at a time feels exhausting. But it is precisely this, that motivates me to make their stories heard. Within their accounts of their lives, alongside loss, has also been resilience, and incredible strength. Some participants have recounted moments of joy and togetherness with others that feel all the more important in the context of the loss they have experienced. The service user involvement group seems to have been an important part in this. I hadn't anticipated the joy I would feel at accounts of social interactions that otherwise might not have felt significant to me. It has reminded me of, and reconnected me with, the reasons why I wanted to do this project in the first place, and has given me renewed energy to complete the project.

Ps. Met with supervisor yesterday, who asked me what I was doing to look after myself whilst analysing data focussed on loss. I realised taking regular breaks from it is not only important for time to think through ideas of interpretation, but also for managing the emotional impact. I'm going to make more effort to do things I enjoy in these short breaks as well, even if it's just getting a quick coffee or going for a walk.

Data Analysis (theme development individual)

February 2018

Early enthusiasm has turned into frustration now. The more and more I look beyond emergent themes to themes I feel like I am chopping up the narratives and losing richness of the data. I think it's partly from being so immersed into an individual's transcript, that it's difficult to hold sight that I will be looking for connections across the transcripts soon. My other concern is that I'm focussing too much on the impact of ABI in my analyses so far. Must make sure to focus on SUI. Will review themes again all together with transcripts to see if SUI sufficiently captured.

Data Analysis – (theme development group level)**March 2018**

I've started looking across the transcripts for themes that occur across participants. Very annoyingly I seemed to have named the themes and emergent themes very individually reflecting each person's individual personal nuances. This is not very helpful at this stage. So I printed off a list of each participants emergent themes and themes with quotes to illustrate each, and I laid them all out and went through each one to consistently name ones that were referring to the same process but worded slightly different. I double and triple checked by reading quotes and reading the relevant full excerpts of the transcripts. If it didn't quite fit together I left them as separate themes. This process has been really helpful in getting an overview of the data and spotting patterns across the themes.

Data analysis – theme development group level**March 2018**

I think I've got my three superordinate themes now but I wasn't sure about two aspects of it so I used supervision to help with this. The first was I wasn't sure why people might feel isolated in neurorehabilitation, whether I was getting this interpretation right, because it seems to me they are surrounded by other people and so it seems a bit strange. Maybe it was hard to relate to from not having been an inpatient for an extended time away from home myself. Leigh said that often people might not feel like they can leave their bay and enter into another bay, because it feels like walking into another person's bedroom. Also some people are quite unwell and unable to talk, and it might feel hard to start a conversation. So he said often people do not venture further than their own bay (in terms of seeking social interactions). This made sense to me and fit with the experiences participants had shared. It was really useful to have this extra information about how personal space might be perceived, and why this might stop people who want more social interaction from seeking this.

The second issue related to the theme of empowerment. Some people talked about empowerment individually (personally) only, and some talked about this at a group level, and some talked about both. I wasn't sure whether this formed one large theme about empowerment, or whether this represented two distinct themes. I discussed this with Monika who advised using two separate themes as the concept of empowerment is broad and these two areas can be seen to form distinct aspects of this concept in the research literature. I agreed with this, as seen as they were not experienced simultaneously by all participants (ie. Some experienced one and not the other) it seemed to me that this was a more fitting framework to represent the data in.

Report writing**April 2018**

I'm now (finally) at the report writing stage (I'll add that it's early April). Writing has allowed me to continually reflect on the themes and clarify my ideas by seeing them on paper. One frustration is that there are lots of really interesting points made by one or two participants about how SU1 experience becomes meaningful, but I can't find a way to fit them all in. For example, one participant brought up how being within the environment in which one is providing feedback brings tension and inhibited

them from sharing some of the more difficult experiences they had experienced with staff because they were still actively dependent on them. This seems a super important consideration for clinicians to know when facilitating SUI/engaging with SUI groups, but it doesn't fit with the IPA writing style for large IPA studies (ie. More than 6 participants) where it is advised only to write about themes that apply to half or more of participants. Unsure what to do. It seems this might actually be something that will form another research question in the future.

Appendix P: NRES End of study form

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Appendix Q: Feedback report for ethics panel and R&D committee

Background: Service user involvement is under-developed with people who experience acquired brain injuries (ABI). Systemic barriers and prejudices may have contributed to this. There is a dearth of research evidence about the experience of service user involvement at the level of service development and governance. Increasing this evidence base may provide information about benefits and barriers of engaging in SUI for people with ABI. At present, only one study exists, which suggested that people with ABI report the influence of SUI in terms of the personal gains they experienced related to their recovery. Therefore, this study seeks to explore the experience of SUI in the context of personal recovery.

Aim: This study aimed to answer the question: “How do people with ABI experience SUI in the context of their process of personal recovery

Method: This qualitative study uses an interpretative phenomenological design (IPA) using Smith, Flowers and Larkin’s (2009) methodology. This design was selected to enable an in-depth exploration of how one type of experience (in this case, SUI) was experienced in the wider context of personal recovery from ABI. Ten participants were recruited from one SUI group facilitated on a neurorehabilitation ward in South East England. Capacity to consent was informally assessed prior to participation. Participants provided written informed consent. Data was collected using one-off semi-structured interviews. Topics included experiences of recovery and experiences of SUI. Interviews were transcribed verbatim, and analysed using IPA.

Results: The results suggested that service user involvement was predominantly a positive experience. Three superordinate themes were identified. Firstly, SUI was found to enable participants to re-connect with pre-ABI life, in the context of perceived total disconnect due to the consequences of ABI. This was because they engaged with SUI from their pre-existing frames of reference. Secondly, SUI enhanced agency in recovery via empowerment. Feeling listened to and feeling heard helped participants to feel more equal to health care professionals. Thirdly, in the context of feeling socially isolated whilst in neurorehabilitation, SUI provided opportunities for developing valued peer relationships. These helped individuals to cope, as they provided belonging and support. However, there was variability in these experiences, with not all participants reporting these benefits. This highlighted barriers to the ways in which SUI might lead to these experiences. Also, the benefits were most often only experienced in the setting in which they occurred (neurorehabilitation).

Conclusions: The small sample used in this study meant that the above findings may not be relevant to the entire population of individuals with ABI. However, the depth of experiential knowledge expressed in this research supports the call for increased SUI with people with ABI. Providing opportunities to engage with service users in ways that are meaningful to them serves only to enhance care and practice. Over time, this may support increased recovery and wellbeing amongst individuals who experience ABI. Further research may support the development of SUI by providing an evidence base from which increasingly effective ways of collaboration can be established.

Appendix R: End of study report for participants



Salomons Centre for Applied Psychology

End of study report

Research study: An investigation into the effect of service user involvement on personal recovery from acquired brain injury.

Dear (INSERT NAME)

My name is Emma Hart. I am a Trainee Clinical Psychologist. I study at Canterbury Christ Church University. We met in (INSERT MONTH) when you took part in my research project. Thank you very much for taking part. Without your help this project would not have been possible.



I am writing now to give you a summary of the results of the study.

Recap of study:

It is good practice for NHS services to talk to people about what they think about services. This is because it can make services better at helping people. One way that NHS services try to talk to people is by running “service user involvement” groups like the (SUI GROUP). But we don’t know very much about what it is like for people who have had a brain injury to take part in these groups.



The research study you took part in was to find out what it was like to take part in a service user involvement group. We wanted to find out if getting involved in these groups had any role in recovery from your brain injury.

To find out about this, we interviewed people about their experience of their recovery, and their experience of service user involvement. Ten people took part in this study between August 2017 and January 2018.

Key results

We looked at what everybody said. We found three ways in which going to the (SUI GROUP) to effect recovery.

Result number 1

Most of you found out when you were in (WARD) that you had a brain injury. Most of you felt very shocked and upset about this. For some of you, it meant that you didn’t really feel like the same person anymore, especially in the early stages of recovery.

Everybody remembered different bits of the (SUI GROUP). We thought about why that might be. It looked like you remembered things that had particular meaning for you. For

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example, some of you had particularly enjoyed being kind and helping people in your life. These people remembered parts of the (SUI GROUP) that involved helping other people. We wondered whether this might have helped you to feel a bit more like “you” again.

Some of you couldn’t remember much about the group. Some of you said you were having memory problems because of your brain injury, which made it hard to remember. Some of you said you didn’t remember much because the group didn’t mean anything to you.

Result number 2:

Most of you said you felt a bit bored on (WARD). Time seemed to drag. A lot of you said you went to the (SUI GROUP) for something to do.

A lot of you felt listened to in (SUI GROUP). This made you feel like your voice mattered. You felt a bit more equal to staff. You helped each other to feel more powerful by trying to make things better together. This was important, because most of you felt that you knew what you wanted to do to get back to your “normal life”. Feeling like you mattered helped you to be more in charge of your recovery. It was also rewarding to know that you were part of something that would help other people in the future.

Some of you didn’t experience this in the same way. Sometimes it was hard to get involved in discussions because of problems with reading things or understanding what people said. We thought this was really helpful to know, because we can now try find new ways to help people to be able to get involved.

Result number 3:

Most of you said you felt lonely whilst you were on (WARD). You liked having friends and family visit, but it wasn’t the same as being home. Most of you wanted to talk to more people, but this was a bit hard. Sometimes this was because other people in your bay weren’t very talkative. Sometimes this was because you were suffering because of your brain injury, which made it hard to talk to other people.

One of the reasons you went to (SUI GROUP) was to meet other people on the ward. This helped you to make friends. It was good to have these friends, because you got to pass time together on the ward. It was also nice to have someone to talk to who knew what you were going through.

Sometimes, meeting other people at (SUI GROUP) proved tricky. Some of you felt quite different from most of the people there. Sometimes there were people you didn’t want to be in a group with. This meant that not everybody was friends. This seemed ok, because most of you found at least one other person to talk to.

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Salomons Centre for Applied Psychology

What will happen to the results of this research study now?



The results of this study have been written up as part of my university course, the Doctorate in Clinical Psychology at Canterbury Christ Church University. I also intend to publish my results in a scientific journal, which are magazines for other researchers to keep up to date.

Contact Details

If you would like to talk to me or my supervisors about this research, you can contact us on the details below:

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Appendix S: Author guideline notes for journal submission

Author Guidelines: *Qualitative Health Research* (QHR)

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7. Additional information

Please read the guidelines below then visit the Journal's submission site <http://mc.manuscriptcentral.com/qhr> to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of QHR will be reviewed.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

1. Article types

Each issue of QHR provides readers with a wealth of information — book reviews, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods.

1.1 What types of articles will QHR accept?

QHR asks authors to make their own decision regarding the fit of their article to the journal. Do not send query letters regarding article fit.

- Read the Mission Statement on main QHR webpage.
- Search the QHR journal for articles that address your topic. Do we publish in your area of expertise?
- Ask these questions: Does it make a meaningful and strong contribution to qualitative health research literature? Is it original? Relevant? In depth? Insightful? Significant? Is it useful to reader and/or practitioner?
- Note the sections: General articles, critical reviews, articles addressing qualitative methods, commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.
- QHR accepts qualitative methods and qualitatively-driven mixed-methods, qualitative meta-analyses, and articles addressing all qualitative methods.
- QHR is a multi-disciplinary journal and accepts articles written from a variety of perspectives including: cross-cultural health, family medicine, health psychology, health social work, medical anthropology, medical sociology, nursing, pediatric health, physical education, public health, and rehabilitation.
- Articles in QHR provide an array of timely topics such as: experiencing illness, giving care, institutionalization, substance abuse, food, feeding and nutrition, living with disabilities, milestones and maturation, monitoring health, and children's perspectives on health and illness.

Look Out for These Regular Special Features

Pearls, Pith and Provocation: This section fosters debate about significant issues, enhances communication of methodological advances and encourages the discussion of provocative ideas.

Book Review Section: *Qualitative Health Research* includes a book review section helping readers determine which publications will be most useful to them in practice, teaching and research.

Mixed Methods: This section includes qualitatively-driven mixed-methods research, and qualitative contributions to quantitative research.

Advancing Qualitative Methods: Qualitative inquiry that has used qualitative methods in an innovative way.

Evidence of Practice: Theoretical or empirical articles addressing research integration and the translation of qualitatively derived insights into clinical decision-making and health service policy planning.

Ethics: Quandaries or issues that are particular to qualitative inquiry are discussed.

Teaching Matters: Articles that promote and discuss issues related to the teaching of qualitative methods and methodology.

2. Editorial policies

2.1 Peer review policy

QHR strongly endorses the value and importance of peer review in scholarly journals publishing. All papers submitted to the journal will be subject to comment and external review. All manuscripts are initially reviewed by the Editors and only those papers that meet the scientific and editorial standards of the journal, and fit within the aims and scope of the journal, will be sent for outside review.

QHR adheres to a rigorous double-blind reviewing policy in which the identity of both the reviewer and author are always concealed from both parties. Ensure your manuscript does not contain any author identifying information. Please refer to the editorial on blinding found in the Nov 2014 issue: <http://qhr.sagepub.com/content/24/11/1467.full>.

QHR maintains a transparent review system, meaning that all reviews, once received, are then forwarded to the author(s) as well as to ALL reviewers.

Peer review takes an average of 6–8 weeks, depending on reviewer response.

2.2 Authorship

Papers should only be submitted for consideration once consent is given by all contributing authors. Those submitting papers should carefully check that all those whose work contributed to the paper are acknowledged as contributing authors.

The list of authors should include all those who can legitimately claim authorship. This is all authors who:

- (i) Made a substantial contribution to the concept and design, acquisition of data or analysis and interpretation of data,
- (ii) Drafted the article or revised it critically for important intellectual content,
- (iii) Approved the version to be published.

Authors should meet the conditions of all of the points above. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

When a large, multicenter group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should fully meet the criteria for authorship.

Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship, although all contributors who do not meet the criteria for authorship should be listed in the Acknowledgments section.

Please refer to [the International Committee of Medical Journal Editors \(ICMJE\) authorship guidelines](#) for more information on authorship.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

2.3.1 Writing assistance

Individuals who provided writing assistance, e.g., from a specialist communications company, do not qualify as authors and should only be included in the Acknowledgements section.

Authors must disclose any writing assistance — including the individual's name, company and level of input — and identify the entity that paid for this assistance.

It is not necessary to disclose use of language polishing services.

Please supply any personal acknowledgements separately from the main text to facilitate anonymous peer review.

2.4 Funding

QHR requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the [Funding Acknowledgements](#) page to confirm the format of the acknowledgement text in the event of funding. Otherwise, state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of QHR to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles. Please ensure that a “Declaration of Conflicting Interests” statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that “The Author(s) declare(s) that there is no conflict of interest.”

For guidance on conflict of interest statements, please see [the ICMJE recommendations here](#).

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the [World Medical Association Declaration of Helsinki](#).

Submitted manuscripts should conform to [the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals](#), and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

In terms of patient privacy, authors are required to follow [the ICMJE Recommendations for the Protection of Research Participants](#). Patients have a right to privacy that should not be infringed without informed consent. Identifying information, including patients' names, initials, or hospital numbers, should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written informed consent for publication. Informed consent for this purpose requires that a patient who is identifiable be shown the manuscript to be published. Participant descriptors should not be listed individually. Because qualitative research is descriptive, it is recommended that participant quotations not be linked to identifiers in the manuscript.

2.7 Clinical trials

QHR conforms to [the ICMJE requirement](#) that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines

The [relevant EQUATOR Network](#) reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a [completed Consolidated Standards of Reporting Trials \(CONSORT\)](#) flow chart as a cited figure, and a completed CONSORT checklist as a supplementary file.

Other resources can be found at [NLM's Research Reporting Guidelines and Initiatives](#).

2.9 Data

SAGE acknowledges the importance of research data availability as an integral part of the research and verification process for academic journal articles.

QHR requests all authors submitting any primary data used in their research articles alongside their article submissions to be published in the online version of the journal, or provide detailed information in their articles on how the data can be obtained. This information should include links to third-party data repositories or detailed contact information for third-party data sources. Data available only on an author-maintained website will need to be loaded onto either the journal's platform or a third-party platform to ensure continuing accessibility. Examples of data types include but are not limited to statistical data files, replication code, text files, audio files, images, videos, appendices, and additional charts and graphs necessary to understand the original research. [The editor(s) may consider limited embargoes on proprietary data.] The editor(s) [can/will] also grant exceptions for data that cannot legally or ethically be released. All data submitted should comply with Institutional or Ethical Review Board requirements and applicable government regulations. For further information, please contact the editorial office at vshannonqhr@gmail.com.

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' [International Standards for Authors](#) and view the Publication Ethics page on the [SAGE Author Gateway](#).

3.1.1 Plagiarism

QHR and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of articles published in the journal. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked using duplication-checking software. Where an article is found to have plagiarized other work, or included third-party copyright material without permission, or with insufficient acknowledgement, or where authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article (removing it from the journal); taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; banning the author from publication in the journal or all SAGE journals, or appropriate legal action.

3.2 Contributor's publishing agreement

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3.3 Open access and author archiving

QHR offers optional open access publishing via the SAGE Choice program. For more information please visit [the SAGE Choice website](#). For information on funding body compliance, and depositing your article in repositories, please [visit SAGE Publishing Policies](#) on our Journal Author Gateway.

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4. Preparing your manuscript

4.1 Article Format (*see previously published articles in QHR for style*):

- **Title page:** Title should be succinct; list all authors and their affiliation; keywords. Please upload the title page separately from the main document.
- **Blinding:** Do not include any author identifying information in your manuscript, including author's own citations. Do not include acknowledgements until your article is accepted and unblinded.
- **Abstract:** Unstructured, 150 words. This should be the first page of the main manuscript, and it should be on its own page.
- **Length:** QHR does not have a word or page count limit. Manuscripts should be as tight as possible, preferably less than 30 pages including references. Longer manuscripts, if exceptional, will be considered.
- **Methods:** QHR readership is sophisticated; excessive details not required.
- **Ethics:** Include a statement of IRB approval and participant consent. Present demographics as a group, not listed as individuals. Do not link quotations to particular individuals unless essential (as in case studies) as this threatens anonymity.
- **Results:** Rich and descriptive; theoretical; linked to practice if possible.
- **Discussion:** Link your findings with research and theory in literature, including other geographical areas and quantitative research.
- **References:** APA format. Use pertinent references only. References should be on a separate page.

Additional Editor's Preferences:

- Please do not refer to your manuscript as a "paper;" you are submitting an "article."
- The word "data" is plural.

4.2 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC or PDF. The text should be double-spaced throughout with standard 1 inch margins (APA formatting). Text should be standard font (i.e., Times New Roman) 12 point.

4.3 Artwork, figures and other graphics

- **Figures:** Should clarify text.
- Include figures, charts, and tables created in MS Word in the main text rather than at the end of the document.
- Figures, tables, and other files created outside of Word should be submitted separately. Indicate where table should be inserted within manuscript (i.e., INSERT TABLE 1 HERE).
- **Photographs:** Should have permission to reprint and faces should be concealed using mosaic patches – unless permission has been given by the individual to use their identity. This permission must be forwarded to QHR's Managing Editor.
 - TIFF, JPED, or common picture formats accepted. The preferred format for graphs and line art is EPS.
 - Resolution: Rasterized based files (i.e. with .tiff or .jpeg extension) require a resolution of at least **300 dpi** (dots per inch). Line art should be supplied with a minimum resolution of **800 dpi**.
 - Dimension: Check that the artworks supplied match or exceed the dimensions of the journal. Images cannot be scaled up after origination.
- Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in color in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.4 Supplementary material

This journal is able to host additional materials online (e.g., datasets, podcasts, videos, images, etc.) alongside the full-text of the article. These will be subjected to peer-review alongside the article.

[Supplementary files](#) will be uploaded as supplied. They will not be checked for accuracy, copyedited, typeset or proofread. The responsibility for scientific accuracy and file functionality remains with the author(s). SAGE will only publish supplementary material subject to full copyright clearance. This means that if the content of the file is not original to the author, then the author will be responsible for clearing all permissions prior to publication. The author will be required to provide copies of permissions and details of the correct copyright acknowledgement.

4.5 Journal layout

In general, QHR adheres to the guidelines contained in the Publication Manual of the American Psychological Association ["APA"], 6th edition (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10:1-4338-0562, spiral bound), with regard to manuscript preparation and formatting. These guidelines are referred to as the APA Publication Manual, or just APA. Additional help may be found online [at http://www.apa.org/](http://www.apa.org/), or search the Internet for "APA format."

4.6 Reference style

QHR adheres to the APA reference style. [Click here](#) to review the guidelines on APA to ensure your manuscript conforms to this reference style.

4.7 English language editing services

Articles must be professionally edited; this is the responsibility of the author. Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE's [Language Services](#).

4.8 Review Criteria

Before submitting the manuscript, authors should have their manuscript pre-reviewed using the following QHR criteria:

| |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>1. Importance of submission: Does it make a meaningful and strong contribution to qualitative health research literature? Is it original? Relevant? In depth? Insightful? Significant? Is it useful to reader and/or practitioner?</p> |
| <p>2. Theoretical orientation and evaluation: Is it theoretically clear and coherent? Is there logical progression throughout?</p> |
| <p>3. Methodological assessment: Appropriate to question and/or aims? Approach logically articulated? Clarity in design and presentation? Data adequacy and appropriateness? Evidence of rigor?</p> |
| <p>4. Ethical Concerns (Including IRB approval and consent):</p> |
| <p>5. Data analysis and findings: Does the analysis of data reflect depth and coherence? In-depth descriptive and interpretive dimensions? Creative and insightful analysis? Linked with theory? Relevant to practice/discipline?</p> |
| <p>6. Data analysis and findings: Does the analysis of data reflect depth and coherence? In-depth descriptive and interpretive dimensions? Creative and insightful analysis? Linked with theory?</p> |

7. Discussion: Results linked to literature? Contribution of research clear? Relevant to practice/discipline?

8. Manuscript style and format: Please evaluate writing style: Length (as short as possible), organization, clarity, grammar, appropriate citations, etc.); presentation of diagrams/illustrations?

5. Submitting your manuscript

5.1 How to submit your manuscript

QHR is hosted on SAGE Track, a web-based online submission and peer review system powered by ScholarOne Manuscripts.™ Visit <http://mc.manuscriptcentral.com/qhr> to login and submit your article online. Each component of the manuscript is uploaded separately: Title page, main document, tables, figures, supplemental material.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne.

5.2 Title, keywords and abstracts

Please supply a title, short title, an abstract and keywords to accompany your article. The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on [How to Help Readers Find Your Article](#) in the SAGE Journal Author Gateway on how best to title your article, write your abstract and select your keywords.

5.3 Corresponding author contact details

Provide full contact details of the corresponding author including email, mailing address and phone number. Academic affiliations are required for all co-authors. Present these details on the title page, separate from the article main text, to facilitate anonymous peer review.

6. On acceptance and publication

6.1 Fees

There are no fees to submit or publish, unless an author chooses to publish with open-access. See "Open Access and SAGE Choice" below. Fees for color reproduction of figures *in print* may also apply.

6.2 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author to make final corrections and should be returned promptly.

6.3 Access to your published article

SAGE provides authors with online access to their final article. There is no set time frame when an article will be assigned to an issue.

6.4 OnlineFirst publication

OnlineFirst allows final revision articles (completed article in queue for assignment to an upcoming issue) to be published online prior to their inclusion in a final print journal issue, which significantly reduces the lead time between submission and publication. Articles published OnlineFirst are assigned a DOI number, but no volume/issue/page number information. Articles will be searchable in PubMed but the citation will not appear with volume/page number information until officially published in an issue. For more information, please visit [our OnlineFirst Fact Sheet](#).

6.5 Open Access and SAGE Choice

Articles accepted in QHR have the option to be published as open access after payment of an article processing charge (APC) paid by either the funder or author. Authors wishing to publish open access should contact openaccess@sagepub.com to make the request. Read [SAGE Choice FAQs here](#).

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the QHR editorial office as follows:

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