

The psychological experience of acquiring a  
communication impairment in adulthood and the  
therapeutic implications

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***“Not being able to speak is not the same as not having anything to say”***

(Dr Rosemary Crossley – Advocate for Human Communication)

## **Abstract**

There is little research exploring the psychological experience of acquiring a CI (communication impairment) in adulthood, possibly due to a perception that people with a CI are unable to participate in an interview (Bronken, Kirkecold, Martinsen, Wyller and Kvigne 2012). This study seeks to challenge this perception and explore the experiences of adults who have had to adjust to a change in their communication due to a stroke or head injury. Five participants were interviewed (3 face to face and 2 by email) about their experience from the moment they realised their communication had changed until the current day. All of the participants were 2 years or more post acquiring their CI. The data was analysed using Interpretative Phenomenological Analysis. Results indicate the levels of fear, anxiety and confusion triggered at the time of acquiring the CI and a need for more awareness of CIs within hospital environments. The importance of compassionate communication and psychological support within healthcare services was noted. An instinctual drive or motivation to find an alternative way to communicate and a determination to keep communicating were also highlighted, as well the challenges of living with a CI; including a lack of awareness within society. The study also highlights the significance of expressive writing, singing, humour, laughter and finding the positive to support recovery, adjustment to living with the CI and psychological well-being in the longer term. Considerations for what could be offered therapeutically by counselling psychologists are discussed throughout. Gaps in the literature and further areas for research are identified, such as attachment history and acquiring a CI, and the impact of a CI on the family homeostasis.

## **Introduction**

This thesis seeks to qualitatively explore the psychological experiences of individuals who have acquired a CI (communication impairment) in adulthood. The research aims to understand what it actually means for a person to experience a change in their ability to communicate. Historically this has been an under-researched area within both academic and clinical literature. Whilst this has evolved there still remains a distinct lack of research relating to this topic within the field of counselling psychology and psychotherapy. Some of the literature suggests that adults with CIs are often excluded from participating in qualitative research interviews as their CI is seen as a barrier to engaging in a meaningful verbal conversation (Bronken, Kirkecold, Martinsen, Wyller and Kvigne 2012; Hayley, Womack, Harmon and Williams 2015; Morris, Eccles, Ryan and Kneebone 2017; Wray and Clarke 2018).

The limited research suggests that our knowledge about clients' psychological experience after acquiring a CI may be based on assumptions; albeit well-meaning but not based on talking to these clients about their individual experiences (Hayley et al 2015; Morris et al 2017). There is very little research exploring the in-depth psychological experiences of adults who have acquired a CI in adulthood. The absence in the literature suggests that researchers need to find creative and innovative ways of obtaining valid and meaningful accounts from individuals with a CI. It is anticipated that through gaining some understanding of individual psychological experiences of living with a CI we can begin to understand what counselling or psychological input may be required and of value. The researcher considered that this research may also shed some light on the individuals' own coping strategies and strengths which may in turn help to inform clinical and therapeutic practice.

## Human Communication

Communication is a dynamic and complex process that is instrumental to every facet of our lives (Ross, Winslow, Marchant and Brumfitt 2006; Holland and Nelson 2014; Stein-Rubin and Adler 2017). It is made up of thoughts, emotions, memories, words, sentences, facial expressions, tones of voice, body movements and social mannerisms. It consists of a complex mix of conscious and unconscious information, verbal and non-verbal language; sometimes expressed with clarity and sometimes not. Our communicative ability is there from the day we are born and developed over childhood; interwoven with life experiences, temperament and personality and variable according to the person or persons we are communicating with. It serves as a medium by which we establish our identity within our family and relationships, at work, in the community and in society as a whole (Worrall 2006). Communication is the tool we use to connect and bond with other human beings to form personal, social and professional relationships.

Holland and Nelson (2014) describe human communication as central to personal growth and a key to interpersonal interaction. Communication is like breathing, is pervasive and frequently taken for granted. In the words of Steven Pinker, a cognitive psychologist and linguist (1994) p 15:

*“Simply by making noises with our mouths, we can reliably cause precise new combinations of ideas to arise in each other’s minds. The ability comes so naturally that we are apt to forget what a miracle it is”.*

It is not until we lose aspects of it that we become aware of its importance.

## Terminology and Definitions

### Acquired Communication Impairments

The Royal College of Speech and Language Therapists estimate that there are approximately 2.5 million people in the UK with a CI (RCSLT 2017). The CI may be present from childhood due to a developmental delay, a neurological condition or a genetic disorder. Alternatively, it may have been acquired in adulthood due to a brain injury, neurological condition, cancer or voice disorder. The CI can range from being mild, such as occasional word finding difficulties or difficulties understanding long spoken sentences, to severe, such as having to rely on a voice output communication aid or being unable to understand any spoken language. CIs can impact on self-esteem, expression of emotions, social relationships, personal relationships and result in isolation, anxiety and depression (Dalton 1994; Brumfitt 2010; McMenamin, Tierney and MacFarlane 2015; Baker, Worrall, Rose, Hudson, Ryan and O'Bryne 2018).

The term "Acquired Communication Impairment" has been used in order to specify that the individual was not born with a CI. Their communication ability developed in a typical manner during childhood and into adulthood. The CI has been acquired in adulthood due to a neurological change that occurred in their adult life. The term impairment is used to indicate that they are still able to communicate, but that their ability to communicate is impeded in some way. The word impairment rather than disorder was chosen as the word 'disorder' can often be associated with disease or mental health difficulties, defined by the psychiatric profession (Woolfe, Strawbridge, Douglas and Dryden 2011).

All of the participants in this research were affected by a CI as a result of an acquired brain injury (ABI). An ABI is defined as '*any trauma to the head which disrupts the function of the brain*' (NICE 2007). It may involve the scalp, the skull, the brain or its protective membranes.



The injury can result in speech, language, communication and swallowing difficulties (RCSLT 2017). Acquired brain injury can be grouped into two main types ([www.headway.org.uk](http://www.headway.org.uk) 2018), according to cause. Traumatic Brain injury (TBI) results from an impact to the head, e.g. from a car accident or a fall. Traumatic brain injury, also referred to as 'head injury', results from an outside force and subsequent complications that can follow and further damage the brain. These can include a lack of oxygen, rising pressure, and swelling within the brain. Non-traumatic (or atraumatic) brain injury are events going on inside the body, such as strokes and vascular events, tumours, infectious diseases, hypoxia, metabolic disorders (e.g liver and kidney diseases or diabetic coma) and toxic products taken into the body through inhalation or ingestion.

There are several types of CI that adults can acquire. However, during this research the clients presented with the following 3 types of CI and therefore only these have been described as part of this thesis.

## **Aphasia**

Aphasia is an acquired, multi-faceted language disorder resulting from neurological damage such as stroke or head trauma. It may affect a person's ability to talk, write and understand spoken and written language whilst leaving other cognitive abilities intact. Aphasia is usually a result of a lesion to the left temporal lobe of the brain and is a long-term condition. There are several types of aphasia. The Stroke Association ([www.stroke.org.uk](http://www.stroke.org.uk) 2017) highlight the three most common types of aphasia: Broca's Aphasia which presents as severely reduced speech, often limited to short utterances of less than four words, limited vocabulary, clumsy formation of sounds and difficulty writing (although ability to read and understand speech may be unaffected). Wernicke's Aphasia which can present as impaired reading and writing, an inability to grasp the meaning of spoken words (although producing connected speech is not affected), an inability to produce sentences that hang together and intrusion of irrelevant words in severe cases.

Anomic Aphasia which presents as an inability to supply the words for the item or subject the person wants to talk about (particularly the significant nouns and verbs), speech that's full of vague expressions of frustration and a difficulty finding words in writing as well as in speech.

The Royal College of Speech and Language Therapists state that *“living with aphasia involves individuals and those in their environment in a process of adaptation to change, in terms of communication style, lifestyle, identity and life roles”*. ([www.rcslt.org.uk](http://www.rcslt.org.uk) 2017).

Persons with aphasia remain at risk as defined by the Mental Capacity Act (2005) (Cairncross, Peterson, Lazosky, Gofton and Weijer 2016) and therefore speech and language therapists are integral to assessing competence for consenting (RCSLT 2018).

### **Cognitive communication impairment**

Individuals with a cognitive communication impairment can often present in a similar way to people with aphasia. However cognitive communication difficulties are often the result of ‘pin pricks’ of widespread damage across the brain affecting one or more of the lobes and therefore the individual can present with a mixture of cognitive and communication difficulties. The frontal lobes are particularly important for cognitive communication skills because of their role in the brain's 'executive functions', including planning, organisation, flexible thinking and social behaviour ([www.headway.org.uk](http://www.headway.org.uk) 2018). A cognitive communication impairment can impact on the person’s social communication skills making it difficult for them to take turns during conversations and manage communicative interactions. They can experience difficulties understanding non-literal language (Winner and Gardner 1977) and often have difficulty grasping aspects of everyday social conversations such as sarcasm, humour and inferential reasoning (McDonald and Pearce 1996; Braun, Lissier, Baribeau and Ethier 1989; Pearce, McDonald, & Coltheart, 1998; Docking, Murdoch and Jordan 2000). Difficulties have also been documented for the extra-linguistic modality (non-verbal language) such as the ability to communicate through

gestures, facial expressions, body posture and proximity (Bara, Cutica and Tirassa, 2001; Rousseaux, Vérigneaux and Kozlowski, 2010). A cognitive communication difficulty can be summarised by the following difficulties: attention and concentration difficulties, memory problems, literal interpretation, reduced reasoning and problem-solving skills, cognitive fatigue, slowed speed of information processing and impaired social communication skills.

### **Locked-in syndrome**

LIS (Locked-in syndrome) is a condition in which a patient is aware but cannot move or communicate verbally due to complete paralysis of nearly all voluntary muscles in the body except for vertical eye movements and blinking. The individual is conscious and sufficiently intact cognitively to be able to communicate with eye movements. LIS is a very rare condition. Brain stem stroke is the most common cause, although more than 20 causes have been documented, such as advanced stages of amyotrophic lateral sclerosis (ALS), head trauma, tumours, and infections. The condition has been divided into three categories (Bauer, Gerstenbrand and Ruml 1979): Classical LIS is characterized by muteness and close to complete paralysis, in which only vertical eye movements and blinks remain under voluntary control. Complete LIS when even limited displays of motor control are lacking, leaving the person completely paralyzed. Incomplete LIS when the person has some residual voluntary muscle control in addition to eye movements, such as lip twitches, control over fingers, or neck movement. In all varieties of LIS, the person is still aware, with intact cognitive functions, but because of the paralysis, they are unable to break their bodily confinement. In addition, most still see, hear, smell, taste, and experience heat and cold, as well as pain and pleasure (Johansson, Soekadar and Clausen 2017).

It must also be noted that an acquired CI rarely happens in isolation. Due to the causes of the impairment (i.e. neurological change) and depending on where the lesions occurred, individuals may also find themselves having to adjust to living with epilepsy, visual, hearing impairments or other sensory difficulties, physical impairment, paralysis in any part of their body, pain, difficulty recognising faces, emotional lability, fatigue, attention and memory

difficulties. It stands to reason that any human who has experienced such changes to their physical and cognitive ability will also have a psychological perspective to their experience, which leads us to the next section.

### **Why the term ‘psychological experience’ has been used?**

All of the participants had experienced a brain injury, which had resulted in neurological damage and a CI. Frequently, literature relating to the social aspects of adjusting to a brain impairment places the individual in the ‘sick role’ or ‘victim role’, and one could argue that this then defines their identity. Some suggest that this may be unhelpful as it places the individual into a position of learned helplessness (Seligman and Beagley 1975; Fredrickson 2001). Holland and Nelson (2014) advocate that a positive psychology approach of moving away from the treatment of ‘what is wrong?’ and moving towards ‘what is right?’ may be more helpful when considering therapeutic approaches. This is echoed in Fredrickson’s Broaden and Build theory (2001), which seeks to consider how the therapist can support the client to mobilise their strengths to deal with the adversities that have befallen them; thus, focusing on strengths rather than weaknesses. There is also the consideration of post-traumatic growth and the possibility that some individuals may have experienced positive emotional and psychological changes since acquiring their CI. With all of this in mind the researcher did not want to approach the study from a place of assumed negativity i.e. that the person was incapable of gaining any pleasure from life and was bereft of any ability to function independently. Or alternatively, that there was an assumed positivity i.e. that the person must have experienced some positive feelings, or an epiphany, as a result of acquiring the CI. The aim was to examine their psychological experience whatever that may be for each individual. Therefore, the term psychological experience was used rather than ‘psychological/emotional impact’ or ‘psychological growth’.

## Literature Review

This review will examine the literature relating to CIs and consider the psychological aspects of acquiring a CI. The researcher has chosen not to make any reference to the LD (Learning Disabilities) literature so as to keep the focus on acquired CIs. The researcher acknowledges that there has been some discussion in the literature about the use of LD therapeutic approaches, such as Talking Mats with adults with aphasia. Whilst it is reassuring to know that different therapeutic interventions for CIs are being explored, the aim of this research was to try and capture the psychological experience of *change and adjustment* to a new way of communicating in adulthood. Furthermore, there is an assumption within society that a CI means reduced intelligence, and therefore the researcher felt that it is important to keep the enquiry explored in this research separate from any discussion related to the LD literature.

The review will begin by summarising CIs in the context of the medical model, and considering how the NHS (National Health Service) system and medical model may shape and influence how we perceive and treat people with a CI. This will lead into a discussion about CIs within the context of society; noting a lack of awareness within society and considering whether society plays a part in disabling people with a CI. The review will then describe what is known about the psychological impact of acquiring a CI in adulthood; this will be followed by a summary of the psychological intervention for CI, as found in the literature. The review will finish with a discussion about who may be the most appropriate clinician to offer psychological intervention for people with a CI. The review will consistently make reference to counselling psychology, giving consideration to, and commenting on what the profession may be able to offer this client group in terms of new and innovative ways of working therapeutically.

## Communication Impairments within a Medical Model

The CIs considered in this thesis are the result of a brain injury; a neurological event that has caused a change in function in an area of the brain. The neurological event is medically assessed, given a medical diagnosis and categorised within the World Health Organisation's International Classification of Diseases 10<sup>th</sup> Revision (ICD10). Subsequently the CI arising from the neurological event is also categorised in the ICD 10 under a section entitled '*Symptoms, signs and abnormal clinical and laboratory findings, not classified anywhere else*'. The types of CIs are further categorised into sub-categories, by the speech and language therapy profession, as a means to inform clinical practice and which seek to tailor therapy programmes to treat each of the sub-categories (Marshall 2010). One could argue that the very nature of this process medicalises CIs and seeks to 'restore a deficit' rather than consider the individual as a human in the context of their unique psychological experience.

Historically, research into treatment for neurological change has often focused on neuroplasticity and how to restore the brain function by re-wiring neural pathways (Arrowsmith-Young, 2013). As a result, research relating to CIs has often been impairment based; viewing the impairment from a neurological perspective and through the lens of the medical model. Wotton (2016) notes that there are a growing number of studies that positively confirm neurological reconfiguration in response to speech and language therapy (Fridriksson, 2011; Marcotte, Roig, Damien, Preaumont, Genereux, Hubert and Ansalob 2012) but suggests that SLTs (speech and language therapists) in the UK remain focused on working at the level of functional communication; operating from a principle of a brain that is localised and unchanging. This possibly highlights a gap between the emerging clinical evidence into CIs and actual clinical practice i.e. transition from the 'lab to the shop floor'. One can only hypothesise possible reasons for this; it is known that research can take up to 17 years to filter down into clinical practice and this may be a factor (Morris, Wooding and

Grant 2011). However perhaps SLTs working face to face with individuals with a CI are possibly sensing that the person with the CI is so much more than 'faulty neurological wiring'.

Wray and Clarke (2018) conducted a qualitative literature review and suggested that the biomedical model of illness is inadequate in understanding the full impact of CI. They highlight that a CI goes beyond the symptoms of the medical model and suggest that there is a need for wider psychosocial factors to be considered. Marshall (2010) suggests that categorising CIs could provide clinicians with 'off the shelf' treatment resources but also argues that classification systems for CIs have limited prescriptive power. Marshall (2010) suggests that selecting a treatment on the basis of sub-category diagnosis is likely to overlook significant individual differences. It is widely acknowledged that every person with a CI is individual and therefore will present in their own unique way. This variability will present itself within members in the same sub-category diagnosis and therefore one cannot assume that all individuals will respond to a treatment in the same way; CIs come in all shapes and forms (Baylor, Burns, Eadie, Britton and Yorkston 2011). McGrath (2004) emphasises the need to move beyond a restoration approach (i.e. attempting to restore the person's physical, cognitive and communicative functions to how they were before the stroke or head injury). Galletta and Barrett (2014) suggest creating a treatment approach that includes both impairment and functional approaches in order to provide a person-centred and multi-faceted treatment programme. Research is increasingly moving towards a bio-psycho-social model, an approach advocated by the World Health Organisation (Galletta and Barrett 2014). The ICF Framework (International Classification of Function, Disability and Health, World Health Organisation) enables a clinician to make an assessment of the person with a CI and consider the biological, sociological and psychological consequences of the loss of communicative ability; the aim being is to see the individual as a whole person and offer a holistic approach. Universally it is the most widely accepted framework and provides an international consensus and consistent terminology between professionals (Worrall and Frattali 2000). The framework looks beyond the impairment and considers the

impact of the impairment for the person at an individual and a social level. Some argue that the ICF framework is too simplistic and not specific to communication, therefore making it too restrictive (Worrall and Wallace 2015). However, others argue that the framework explains the functional consequences of the CI and therefore encourages and enables a therapist to specifically plan intervention according to each individual's circumstances and idiosyncrasies (Garcia, Barrette and Laroche 2000; Galletta and Barrett 2014).

Davies (2016) discusses health psychology and highlights the importance of seeing the patient as an individual and treating them holistically. This involves giving them the chance to tell their story rather than a clinician (i.e. GP, consultant, psychologist) assuming the medical notes or reports are the whole truth. However, what happens to individuals with a CI if they are unable to verbally tell their story? Do they ever get the opportunity to share their story? Does the medical model and NHS system make space for these individuals to be met with a humanistic approach and seen as a whole person, or are they deemed inappropriate for a service and perhaps listed in the clinical statistics as an 'unmet need'? The literature does not appear to give any attention to this matter, further silencing these individuals.

With this in mind, it is important to consider the impact of the medical model within an organisation such as the NHS, and the influence the system may have on shaping how an individual makes sense of their CI. A person's subjective experience of a health condition begins from their first encounter with a doctor or medical professional (Davies 2016). This may be due a number of factors, such as the use of language (e.g positive, negative, complex, flippant), medical terminology, formal clinical expressions, overuse of statistics in explanations, sense of hope or loss expressed by the clinician. This is very apt when considering how a person with a CI may experience being told about their diagnosis of a CI. The use of language can be powerful in shaping the construct of the impairment but this goes to another layer when considering people with a CI. Due to the very nature of their impairment we need to consider whether they understood everything that was said to them



during the medical consultation and if not, how did they make sense of the parts they did not understand.

Some research indicates that after acquiring aphasia, clients and families often say that things were not explained to them (Holland and Nelson 2014; Stroke Association 2013). This could be the reality and/or could indicate the need to repeat things several times over the course of several weeks and months and offer the information in a written format. It could also be that attention or memory difficulties related to their neurological event also impacts on how they receive and retain verbal information. In contrast, Stein-Rubin and Adler (2017) suggest that perhaps too much information is delivered to patients with a CI and questions whether this actually creates distance. There is room for far more discussion about this within the literature as there is a distinct lack of attention given to the matter of how and when a diagnosis of a CI is given.

We must also acknowledge how clinicians have been trained and therefore consider the influence of this on therapeutic intervention for CIs. Historically, clinical psychologists' and SLTs' training has been funded by the NHS and therefore they have been trained to predominantly follow a medical model seeking to treat the specific impairment (Brady, Kelly, Goodwin and Enderby 2012; Sellars, Hughes and Langthorne 2005). NHS culture is increasingly being driven by evidence base and outcome measures, with patients often being discharged if no change is seen within a limited period of time. This is likely to impact on people with CIs. Mandelstam (2011) describes the NHS as a 'pyramidal, command and control structure'. Some suggest that rigid NHS targets may be resulting in unintended and dysfunctional consequences to patients and staff (Mannion and Braithwaite 2012), which may have a blunting effect on compassionate care (Newdick and Danbury 2013). In addition, there is often an 'unspoken' social and professional pressure to work within a medical model so as to be accepted and validated by peers and the hierarchy of the system (Obholzer and Roberts 1994; Mandelstam 2011; Rankin 2013; Pope 2017). This often leaves little space

and time to consider the person with the CI as a unique individual with their own ‘backpack’ of thoughts, feelings and emotions.

Tanner (2010) highlights that the topic of CIs transcends several complex disciplines such as human anatomy and physiology, neurology, psychiatry, psychology and neuropsychology and yet, in spite of the vast literature on aphasia, there is very little evidence of collaborative work between medicine, psychology and linguistics. Gyorfi and Rebek-Nagy (2015) suggest that joint efforts between disciplines may produce more fruitful results in understanding CIs. The very nature of human communication is fundamental to who we are as individuals and therefore it is questionable whether the medical model alone can fully understand and explain the emotional and psychological complexity of a CI. Perhaps counselling psychology could bring its humanistic roots to exploring the topic alongside SLTs and other clinicians.

### **Communication Impairments within Society**

Research indicates that most members of the public have not heard of the term ‘aphasia’ (Flynn, Cumberland and Marshall 2009) let alone understand the impact of a CI on someone’s life. Public knowledge of aphasia and its effects is thought to be consistently low and significantly lower than other disorders with a similar prevalence (Sheratt 2011). This is echoed in the literature (albeit sparse) about LIS (Locked-in syndrome). Individuals with LIS frequently face social barriers including social exclusion, stigmatization and an underestimation of their cognitive abilities (Johansson, Soekadar and Clausen 2017). Some sources suggest there is a general ignorance about CI within society resulting in the belief that many perceive a person with a CI as having an intellectual impairment (Cunningham and Ward 2003). O’Brien (2016) suggests that the inability to use language hinders people from showing themselves as thinking and acting individuals in everyday life. It is thought that this unhelpful assumption is upheld because society incorrectly ties intelligence and maturity of language (O’Brien 2016).

Individuals with a CI also present a unique challenge, as they may retain decision-making capacity but often lack the means to adequately express their decisions (RCSLT 2018; Cairncross, Peterson, Lazosky, Gofton and Wieger 2016). Their communication may be compounded by cognitive capacity issues, particularly in the early stages of brain injury which could skew other's perceptions of their ability to make decisions. Perhaps this may be causing confusion for healthcare staff and society at large. Sutt (2017) carried out research related to patients in intensive care units and highlighted that clinical staff reported feeling that it is easier to establish the presence of confusion/delirium when patients are verbally communicating. The research indicates that patients' inability to communicate their needs to clinical staff can lead to decreased exchange of vital diagnostic information, decreased adherence to recommendations and poor patient satisfaction with the healthcare service. This highlights the importance of raising awareness and gaining greater understanding about people with CIs and their experiences within a hospital environment. This could serve to inform future clinical and therapeutic practice with an aim for more effective patient care outcomes.

Due to the fundamental nature of communication for interacting within our social environment, this begs the question of how the social world further impacts on the individual's experience of living with a CI. Hilari and Northcott (2016) describe how aphasia can profoundly affect a person's social relationships, and highlight the impact of the challenges they face maintaining friendships and social relationships. Aphasia can create awkward moments, or silence that many find uncomfortable, and can create challenges engaging in in depth discussions, gossiping, and making jokes (Northcott, Marshall and Hilari 2016). A person with LIS may communicate via a computerised voice system, which can result in long pauses and an absence of non-verbal language such as tone of voice, facial expressions and gesture. Dalemans, de Witte and Wade (2010) describe how friends seemed reluctant to get in contact with the person with communication difficulties. This suggests that there is some level of discomfort in accepting and adapting to a person with communication difficulties, which places them at risk of losing friends. A meta-ethnographic

synthesis of qualitative studies exploring social support post stroke found that communication difficulties were a major reason for friendship loss (Northcott, Burns, Simpson and Hillari 2015). The CI can often be accompanied by a physical disability and fatigue, which can impact on physical and practical challenges such as transport and accessing certain venues easily. This can further impede the person's ability to access social engagements.

Disability literature suggests that as a result, society may unknowingly place people with a CI in a category of being less able or of less value, therefore making them into inferior members of society who experience social disadvantage (Dimitris, Anastasiou and Kauffman 2013). Research into disability has shown that when members of society are placed into this inferior category they are often given jobs that are the least rewarding in terms of pay, opportunities, professional status and psychological satisfaction (Scase 1992; Darcy, Taylor and Green 2015). This restricts the person's earning potential and career aspects, which can restrict their access to housing and consequently places them in a lower social class (Meershoek, Krumeich and Vos 2007). Subsequently this serves to perpetuate society's perception that disability is an inferior state. Oliver (1990) suggests that people with disabilities usually build their subjective experience through their interaction with their social environment. The disability literature highlights that for many people with disabilities, the social discrimination, hostility, ostracism and exclusion are worse than the impairment itself (Dimitris et al 2013). This appears to be echoed in the literature regarding CIs as research highlights that people with aphasia are more likely to experience hurtful negative responses from others (Northcott and Hilari 2018) and that the lack of social companionship has been linked to poorer health related quality of life (Hilari and Northcott 2006).

Literature describing the social impact of neurological impairment tends to place the person into a victim, or sick, role often suggesting that society upholds the disability (Darcy, Taylor and Green 2016). This point was recognised by the Stroke Association some years ago when they moved from the term 'stroke victim' to 'stroke survivor'. SLTs also began using the

term 'person with aphasia' rather than describing a person as 'aphasic'. Nonetheless there are still social barriers that stop a person with a CI from participating in some areas of everyday life. The ever-increasing trend towards global brands of fast food and drive-through outlets that require a verbal commentary from the customer can restrict a person with a CI from using the service. Likewise, the growth of call centres and voice-activated systems, with a focus on speed and volume of calls, play a big part in disabling a person with a CI. That said, one could also argue that the rapidly evolving use of the internet to communicate with other humans may be an advantage to a person with a CI and reduce feelings of social isolation compared to perhaps 20 or 30 years ago. Research looking at internet blogs of people with aphasia suggested the use of social media should be explored as a way for people with aphasia to feel connected to the community (Fotiadou, Northcott, Chatzidaki and Hilari 2014).

Tanner (2010) wrote about the power of motion pictures to shape public opinion within society. He recognised that the media could possibly be an institution in propagating stereotypes but also in advancing facts and dispelling myths about the reality of living with a CI. He concluded that if films portrayed individuals with CIs with positive personality traits then it could help to eliminate negative stereotypes and prejudices. There are 2 high profile films that illustrate some of the diversity of CIs adults experience and may have contributed towards an increase in awareness. The Diving and the Butterfly film (2007) raised public awareness of LIS. This film was a true story of Jean-Dominique Bauby, who survived a stroke and was left physically paralysed yet cognitive completely intact. The film portrayed the impact of his CI and the need to use other forms of communication such as eye blinking. Secondly, the Theory of Everything (2015) about Stephen Hawking portrayed the gradual decline of his communication and is eventual transition to a 'robotic' sounding computerised voice output system. Media occasionally report short features related to CIs – for example *"Completely locked-in' patients can communicate"* (BBC News 1<sup>st</sup> February 2017) describing the development of a computerised system that is able to measure the fronto-central oxygenation changes in a person's brain when they are asked yes and no questions

(Chaudhary, Xia, Silvoni, Cohen and Birbaumer 2017). It is promising that the topic of CI occasionally reaches mainstream media, however the focus is often on sensationalising the story or reporting advances or breakthroughs in medical science. Very little is mentioned about the individual psychological experience of these individuals.

Sheratt (2011) notes that the media's depiction of aphasia is often confusing and inaccurate with an emphasis on dramatic aspects or medical opinion. Aphasia is often used colloquially to indicate 'silenced' or 'tongue tied' or difficulty finding a word or naming an item (Sheratt 2011). A study in Ireland highlighted a relative invisibility of CI in newspaper narratives of chronic illness and disability (O'Maley-Keighran and Coleman 2013). The authors concluded that the under-representation of the lived experience of individuals with CIs within newspapers may be contributing to a general lack of understanding and awareness of CI within society. They suggested that this under-representation and lack of awareness could impact on the individual's ability to re-integrate into society post acquiring their CI. Perhaps counselling psychologists can play an active role in raising awareness of CIs.

## **The Psychological Impact of Communication Impairments**

As discussed previously, the CIs considered in this thesis are the result of a neurological event causing a brain injury. With this in mind, much of the literature focuses on the psychological impact from the perspective of the overall brain injury, not just the communication difficulties. Subsequently the literature discussed in this section of the review has been gathered from a range of journal articles, and therefore is written with a thread of interchangeability between research that has specifically focused on CIs and research that has focussed on the overall psychological impact of stroke and brain injury.

Individuals with a CI are reported to be at high risk of mental health difficulties, such as depression due to social isolation and relationship breakdown (Hilari, Needle and Harrison 2012; Baker et al 2018). There is also a suggestion of an association between CIs, depression and a learned helplessness (Seligman 1975; Van Dijk, Wideman-van Ginkel and

Hafsteindotter 2016). One could argue that aspects of learned helplessness are further upheld by society (as discussed in the previous section), however one must also consider that the CI rarely occurs in isolation and therefore the individual may also be adjusting to other physical and cognitive difficulties; all of which may contribute towards the experience of depression and learned helplessness.

Brumfitt (1998) noted that early research into acquiring aphasia suggested psychological changes were exclusively due to brain damage, with no discussion relating to the emotional or psychological impact of a traumatic event. There is now an understanding of the difference between emotional responses relating to the site and type of brain lesion and those relating to a life changing catastrophic event. However, the literature suggests that there is still a prejudice from health and medical professionals who may assume that depression is an inevitable consequence of a brain injury. As a result, they may end up appearing dismissive of the individual's psychological difficulties and attribute any low mood to neurological changes or loss of function (Baker, Worrall, Rose, Hudson, Ryan and O'Bryne 2018).

Depression following stroke and brain injury is well documented in the literature (Coetzer 2007; Sekhon, Douglas and Rose 2015, Hildebrand 2015). There are also documented increased risk factors for suicide after stroke or head injury (Hackett, Anderson, House and Halteh 2008). In addition, depressive symptoms following a stroke are associated with a faster recurrence of stroke (Robinson and Spalleta 2010) and poorer rehabilitation outcomes (Ayerbe, Ayis, Rudd, Heuschman and Wolfe 2011). Yet despite this awareness, the research also highlights that post stroke depression remains unrecognised, undiagnosed and undertreated (Miller, Murray and Richards 2010).

As well as depression, there are a myriad of other thoughts, feelings, and emotions that can be triggered as a result of a brain injury. A person can experience apathy, embarrassment, loss of confidence, altered body image, emotional lability, fear, frustration, apathy, shame

and anger (Coetzer 2007, 2014). Attention and language are intertwined and subsequently both are impaired in CIs such as aphasia causing confusion and distress (Shisler-Marshall, Laures-Fore and Love 2018). Additionally, pharmacological interventions can have a profound effect on communication. For example, an individual may have also acquired epilepsy as a result of the brain injury and be taking anti-epileptic medication. This medication has the potential to affect cognition and speech negatively (Maguire 2000; Pakhomov, Marino, Birnbaum, Hawkins-Taylor and Lepik 2010) and again, cause confusion and distress. All of these factors place heavy demands on the person's psychological and emotional resources. Furthermore, we do not know the impact of previous life experiences and how previous psychological resources or challenges may help or hinder the person's journey and experience of acquiring a CI. Brumfitt (2006) highlighted that the literature discussing the psychosocial impact of aphasia does not consider the individual's pre-morbid psychological history. This certainly seems to be the case as much of the literature discusses depression with an assumption that the brain injury has been the main cause. This supports a need to consider the person with the CI in the context of the whole life experience (Coetzer 2007).

Furthermore, people who have experienced a change in physical or communicative ability following a brain injury are likely to experience feelings of loss and therefore may go through a process of grieving the loss. Thirty years ago, Tanner and Gerstenberger (1988) suggested that acquiring aphasia was parallel to a grief response. At the time, this was considered to be a controversial discussion; however, clinical discussion on this topic has since evolved and it is now more widely accepted that acquiring a CI can trigger a grief response (Wray and Clarke 2018; Coetzer 2007,2014; Brown, Davidson and Worrall 2013). Grief is a natural reaction to loss of any kind and is a process of adaptation, therefore it seems reasonable to suggest that an individual may grieve the loss of their 'communicatively able self' (Grohn, Worrall and Simmons-Mackie 2014). The overall sense of loss can be due to a loss of communication, self-identity, friendship and previously valued activities (Wray and Clarke



2018). A study in 2016 described the loss associated with acquiring aphasia as disenfranchised grief due to the fact that there is so little awareness of CIs within society (Doughty-Horn, Crews, Guryan and Katsilometes 2016). There is also current research emerging regarding traumatic brain injury and a loss of a sense of self (Ownsworth 2014). Qualitative studies highlight that people with TBI experience complex changes in their sense of self and many individuals report losing something of themselves that they valued but that it is difficult to define (Beadle, Ownsworth, Fleming and Shum 2016). The literature suggests that the loss or change of self-identity after TBI as a phenomenon does exist. The changes described by people range from a vague feeling of no longer being the same person as before, to no longer feeling like a person at all. Some have described 'fragmentation of one's self' whilst some reported a complete loss as a 'death of the self and being reborn' (Thomas, Levack and Taylor 2014).

This leads us to consider whether the person's experience has resulted in a more existential type enquiry or questioning. Nystrom (2006) discusses this in light of aphasia and recognises the loss of self-esteem associated to existential loneliness. Feelings of being alone, imprisoned in the body, appear to create a distance to other people, leaving the person with the CI questioning who they are now that they cannot communicate in the same way. It is thought that existential loneliness seems to increase when other people ignore or make light of the CI. In the most harrowing moments there are feelings of alienation, humiliation and loneliness that include both internal life and the surrounding world. These are significant aspects of acquiring a CI that counselling psychologists may be able to explore in psychotherapy.

As well as loss, there may also be a level of anxiety. Due to the neurological event, the individual may have experienced a life or death situation triggering new trauma, Post-Traumatic Stress Disorder (PTSD) and/or pre-morbid traumatic experiences. A study into LIS explored the impact of a near-death experience on long-term psychological health (Charland-Verville, Lugo, Jourdan, Donneau and Laureys 2015). They suggested that

experiencing a negative near-death experience could lead to the formation of PTSD symptoms leading to a lower quality of life, thus pointing to the importance of psychological follow up. The prevalence of anxiety and PTSD amongst people with aphasia is unclear at present due to these patients often being excluded from studies (Morris, Eccles, Ryan and Kneebone 2017); however anxiety is thought to be high. We also need to consider that many of these individuals may have experienced a level of fear and/or trauma in Intensive Care and be experiencing Post Intensive Care syndrome. Overall, they may feel forced into coping with acute and threatening illness with a confusing combination of physical and psychological difficulties and a loss in the ability to communicate these feelings.

In addition, the CI does not just happen to the individual; it ripples out to affect the whole family on some level psychologically. Family Systems Theory suggests that when a member of the family changes, the other family members seek to restore the homeostasis (Michellet, Treteault and Le Dorse 2003; Huejung and Rose 2014). Given that communication is central to a family unit's functioning, one can only assume that a CI would impact on the family homeostasis. Unfortunately, there does not appear to be any specific research focusing on the area of family systems and CIs at present. Nonetheless some research into the impact on family is emerging. Northcott and Hilari (2017) highlight that after a stroke, shifts in family roles can cause great distress impacting on parent ability and reciprocity in relationships. There is also some research into the psychological impact of LIS on relatives, which concluded that family members would value more emotional support to adjust to the change and ongoing stress (Lugo, Pella, Blandin, Laureys and Gosseries 2017). The literature for aphasia suggests that individuals readily identified the importance of their family and friends for providing support on a practical and emotional level (Wray and Clarke 2018).

When considering family units, it is also worth noting that early language acquisition takes place at the same time as attachment to the main caretaker (most frequently but not exclusively the mother). It is well documented in psychological theory that adult relationships reflect the attachment history we experienced from our main caregiver whilst

acquiring language as a child. To effectively complete the acquisition of human language, children require a positive and consistent attachment experience (Onnis 2017; Orbach 2000). Therefore, with this in mind we may want to consider the adult with the CI attachment experience as a child. Research into peoples' perceptions of care and support following a stroke indicates that their perceptions of effectiveness vary according to their coping strategies, life experience, personality, support network and philosophy to life (Worrall 2006). More recent research hypothesised that a person's perception of functional support may in fact reflect their attachment style (Northcott and Hilari 2018). Each individual has a rich biography full of emotional imprinting and relational templates, laid down long before the change in their communication. We know from psychological theory that a person's past impacts on how they respond in the present and therefore it is likely that this will come into play in how a person responds to acquiring a CI in adulthood. What might be the impact of a CI that places the person back into pre-linguistic territory? How do they seek to get their needs met and is there a risk of them being infantilised due to their CI? Could it be that a loss of language triggers a disrupted or difficult attachment history and if so, how might this impact on the person's sense of self? What if the individual with the CI had a fragile attachment style prior to their neurological event; is this further exacerbated by a reduction in communication ability? There are many questions that have not yet been explored. Joseph, Murphy and Regel (2012) highlight that people whose previous life experience has been unsupportive of their basic psychological needs, and whose psychological well-being was not already well developed prior to the trauma, may require more therapeutic attention as they lack the developmentally acquired psychological wellbeing. This certainly fits in with psychological understanding of attachment theory, which for most psychologists is likely to be an important consideration when planning therapeutic intervention for any clients, with or without a CI. However, the topic of attachment history and CIs remains an un-researched area. Perhaps exploring this topic could in fact shed light on ways to tailor specific therapeutic intervention for adults with CIs and again could be an area for counselling psychologists to explore.

Overall, the literature indicates that experiencing a neurological event and acquiring a CI is a complex 'soup' of neurological processes and changes that is likely to require time to adjust to and make sense of in the context of each individual's life history and psychological resources.

## **Psychological Intervention for Communication Impairments**

Interestingly, Sigmund Freud (1856 – 1939), wrote about aphasia when he published 'On Aphasia: a critical study' in 1891. It is unclear whether Freud actually ever examined a patient with aphasia but he attempted to outline a theory of cognition on the basis of aphasiological data (Tikofsy 2012; Greenberg 1999). The literature suggests that Freud viewed his aphasia book as a stepping stone to development of a theoretical framework for psychoanalysis. Freud described his psychological approach of psychoanalysis as the 'talking cure' and introduced the concept of catharsis as a form of therapy based on the idea of healing of emotional blockages by uninhibited talking. This approach relied heavily on the client using verbal communication; the emphasis being on the instructions to 'describe' and 'tell' (Collin, Benson, Ginsburg, Grand, Lazyan and Weeks 2012). In its classical formulation, psychoanalysis deals almost exclusively with language (i.e. interpretation and free association) (Theisen Simanke 2017). There is some suggestion that Freud believed a Freudian slip and aspects of word errors seen in patients with aphasia to be revealing a similar unconscious communication. Whilst this notion may make us pause for thought and ponder, many would argue that Freud's theory was rudimentary. Are we really to suggest that an individual with linguistic difficulties as a result of brain cell death is suddenly exposing all of their unconscious thoughts? Perhaps this reflection on some of psychology's earliest theories highlights how our understanding of the complex systems of the brain has evolved. In the current day, perhaps some aspects of Freud's theory may be described in the context of disinhibition following certain types of brain injury (Coetzer and Balchin 2014).

Fast forward to today within the NHS in the UK, and psychotherapy, counselling and psychological therapy are referred to as the 'talking therapies' ([www.nhs.uk](http://www.nhs.uk) 2017), again the emphasis being on verbal communication. Almost all forms of psychotherapy agree that talking about emotional experience is an important component of the healing process (Beck 1976; Ellis 1962; and Rogers 1951). However, what happens if a person is having difficulty using verbal communication due to a CI? Conventional 'talk based' psychological therapies such as Cognitive Behavioural Therapy (CBT) and motivational interviewing to target depression post brain injury are considered to be a significant barrier for a person with a CI (Sekhon, Douglas and Rose 2015). Within the 'talking therapies' evidence base the therapeutic relationship is often cited as the most significant influential factor for the effectiveness of the therapeutic intervention. This therapeutic relationship is central to a counselling psychologist's approach and is developed with two-way verbal communication between the therapist and client. However, what happens if the client is unable to use verbal language in a fluent conversational manner? Does this mean that the therapeutic relationship struggles to develop? Bugental (1992) wrote about the critical change that can occur within psychotherapy at a certain level of communication. Bugental theorised that communication was layered at different levels according to our environment and our communication partner. This raises the questions of whether this depth of communication and the opportunity to experience this change in therapy is possible for individuals who have a CI.

The literature suggests that thousands of people are affected by neurological conditions (and we can assume that a percentage of these have a CI); however, it is thought that the majority of these individuals have little access to psychologists (Ward and Fairfax 2017). Depending on the type of neurological condition and location of the individual they may have access to a neuropsychologist, however this is likely to be in the context of a psychometric assessment of cognitive ability and functioning. They are unlikely to be offered a supportive therapeutic relationship that helps them overcome the trauma (Ward and Fairfax 2017) and allows space for exploration and acceptance. Coetzer (2007) notes

that in the past it was fairly common view that psychotherapy was inappropriate for brain injured clients. This viewpoint has since evolved and clinicians are starting to acknowledge the effectiveness of this type of therapeutic intervention. NHS Improvement (2011) stated that UK stroke services recommend that psychological well-being is considered as important as physical well-being. The report raised concerns that a small sub-group of people with aphasia were receiving inadequate psychological support (Northcott, Simpson, Moss, Ahmed and Hilari 2017). It also highlighted that mental health services are often inaccessible to those with a moderate to severe CI. The Stroke Association (2013) found that half of stroke units in England, Wales and Northern Ireland do not have access to psychology and it is thought that neurorehabilitation units focus on physical and cognitive rehabilitation giving considerably less attention to emotional difficulties and the process of longer-term adjustment (Coetzer 2014). This is further compounded by the phenomenon of 'neurophobia', when clinicians express an inability to work with clients who have a neurological diagnosis. There is an assumption that only specialist neurologically trained clinicians can work with these clients (Nicholl, Aojula, Hassan-Smith, Amer and Nightingales 2017). Coetzer (2007) notes that after brain injury clients can present with poor self-awareness, memory difficulties, perceptual problems and impairments of language functions, which can pose barriers to clinicians working with this client group. The literature suggests that the result of all of these factors is a massive unmet need for the clients, as they are not receiving psychological support. Northcott et al (2017) conclude that in order for psychological care for people with aphasia to be valued and delivered collaboratively by a multidisciplinary team, a cultural shift is needed.

Hildebrand (2015) conducted an evidence base review for the effectiveness of interventions for adults with psychological or emotional impairment after stroke. They concluded that more research is required to ascertain what interventions are effective for people with psychological impairment, however there was no discussion relating to the impact of acquiring a CI. A systematic review of rehabilitation interventions to prevent and treat depression in post-stroke aphasia concluded that some interventions may improve

depression outcomes, but noted limited levels of psychology services and a general lack of confidence in other professional disciplines to provides interventions such as counselling due to communication barriers (Baker et al 2018). Haley et al (2015) suggest that rehabilitation and medical staff working with adults with CIs may be missing opportunities to discuss moods and emotions. Subsequently they may be missing opportunities to resolve unhelpful assumptions about their life circumstances in order to avoid negative mood escalation. It is suggested that people living with aphasia and their significant others require collaboration of stroke health professionals and mental health specialists to 'bridge the gap' in clinical care and meet stroke rehab objectives (Sekhon et al 2015). Coetzer (2014) recognises the limitations of funding within the NHS, and how funds are often directed towards trauma and acute care rather than post-acute community services. This could suggest that exploring psychological experiences is perceived as a secondary service relegated to an abyss due to funding, lack of time and waiting list pressures. However, perhaps the relegation is due to a lack of specialist knowledge, skill and/or confidence.

Coetzer (2007) highlights that due to the dynamic nature of the recovery in brain injury that continual assessment is required. Van Dijk, de Man-van Ginkel, Hafsteinsdóttir and Schuumans (2016) note that the assessment of post-stroke depression in individuals with aphasia is complicated. The general method for diagnosis of depression in patients after stroke is a psychiatric interview according to the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association 2018) diagnostic criteria for depression. This is further complicated if the person with the CI is unable to reliably respond to a clinical interview, as the majority of standardized instruments for the assessment of depressive symptoms depend on the individual's ability to communicate at a certain level. Consequently, it is suggested that a CI can impede the assessment and diagnosis of depression (Van Dijk et al 2017). However, once again, although the challenges of the communication difficulties are often noted, very little attention is given in the literature to psychological intervention for individuals with CI.

In 1994 Peggy Dalton (a SLT and counsellor) published a book called 'Counselling People with Communication Problems' and explored the idea of using a Personal Construct Approach when counselling individuals with communication difficulties. She described the counsellor/psychologist's need to be inventive and to encourage experimentation in clients who may find they have resources within themselves that have never been tapped before. She encouraged the use of drawings, pictures, sounds and other non-verbal material to express feelings that might usually be masked by words. Dalton further highlighted that taking the emphasis off the struggle to speak can in itself facilitate spontaneous verbal expression. These strategies are commonly used in a range of psychological therapy approaches for clients who do not have a CI and, therefore many counsellors/psychologists may already be using these skills without realising their significance for individuals with a CI. Dalton also discussed peoples' perceptions of engaging in a psychological therapy for exploring emotions. She notes that patients rehabilitating after stroke may access physiotherapy or speech and language therapy and see repeating drills as an appropriate therapeutic input. However, they may not see the relevance of accessing a therapy to process any feelings of loss or anxiety. In fact they may see this as rather an alien concept with their focus being solely on restoring function, not adjusting to loss of function. Dalton emphasises that if the person is of this belief that they may find counselling or being asked about the feelings a 'psychological intrusion' and therefore this should not be imposed on them. The book was written from her experience of working as a speech and language therapist and counsellor. It is unclear whether she consulted any clients for the opinions on suitable psychological interventions or whether the book was based on a clinical experience and anecdotal feedback.

In 1998 Rosemary Cunningham carried out a small piece of research called 'Counselling someone with severe aphasia: an explorative case study'. This study was with one participant who attended 6 sessions. The researcher used repertory grids that had been adapted for persons with severe aphasia. She concluded that a counselling approach is



possible with someone with severe aphasia however the study only included one participant and was not developed any further within the evidence base.

Brumfitt (1998) introduced the construct of psychological well-being and discussed its relevance to SLT. Brumfit (1998) acknowledged that there was no tradition of measuring psychological well-being in SLT context, even though the clinical significance of well-being to therapeutic outcome was recognised. Brumfitt (1998) highlighted that whilst SLT intervention was focused on symptoms with a theoretical underpinning and an evidence base, the SLTs assessment of their individual's psychological well-being was often just based on a subjective appraisal and reported as a comment. The Visual Analogue Self Esteem Scale (Brumfitt and Sheeran 1998) was developed to give an indication of the level of self-esteem for the individual with the CI. This scale uses pictures rather than just words and provided SLTs with a basis for conversation about feelings, enabling some expression of distress. This innovative measure seems to mark a point in time where the psychological experience of acquiring a CI was being recognised and discussed in greater depth.

Some 20 years later, the research certainly includes more discussion regarding the psychological effects of acquiring a CI, yet in spite of this research there appears to still be a lack of services skilled in providing the required counselling and psychological therapeutic intervention (Shrubsole, Worrall, Power and O'Conner 2016). Wray and Clarke (2018) note that to date there has been no systematic review and synthesis of qualitative research exploring the needs for stroke survivors with communication difficulties in relation to longer-term care. Psychological research into neurological impairment often focuses on ways to move the person from 'depressed' to 'not depressed', as if it is a finite move. Nonetheless, there have been a range of studies and some of the most relevant ones are discussed below.

A study reported in 2001 (Murray and Ray) indicated that relaxation training for low mood resulted in improved syntactic function. It was theorised that by treating the low mood, the demands on the attentional resources were reduced, giving the individual more capacity to

focus on language processing. Stress may place an additional burden upon the already fragile language skills of someone with a CI. This study aimed to raise understanding of how psychological responses to stress may affect the language processing abilities of adults with aphasia and echoes Dalton's (1994) thoughts about how taking the emphasis off the struggle to speak can have positive effects on expressive communication.

Baylor, Burns, Eadie, Britton and Yorkston (2011) conducted a qualitative study looking at different types of exercise and strategies to treat CI but acknowledged that it did not allow for open-ended exploration of patients' experiences about adjusting to the CI. In 2011 Cruice, Worrall and Kickson carried out some research to measure whether older people with aphasia experienced greater psychological well-being after a group intervention. Whilst this research recognised that there is a psychological experience to acquiring the CI, it did not seek to explore the individual's experiences or offer any thoughts on one-to-one counselling or psychotherapy for these individuals. The measure was a questionnaire with set questions providing quantitative data with the overall aim being to create an improvement in the individual's sense of wellbeing; in a sense it aimed to see a movement away from sadness as a finite psychological state. Research by Haley et al in 2015 sought to extend beyond sadness to other mood states including positive mood states. They suggest that whilst lots of attention is given to depression, which is a mood disorder, not so much is given to mood states. They recognise a need to consider the impact of external and internal factors on the mood states of each individual. The research used a visual rating scale to enable participants to choose from a range of mood states however the research did not explore mood states in depth or individual experiences.

Musser, Wilkinson, Gilbert and Bokhaur (2015) interviewed 12 participants with aphasia about their changes in identity after their stroke. The researchers recognized the challenges of interviewing individuals with aphasia but described how these individuals experience identity post stroke and develop new identities over months and years. This study was

carried out in the USA and only focused on aphasia and identity. It did not consider any other types of CI or in-depth psychological experience.

Research by Dickinson, Friary and McCann (2016) reported that a Mindfulness programme appeared to be effective in reducing an anxiety score in a person with a CI. Improved language changes were also evident in a confrontation naming task, however this research was only carried out on one person and therefore cannot be generalised to the population. Furthermore, it did not explore the psychological journey of the participant in relation to their CI. Nonetheless it weaves into the theme previously mentioned, i.e. taking the emphasis of speaking, reducing anxiety and how this can have positive effects on expressive communication.

More recently some psychological researchers have started to consider treatment options for adults with mental health difficulties and a CI. This is a promising move forward and suggests that the psychology profession is beginning to explore interventions that do not require verbal output. A recent study has sought to trial a clinical psychological approach with a CI. Guina and Guina (2018) noted that psychotherapy options for individuals with aphasia were limited and trialled EMDR (Eye Movement Desensitization and Reprocessing) with a 50 year-old female with post stroke depression. They concluded that as verbal expression of information is not necessary for EMDR, the individual was able to process her story non-verbally and move forward with a worthwhile life. Furthermore, they reported an improvement in this individual's mood and her aphasia. Although they acknowledged this as anecdotal findings and hypothesised whether the reduction in depression had resulted in a greater ability to connect with others and therefore gain practice and confidence in communicating. Whilst this research was only with one person, the approach of EMDR for individuals with a CI and co-morbid psychological difficulties may warrant further exploration.

Stress induced deactivation in the Broca's area has been repeatedly implicated in the difficulty that trauma survivors have with discussing traumas and the Broca's area is often the affected area of language after stroke. A research study was carried out by Bessel van der Kolk (2006) using fMRI scans to measure two brain regions; the results indicated that when clients spoke about the trauma the Amygdala region became activated and the Broca's area went dim. As the participants spoke about their trauma there was a shutdown in their Broca's area. Levine (2010) describes trauma as 'wordless terror' and highlights the language barrier in traumatised individuals makes it important to work with body sensations rather than words. This is something to consider when working with an individual who has experienced trauma and/or a loss of communication. Interventions with reduced language and communication demands are likely to be more appropriate and effective (Sekhon, Douglas and Rose 2015).

There are a number of body and somatic type psychotherapies emerging, which may be well placed to meet the needs of individuals with CI. This is further supported by discussions in the literature regarding psychological intervention for adults *without* a CI. James, Southam and Blackburn (2004) note that in the past psychological therapists may have not fully understood that the term cognition involved a multitude of complex processing; rather than language. They discuss schemas and how these can be activated, both consciously and unconsciously, with memories that may have a range of cognitive and sensory triggers such as kinaesthetic and olfactory. With this mind, they highlight the possibility that just targeting language during psychological therapy could cause harm. They advocate a psychological approach that targets behavioural, sensory and experiential memories. Therefore, the literature is pointing towards more sensory based psychological interventions, which may be doubly appropriate for clients with a CI.

Furthermore, there is a growing body of literature related to music therapy and how it may be an effective treatment to use with individuals with a CI following brain injury, to address low mood and self-esteem difficulties (Magee, Brumfitt, Freeman and Davidson 2006).

There is also an emerging field of dance therapy which is found to be effective with adults with Parkinson's disease (Sharp and Hewitt 2014), and more recently with adults with dementia (Karkou and Meekums 2017). Further research could explore the use of dance therapy with adults with a CI. Again, all of these are areas of psychological intervention that counselling psychology could seek to explore, possibly alongside SLTs.

### **Which clinician is best placed to offer psychological and counselling support to people with communication impairments?**

Which brings us to the question of whose role it is to offer psychological or counselling support to adults with an acquired CI. When an adult acquires a CI, it makes sense that they would be referred to a SLT. SLTs are the clinicians trained and qualified to assess, diagnose and treat CIs (RCSLT 2017). SLTs are trained in basic counselling skills however research in 2011 highlighted that many SLTs may be missing opportunities to address psychological issues during communication therapy sessions (Simmons-Mackie and Damico 2011). This appears to be due to a number of reasons such as SLTs feeling unskilled or restricted by time. As a result, SLTs may deflect emotional conversations with humour or standard staged responses. Alternatively, they may shift focus to object based therapy tasks to meet NHS driven targets and objectives (Simmons-Mackie and Damico 2011). Research also suggests that growing demands from the NHS may actually sway therapists to focus on impairment-based interventions. This subsequently enables them to gather quantitative data in order to prove their effectiveness and justify their role.

Stein-Rubin and Adler (2017) noted that that during speech and language sessions there are 'missed moments' that could be counselling moments. These are considered to be moments in dialogue when opportunities to have a more intimate and probing conversation reveal themselves. Stein-Rubin and Adler suggest that SLTs may have fears of being overpowered, or be uncertain and insecure about dealing with the pain, worry and fear of the clients or patients. One must consider that whilst SLTs are trained in counselling skills their specialism

is communication and therefore their professional remit is to restore or facilitate functional communication. SLTs are skilled in facilitating and encouraging people to talk but counselling requires a deeper understanding of the psychological processes and the time to focus on these processes (Dalton 1994). Some may argue that by trying to meet every therapeutic need we run the risk of becoming 'jack of all trades, master of none'. Brumfitt (2006) noted that widening the scope of practice could create uncertainties over professional boundaries and roles and lead to potential confusion amongst clinicians.

Counselling services often follow a philosophy that 'people are people, regardless of their communication style'; however the literature suggests that SLTs are often reluctant to refer their clients onto counselling or psychology services due to a perceived lack of understanding and a fear that the talking therapists do not have the skills needed to support CI (Syder 1998). Research studying the psychosocial impact of living with post stroke communication difficulties concluded that speech and language interventions need to go beyond the CI to address and promote psychosocial well-being, reduce the likelihood of feelings of stigmatization and changes in self-identity (Dickson, Barbour, Brady-Clark and Paton 2008). However SLTs report not feeling comfortable to address psychological issues. A more recent study (Northcott, Simpson, Moss, Ahmed and Hilari 2017) looked at how SLTs address the psychosocial well-being of people with aphasia. The findings reported that 100% of SLTs use supportive listening but only 42% felt confident in addressing the psychological needs of their clients. The main barriers cited for this were time and caseload pressures, feeling under-skilled and lack of training and support. The main barrier to SLTs referring their clients to mental health professionals (MHPs) were that MHPs were perceived as under-skilled in working with people with a CI, that MHP's were difficult to access and that they only provided a limited service. The conclusion reached from this study is that more specialists are needed.

Some organisations such as Headway and the Stroke Association provide fact sheets explaining the CI and the emotional impact of this to an individual and their family members. The fact sheets often suggest that should the client require more support to

contact a counsellor, therapist or psychologist with specialist experience of their condition or impairment. However, an absence of discussion in the literature raises the question of whether talking therapists with specialist experience in this area actually exist and if they do, are they an 'exception' rather than the 'rule'.

In 2013 the Stroke Association published a report called 'Feeling Overwhelmed': the emotional impact of stroke. Their research stated that as many as one in three stroke survivors will experience aphasia. The report also highlighted the lack of psychological and counselling support available for clients after they have experienced a stroke even though statistically they are at a high risk of developing mental health difficulties. Stroke survivors interviewed for the report described being offered medication from their GP and 3 sessions of speech and language therapy but no other psychological support. Some described being given information that was too much for them to understand due to their CI. The report stated that one area was running a pilot scheme where a SLT was also trained as a counsellor and therefore clients with communication difficulties could be referred to this specialist therapist. However at the time this service did not appear to be offered anywhere else and even now in 2018 it is definitely not the norm throughout the UK.

An NHS Speech and Language Therapy Service report that existing counselling services are often inaccessible to people with CIs and therefore in many cases there is no counselling psychological support available for these clients (Wilkinson 2013). Subsequently many speech and language therapy sources suggest that clients with CIs may be falling between services, as neither profession feels skilled to offer the appropriate support (Breaking Through 2015). That said, this argument is strongly weighted from the perspective of the speech and language therapy services (Simmons-Mackie and Damico 2011) and there does not appear to have been any research into the matter from the perspective of the counselling psychology profession, which could indicate that these clients are not yet fully on their radar. Fairfax (2016) discusses neuropsychology and counselling psychology and suggests that counselling psychologists can offer something valuable in working with clients

with neurological difficulties. He highlights the importance of neuropsychological assessment for clients with a severe brain injury and how the assessment can bring psychological understanding ensuring that the client's voice is represented in circumstances where they cannot speak. However, he also notes that there may be some ambivalence amongst counselling psychologists about whether neuropsychology could medicalise therapeutic practice. Furthermore, at present, counselling psychologists are unable to access the neuropsychology training that could impede their opportunities to gain further training and qualifications in this area.

The literature suggests that SLTs are the clinicians that spend the most amount of time working with adults with CIs and are highly valued by these adults. However due to various reasons they are not exploring psychological issues. Tanner (2010) raises the issue that whilst SLTs learn about the neurology of CIs, the psychology is addressed minimally or neglected all together. He suggests that most text books about CIs refer to the psychological impact at the end of the book almost as an incidental after thought. In contrast, it is interesting to note that historically, counselling psychologists have not covered modules in neurology or neuropsychology. So perhaps we have two highly skilled professions but neither one feels skilled enough to fully meet these clients' needs. Or perhaps we need to dovetail these professionals' knowledge and experience to provide specialist tailored therapeutic services for clients with CIs.



## Research Rationale, Aims and Questions

The literature reviewed above suggests that research is emerging regarding the long-term psychosocial impact of acquiring a CI. This is certainly a move in the right direction, yet there still remains a distinct lack of in depth research into the psychological experiences of these individuals. The voice of people with CIs continues to be limited with published healthcare literature. No-one has asked individuals with an acquired CI in depth about their thoughts, opinions and emotional experiences. One might wonder how we can we truly tailor a psychological approach for these clients if we have never asked them about their psychological experience. It could be suggested that the people who have acquired the CI, and their families, could add significant knowledge and experience of living with a CI to psychological understanding and therapeutic practice. As already mentioned, it seems the communication difficulties may act as a barrier to researchers including them in studies (Wray and Clarke 2018). The literature suggests that research is limited due to perceived challenges in how to conduct a verbal interview with individuals with CIs. Research carried out in 2012 about the psychosocial well-being in persons with aphasia participating in a nursing intervention after stroke highlighted that *'persons with aphasia are systematically excluded from research projects due to methodological challenges'* (Bronken et al 2012). Hayley et al (2015) suggest that most studies have avoided direct input from people with a CI because it is felt that their CI may prevent them from responding confidently to customary verbal questionnaires and interview.

As mentioned in the literature review, Wray and Clarke (2018) carried out a synthesised literature review of the longer-term needs of stroke survivors with communication difficulties. The study highlighted a range of psychosocial difficulties and explored these in some depth. However it also acknowledged its limitations openly by stating that none of the studies had directly asked individuals about their needs and experiences. Analytical themes had been developed from reviewing the studies, which had resulted in 'inferred and theorised' suggestions about the needs of stroke survivors with communication difficulties.

The literature review strongly suggests that there is a clinical need for this study. Statistics highlight that since 2015, UK admission for head injuries have risen by 35.5 percent, with traumatic brain injury being considered the most common cause of disability in young adults aged 18 – 25 years (Seeto, Scruby and Greenhill 2017). The higher prevalence of head injuries is likely to result in more individuals acquiring a CI and therefore indicates a need to really understand the psychological of experience of acquiring a CI. Furthermore, the global burden of stroke is set to rise, and by 2030 there will be 70 million stroke survivors; approximately one third of which will experience communication difficulties (Wray and Clarke 2018). This will impact on healthcare and society at large and therefore we need a greater understanding of how to support these individuals.

### **Research aims**

The aim of the research was to interview adults who had acquired a CI in adulthood and obtain personal accounts of their experiences. The research aimed to gather data on these individuals' psychological experiences (i.e thoughts, feelings and emotions) from the moment they acquired the CI until the current day. The aim was to gather information about the whole spectrum of the person's experience; the ebbs and flows and everything in between so as to try and understand the psychological journey these individuals travel. Subsequently, an overall research aim was to gather information that could inform therapeutic practice for counselling psychologists and training for a range of clinicians in the context of working with adults who have acquired a CI.

### **Research questions**

The research was seeking to explore the following questions: What were the participants' memories of their thoughts and feelings at the initial onset of the CI? Who explained to them that they had a CI? What types of therapies were offered to them and what were their experiences of this? What was their overall individual journey since acquiring the CI and

how they have made sense of it? Have they noticed any positive changes since acquiring the CI?

## **Methodology**

The research was a qualitative piece of research. Whilst BPS (British Psychological Society) (2018) have recently reported restrictions of qualitative research in some journals, the researcher recognised the value of qualitative research in relation to the issue of acquired CIs. Black, Busby and Hitch cited by BPS 2018, suggest that few research topics related to health can be answered through quantitative research alone. Narratives enhance our ability to understand the lived experiences of others. The richness and insight can then inform others research or add value to quantitative research. The researcher felt it was important for these individuals' narratives to be heard, rather than have their experiences condensed and reported as statistics and numerical data; further silencing their voices. This further confirmed that qualitative research was the most appropriate choice.

Within qualitative research there are several methods of analysis and the researcher contemplated several of these in the process of planning the study. Narrative Psychology and Discourse Analysis type approaches were ruled out as these methods rely heavily on analysing large amounts of language from stories and narratives. Given that the participants all had a CI (several of which was aphasia) the researcher was aware that the amount of language gathered would be insufficient and therefore these approaches would not be utilised to their full effect, thereby potentially impacting on the quality of the research findings.

Grounded Theory (Glaser and Strauss 1967) was considered, as this was one of the first formally-identified methods for qualitative research (Smith, Flowers and Larkin 2009). The researcher acknowledged the lack of research into the psychological experiences of adults with CIs and therefore considered that a Grounded Theory method could seek to develop an

explanatory level account of the overall experience of these individuals. However, the researcher was also aware that Grounded Theory requires approaching the study without any theoretical perceptions. The idea being, that one does not know what is being studied until a significant amount of the analysis has been completed. The researcher felt that given her previous personal and professional experiences of CIs, it would be impossible to approach the research without any preconceived ideas of what may arise. Furthermore, the aim was to give the participants a voice and forum to be heard, rather than generate a theoretical account of the collective experience.

Thematic Analysis was also considered, as this approach seeks to find themes in data. The researcher wondered if Thematic Analysis may highlight commonalities between participants so as to try and draw some consensus from the experiences, which could inform therapeutic practice. However, the researcher was also aware that although Thematic Analysis may have highlighted themes and therefore 'sameness', it would not as easily show differences in experiences or difference in thoughts and feelings about an experience. For example – subtheme 3 d about the participants' experiences of counselling and therapy showed some variation in their experiences and perceptions of therapy.

After much consideration, IPA (Interpretive Phenomenological Analysis) was considered to be the most suitable approach in order to explore the depth and range of experiences. IPA is commonly used for analysing qualitative research often within health and psychology fields of study. It seeks to explore how individuals make sense of their major life experience in terms of their personal and social world (Charlick, Pincouber, Mckellar and Fielder 2016). The approach is phenomenological in that it attempts to explore an individual's personal perception rather than produce an objective statement of an event (Danvas, Bharmal, Keenan, Jones, Christaprasad-Karat and Kalyanaraman 2016). An adult acquiring a CI could be deemed as a major life experience with an impact on both their personal and social world.

IPA involves a two-stage process of interpretation known as double hermeneutic. That is, the participant trying to make sense of their world, whilst the researcher is also trying to make sense of the participant making sense of their world (Farrell, Keenan and Keubbs 2013). The approach requires the researcher to interpret peoples' mental and emotional state from what they say. It is then the duty of the researcher to make those interpretations explicit and open to challenge and modification (Danvas et al 2016). It assumes a chain of connection between peoples' use of language and their thinking and emotional state. However, it also recognises that it is impossible to gain an insider's perspective completely, as the process depends upon and is complicated by the interpretations of the researcher (Murray and Chamberlain 1999). In this particular study this is further complicated by the very nature of the topic, i.e. the participants had a CI, the majority of which was a language based impairment aphasia. The researcher gave this careful consideration in terms of the level, quality and quantity of language that was likely to be gathered and whether this would offer sufficient data to analyse and make sense of for research purposes. IPA as a method recognises that people struggle to express what they are thinking and feeling and therefore in this respect it allows space for the researcher to spend time analysing the language. The researcher gave this some thought and felt that her training as a speech and language therapist could lend itself in terms of conducting the interviews, gathering the data and analysing the language content. The language would need to be considered in context and analysed accordingly. For example – if a participant was unable to pronounce the word they meant but was able to express the meaning via another means such as gesture or writing, then the researcher would ensure that the meaning was interpreted rather than the mispronunciation. The mispronunciation needed to be considered in the context of a CI due to neurological damage rather than an unconscious Freudian slip.

Smith, Flowers and Larkin (2009) suggest between 4 – 10 participants for an IPA doctoral study. 5 participants with an acquired CI were interviewed. The researcher deemed this to be a suitable number of participants as due to the very nature of a CI and the likelihood of periods of silence and clarification, the interviews were likely to take longer. Furthermore,

the researcher needed time to reflect on the interviews to ensure that any breakdowns in communication due to the CI were not misinterpreted and therefore incorrectly analysed. This was particularly important in the context of aphasia when some participants were using a range of gestures, writing, facial expressions and words with grammatical and phonological errors. Smith et al (2009) suggest sufficient participants to provide development of meaningful points of similarity and difference between the participants but not so many that the researcher ends up becoming overwhelmed by the amount of data generated.

### **Role of the researcher in the research process**

The BPS (2017) advocate that counselling psychologists are reflective practitioners, aware of how their professional training and personal histories will inevitably form part of how they create meaning of an intersubjective experience. IPA aims to understand the world of the participant and holds that this understanding can only be achieved through the researcher's engagement with and interpretation of the participant's account. The analysis is therefore both phenomenological, representing the participant's view of the world, and interpretative, dependent on the researcher's own views and standpoint (Willig, 2001). The researcher will experience the encounter and see the material through their own lens of prior experiences, assumptions and preconceptions and cannot help but look at any new stimulus in the light of their own prior experience (Heidegger 1962). Reality is constructed as multiple subjectives realities and does not exist objectively (Hyland 2009).

### **Rationale for chosen methodology**

During the early stages of choosing the research topic the researcher considered several ideas and approaches. A quantitative approach for gathering data on the amount of people with CI who had been offered or accessed psychological or counselling therapy was considered. However the researcher was aware that this would simply gather more statistical data rather than the actual lived experience. The researcher believed that

qualitative research could give voice to those who may feel 'voiceless' in everyday life. By enabling the participants to share their experiences and express their thoughts, feelings and opinions there is the possibility that this will inform 'needs led' service provision and psychological intervention.

### **Implications of involving people with communication impairments in qualitative research and how challenges were met**

The researcher was aware that there were several factors to consider when working with participants with CI. Each participant's CI had to be considered individually to ensure that the researcher was able to pitch the interview with the appropriate level of language. Too complex could be confusing and unable to be understood by the participant but too simple could be patronising and miss the opportunity for an in-depth discussion about certain issues.

The following factors were considered:-

**Receptive language difficulties** – the researcher considered how much information the individual was able to comprehend in terms of both written and verbal language. This influenced how the research information and consent forms were presented and explained as well as how the interview questions were asked.

**Aphasia friendly documents** – participants were offered the information in aphasia friendly documents.

**Mobility** – The researcher was aware that all of the participants had not experienced their CI in isolation and therefore they were also experiencing physical difficulties which impacted on their ability to travel to and/or access some buildings. Where a face-to-face interview was carried out the researcher travelled to the participants.

**Fatigue** – The researcher was aware that many individuals can experience fatigue after a brain injury and therefore she stayed mindful of this throughout the interviews so as to ensure that they knew they could stop if they wanted to. She was also aware that fatigue (Coetzer and Balchin 2014) can impact on communication ability.

**Cognitive difficulties** – The researcher was aware of the cognitive difficulties associated with brain injury and how these can impact on communication and conversation such as memory and attention.

**Anxiety** – The researcher was aware that each participant was meeting her for the first time and therefore they may have been experiencing some anxiety. She was aware that anxiety can impact on communicative ability if the body is experiencing a physiological stress response.

**Potential negative emotions** – the researcher was aware that for some of the participants it may have been the first time they had been given an opportunity to explore their experience. The researcher considered the risk of ‘churning up’ old unresolved emotions. Furthermore if the CI was as a result of a trauma whether there were elements of PTSD present and if whether there was a risk of re-traumatising the individual. The researcher was also aware of emotional lability after brain injury.

**Recording the interviews** – the researcher gave some thought to the act of recording the sessions and the potential risk of evoking shame in the participant if they felt self-conscious of their CI. Subsequently, the researcher decided to make it very clear from the start of recruitment process that the interviews would be recorded and clarified confidentiality and anonymity. The participants were given time (approximately 1 week) to consider whether they wanted to participate and the researcher asked them again at the start of the interview. None of the participants expressed any concerns about the recording device.



All of these factors were considered prior to recruitment and managed accordingly during the interviews. All of the participants were told that they could be signposted to counselling services should they require this after the interview. None of the participants have asked the researcher to be signposted to further services as of yet.

## **Data Collection**

### **The Research Instrument**

The research instrument was developed over time in order to consider the level of language and how questions would be asked and answers explored.

The questions were asked by means of a semi-structured interview schedule (Appendix E). The same structure was followed for face to face interviews and email interviews. The semi-structured interview schedule began with some fact-finding questions related to the cause of CI and the amount of years living with the CI. The interview then moved on to a number of broad open-ended questions and prompts used to elicit narratives. All of this structure was 'scaffolded' with the use of Supported Conversation Strategies such as allowing time and silence, the use of writing, drawing and pointing, gesture, facial expressions, reducing language and checking understanding.

### **Participants**

A purposive sample was employed in that all of the participants were selected on the basis that they all had characteristics of a specific population (i.e an acquired CI) which was required to meet the objective of the study.

### **Inclusion criteria:**

**2 years post acquiring diagnosis of a CI** – Current rehabilitation research indicates that the greatest recovery occurs within the first 2 years post neurological impairment (Seeto, Scruby and Greenhill 2017). Individuals have usually been discharged from NHS services by 2 years and have been living with the CI for that amount of time. Taormina-Weiss (2013) writes about the psychological and social aspects of disability and describes a CI as an invisible disability. Taormina-Weiss (2013) suggests that a person may move through up to 12 emotional stages after acquiring a disability. These stages range from shock at the beginning through to adjustment listed as the final stage. Psychological research also indicates that humans adjust to a cycle of change over the process of 2 years (Seeto et al 2017). The researcher aimed to interview participants that were nearer to the adjustment end of the spectrum or cycle of change although recognised that this is not rigid and absolute. The aim was to find participants who would be able to reflect on their overall psychological experience of acquiring a CI.

**Over age 20 years** – this is because the study is looking at acquiring a CI as an adult and 2 years post acquiring the CI i.e 18 years + 2 years = 20 years.

**Receptive language intact sufficiently to understand simple sentences of at least 5 words** – the researcher was aware from her experience as a speech and language therapist that in order to ask the type of questions needed to explore this topic, the participants needed to have a baseline level of verbal comprehension to understand the complexity of some of the questions.

#### **Exclusion criteria**

- Participants that did not have a diagnosed acquired CI were not invited to participate.
- Participants that the speech and language therapist assessed to be emotionally vulnerable were not invited to participate.
- Participants with weak receptive language were not invited to participate.

## Participant information

**Table 1: Overview of Participant Information**

| Participant Number | Demographic Information  | Therapy Information                                 | Type of CI                         | Cause       | Age CI acquired |
|--------------------|--|---|------------------------------------|-------------|-----------------|
| Participant 1      | Male<br>57 years old<br>White British<br>Single and living alone independently | Currently engaged in counselling through GP surgery | Broca's aphasia                    | Stroke      | 52 years        |
| Participant 2      | Male<br>65 years old<br>Living with wife<br>White British                      | Not offered counselling                             | Anomic aphasia                     | Stroke      | 57 years        |
| Participant 3      | Female<br>50 years old<br>Living with husband<br>White British                 | Not offered counselling                             | Broca's aphasia                    | Stroke      | 45 years        |
| Participant 4      | Male<br>49 years old<br>Living in nursing care<br>Maltese                      | Not offered counselling                             | Locked in syndrome                 | Stroke      | 32 years        |
| Participant 5      | Female<br>56 years old<br>Living at home with family<br>White British          | Paid privately for counselling                      | Cognitive Communication Impairment | Head injury | 50 years        |

## **Ethical Considerations**

### **Ethical Approval**

This researcher received ethical approval from the Faculty Research Ethics Committee (FREC) at the University of the West of England for this project.

### **Consent process**

The three participants with aphasia were recruited via a senior lecturer and speech and language therapist at a university in the South West of England. The participants were attending a reading and writing group for aphasia delivered by the lecturer/speech and language therapist. She made the assessment that they met the criteria and gave the researcher a summary of their level of receptive and expressive language. The lecturer/speech and language therapist made contact with the suitable participants to ask whether they would be interested in taking part. If they agreed then the researcher made contact with them to arrange a date and time for an interview. The participants were sent an aphasia friendly participant information sheet (Appendix C) and consent form (Appendix D) prior to the interview. The aphasia friendly documents were designed and created by the researcher following guidance from the Stroke Association (2016) and the Royal College of Speech and Language Therapists. The other two participants with CIs were recruited via a brain injury forum on social media. The participant with the cognitive communication impairment was offered the aphasia friendly documents and the participant with LIS was offered both aphasia and non-aphasia friendly documents (Appendix A and Appendix B).

All participants signed consent forms or sent a confirmatory email to confirm that they had read and understood the participation information and consent form, before the interview. All participants with CIs had previously been assessed by a speech and language therapist and there were no issues indicated relating to mental capacity to consent.

The two email interviews took place over the course of several weeks. Both participants had supportive partners who spontaneously and voluntarily made contact with the researcher to confirm that their partner was happy to participate. The researcher made a point of establishing a consistent Yes and No response before each interview and then kept checking in with the participants throughout the interviews both face to face and by email. The researcher asked *“is it ok to ask you some more questions about this?”* and *“are you happy to continue”*. These were closed questions that only required the participant to respond with yes or no. The researcher also made it clear to the face to face participants that if they wanted to stop at any time or did not understand what was being said to raise their hand as a gesture to ask the researcher to stop or pause. The researcher also made a point of double checking the participants understanding if the question was more abstract or complex in nature.

### **Right to withdraw**

Participants were informed that should they wish to withdraw from the study during the interview they could. This information was initially given via the participant information sheet in an aphasia friendly and non-aphasia friendly formats. The advice was explicitly repeated after the interview had taken place. They were reminded that should they wish to withdraw within 3 weeks of completing the interview they could email the researcher or the Director of Studies and their data would be removed. Two of the participants asked for their narrative about specific sensitive pieces of information not to be written verbatim in the final document. They were happy for the information to be considered as part of the overall analysis but they asked not to have their specific quotes documented in the thesis. Their requests were respected, acknowledged and confirmed by the researcher. The researcher

made a judgement that these requests would not impact on the overall quality of the data as it only accounted for approximately two sentences of the overall narrative. The researcher's thoughts and feelings around this will be discussed in the reflexivity section.

### **Confidentiality**

The researcher ensured that any names used throughout the interviews have been removed from the transcripts (i.e names of people such as partners, family members or staff members and names of places such as rehabilitation centres, hospitals and places of work). This is to ensure that there is no information that could make the participant or their family identifiable.

Over the course of this research personal information about the participants such as email addresses, telephone numbers and personal addresses. This information is stored on a password protected spreadsheet on a computer that is not shared with anyone else.

The audio data was kept on an encrypted memory stick and stored in a locked cabinet in a locked room. The researcher is the only person to have access to this data. The email interviews are stored within password protected email file on a computer that is password protected with virus protection and not shared with anyone else.

All of the personal information and audio recordings will be destroyed confidentially once the research has been completed.

### **Recruitment**

Three of the participants were identified by an experienced speech and language therapist who was also a senior lecturer in speech and language therapy. She identified participants that met the inclusion criteria and asked them if they would be interested in participating. If they agreed, then the researcher made initial contact with each participant to confirm their interest.

Two of the participants were recruited via a brain injury support group. One provided information via his website to confirm diagnosis of his CI. The other showed a copy of a speech and language report confirming her diagnosis of a CI. Both confirmed that they were happy to participate. There were no concerns regarding emotional vulnerability.

### **Interview Process**

Participants that were interviewed face to face were interviewed for approximately 1 hour in their home environment. Participants that were interviewed via email were interviewed over the course of a few weeks. The face to face interviews were recorded digitally on an encrypted memory stick. The email interviews were stored in date order.

### **Risks and Risk Management**

The risk element of this study was assessed as relatively low, however as acknowledged above the researcher needed to be aware of the some of the implications associated with CIs. With this in mind the researcher implemented the following actions throughout the whole research process:

- The researcher established a consistent yes and no.
- Participants were reminded at the beginning and during the interview that they could refuse to answer any questions and stop the interview at any time. They were also given the option to do this via a gesture in case they felt unable to verbalise their request.
- The researcher monitored the participants for signs of distress such as changes in body language, pace of breathing and engagement, with an awareness that the interview could be stopped and closed down in a safe and calm manner.

- None of the participants opted to terminate the interview, although if this had occurred, the researcher would have offered the participant a debriefing session or a grounding activity to alleviate distress before leaving interview setting.
  
- The researcher aimed to finish the interview on a positive note and a topic of joy for the participant. The researcher also spent approximately 10 – 15 minutes engaging in small talk (not recorded) at the end of the interview. Firstly, this was to monitor whether the participant was experiencing any distress and secondly to bring their mind back to a lighter and fun topic. The researcher considered the Recency Effect (Miller and Campbell 1959) and how the participants may be more likely to remember the more joyful aspects of the conversation once she left them. Furthermore, if they had been feeling anxious or distressed during the interview then it gave an opportunity for their nervous system to settle and to return to a calmer state free from interview questions about a potentially difficult area.
  
- All of the participants were sent a thank you card or letter approximately 1 week after the interview with a reminder of contact details and participant information.

### **Transcription**

The interviews were transcribed verbatim in line with issues of privacy and confidentiality of data handling and storage and in line with UWE policy and procedure.

### **Data Protection**

The anonymised typed transcripts and digital recordings were stored in line with UWE policy and procedure as agreed by the university ethics board during the progression process of the research.



In terms of confidentiality and data protection, consent was gained to use verbatim extracts from the interviews in any write-up with the reassurance that all identifiable information would be removed to ensure anonymity. All data gathered by the project: written, electronic and audio-taped, was kept securely with reference to guidance from the Data Protection Act (1998). Data shared with the research supervisors was anonymised. On 23rd May 2018 the Data Protection Act (1998) was superseded by the Data Protection Act 2018 which supplements the General Data Protection Regulation which came into effect on 25<sup>th</sup> May 2018. No further data was collected or stored after this date.

### **Data Analysis**

IPA was used to understand the content and complexity of meanings. Smith et al (2009) noted there was no prescribed single 'method' for analysing data using IPA. The researcher found the process of analysis was not linear and was a mix of logical, creative, intuitive and academic processes. The researcher followed the steps to analysing IPA as advocated by Smith et al (2009):-

- **Reading and re-reading** - the researcher began the data analysis by reading and re-reading each transcript so as to become familiar with the material.
- **Initial Noting** – the researcher started to make pencil notes on the first transcript related to aspects of language and semantic content. In line with Smith et al (2009) steps she made notes of descriptive, linguistic, conceptual comments.
- **Developing emergent themes** – the researcher sought to establish emergent themes that captured and reflected the participant's experiences.
- **Searching for connections across emergent themes** – the researcher started to explore how the themes may fit together.

- **Moving to the next case** – the researcher then repeated this process with each transcript.
- **Looking for patterns across cases** – the researcher looked at all of the themes and analysed for potency or connections in themes.

Throughout the process of data collection, transcription and analysis the researcher regularly made space to reflect on her thoughts and feelings about the data. This reminded her to stay open-minded and enabled her to consider the implications of personal and epistemological assumptions about the research.

## **Reflexivity**

While IPA aims to explore the participant's experiences from their perspective, it recognises that such an exploration cannot easily be separated from the researcher's own view of the world, and the nature of the interaction between researcher and researched (Willig, 2001). Therefore it is important to engage in what Wilkinson (1988) terms 'personal reflexivity' which involves reflecting on prior assumptions that the researcher may hold about the area of investigation and what motivated that researcher to engage in that topic in the first place. The researcher aims to explicitly highlight the influence of previous life experiences on gravitating towards this research topic and in response to this how this was considered throughout the research process.

The researcher is a qualified and experienced Speech and Language Therapist who worked in the NHS Service and private sector for approximately 8 years. Therefore, the researcher worked with clients with CIs on a daily basis. Furthermore, the researcher's mother (deceased) had a traumatic brain injury and as a result lived with aphasia for approximately 14 years. The researcher accepts Heidegger's (1962) assertion that a person can only view

another individual's experience in light of their own prior experiences. Thus, by making these assumptions explicit, readers of this thesis can make their own judgments as to issues of quality. The researcher is aware that the previous personal and professional experience of interacting with people with a CI can be helpful in terms of utilising skills and knowledge to support conversation. However, the researcher is also aware that previous experiences of hearing clients and her mother talk about their experiences of acquiring a CI are likely to have been a motivating factor in carrying out this research. When carrying out the interviews and analysing the data the researcher had to continuously find the balance between being a speech and language therapist, a counselling psychologist and a researcher. The fact that the researcher had training and skills in each area offered uniqueness and weight to the nature of the study. However, there was also a risk that the researcher could end up jumping between roles, potentially losing sight of the main researcher role.

Furthermore, the researcher had to be mindful of the impact of her personal experience when interviewing the participants. The researcher approached the interviews with an aim to not ask leading questions based on previously held beliefs or assumptions that she may have acquired through her own personal and professional experiences. The whole aim was to give the participants space to express their own thoughts, feelings and experiences whatever these may be. Being a psychologist the researcher also aimed to be aware of any counter-transference that might play out in the room if she was presented with a female with a similar CI to her mother. The researcher was aware of the importance of not feeling pulled into acting as a therapist, parent figure or a child. Counselling psychologists undergo personal therapy as part of their training together with a continuous emphasis on self-awareness skills. Subsequently the researcher felt equipped to stay mindful of these factors and discuss with her research supervisor or personal therapist should it have been required.

In relation to the right to withdraw section the researcher considered the impact of participants asking for sentences to not be quoted. The researcher considered this an interesting factor in terms of psychodynamic theory; an aspect of counselling psychology

practice. The researcher considered her feelings about the minor censorship and considered this could be a contribution to the overall discussion in terms of a feeling of being silenced and unable to express all of the words. This would certainly echo aspects of living with a CI and may warrant further exploration.

## Results and Discussion

The aim of the study was to explore the psychological experience of acquiring a CI and the 4 themes that emerged appeared to chart this experience from the initial stages of acquiring the CI through to a place of adjustment, coping and enjoying new aspects of their lives. The following table charts the 4 themes that emerged from the interview data.

|   |  |
|---|--|
| <p><b>Super-ordinate Theme 1:</b><br/><u><b>The unconscious/conscious experience</b></u></p>      | <p><b>Sub-theme 1a:</b><br/>Hearing others but unable to talk</p> <p><b>Sub-theme 1b:</b><br/>Feelings of fear</p> <p><b>Sub-theme 1c:</b><br/>Weird, isolated and not knowing</p> |
| <p><b>Super-ordinate Theme 2:</b><br/><u><b>Finding an alternative way to communicate</b></u></p> | <p><b>Sub-theme 2a:</b><br/>The motivation to keep communicating</p> <p><b>Sub-theme 2b:</b><br/>The experience of communicating through another person</p>                        |

|  |  |
|--|--|
|  | <p><b>Sub-theme 2c:</b></p> <p>The significance of clinicians who take time to communicate and listen</p>  |
| <p><b>Superordinate Theme 3:</b></p> <p><u><b>The emotional journey</b></u></p>  | <p><b>Sub-theme 3a:</b></p> <p>The experience of loss and difficult emotions</p> <p><b>Sub-theme 3b:</b></p> <p>The challenges of living with a CI</p> <p><b>Sub-theme 3c:</b></p> <p>The experience of living with a CI within in society</p> <p><b>Sub-theme 3d:</b></p> <p>Thoughts and experiences of therapists and counselling</p> |
| <p><b>Superordinate Theme 4:</b></p> <p><u><b>Finding coping strategies and new activities as part of their recovery</b></u></p> | <p><b>Sub-theme 5a:</b></p> <p>The significance of writing</p> <p><b>Sub-theme 5b:</b></p> <p>The joy of singing</p> <p><b>Sub-theme 5c:</b></p> <p>The benefits of humour and laughter for psychological well-being</p>   |

|  |   |
|--|---|
|  | <b>Sub-theme 5d</b><br>Finding the positive in their experience |
|--|---|

### **Super-ordinate Theme 1: The unconscious/conscious experience**

This theme relates to the fragmented experiences of being unconscious and conscious and how these experiences have been held in their memory. All of the participants were asked to recall the moment when they realized that their communication ability had changed and they were unable to talk in the same way. The aim was to pinpoint the first thoughts and feelings that occurred at the initial time of being unable to verbally communicate. When recalling these memories, all of the participants described the experience with a mix of their own memories and part narratives told to them by loved ones, relatives or health professionals after the event. Their descriptions were interwoven with references of being unconscious or in a coma for several days. The personal memories of their initial experiences were made up of significant moments often associated with an ICU (Intensive Care Unit) or a hospital environment. The participants' own memories which were often related to sensory experiences such as sounds, temperature, touch and visual memories of images or objects. These narratives suggest that the participants have been left with an embodied sensory memory of the experience. Gaps in their memory relating to facts such as dates, times and medical procedures have been 'filled in' by others who observed the experience from outside of their body. This is illustrated in the following examples: -

**Participant 5:** *"Was in coma for some days I think. My husband say...I was coma...in...in coma...oper...op..popper..opratiion.....on head. All I remember was hearing sound of the...the beep beep....beep beep...machine...horrible... intens...intensive care... and boots on feet...feel hot...so hot...sleep...wake...beep and hot boots...wanted them off".*

The participant had a very powerful memory of the sound of the equipment in the ICU and the feeling of the 'boots' used to prevent DVTs. As she described these auditory and sensory memories her facial expression changed to one of 'disgust' and 'fear' possibly signalling some psychological arousal and emotionally charged memories. In contrast, when she described her husband's account of the coma and an operation to remove part of her skull, she seemed emotionally disconnected to this part of her experience, perhaps because the memory is unconscious or not her own memory of the experience.

Similarly, in the next narrative from Participant 3 we can see that much of her narrative consists of her husband's recollection and account of the experience. She can remember going in and out of consciousness but it would seem that the gaps in her memory have been filled by her husband providing a narrative of when and what he did during this time. This interview was done by email and therefore there was no non-verbal language to observe.

**Participant 3:** *"I was comatose (my husband's account) for 3 days; I remember going in and out of consciousness every few days... [...] ... my family were contacted – my husband made up his mind to get my speech back... [...] as soon as [husband's name] saw me gain consciousness, he attempted to describe to me that I'd had a stroke."*

One may consider how an individual makes sense of this mix of conscious and unconscious information. Does the narrative offered by their husbands help them to recall the experience in a concrete manner? That is by having some of the gaps filled does this enable them to process the whole experience in some way or does it create confusion when trying to integrate sensory information and another person's memories. Both parties will have been experiencing the event from different perspectives and levels of awareness.

In the next example, the participant recalls his memory of the conscious and unconscious experience.

**Participant 4:** *"It was early evening when it happened. Suddenly everything began spinning and I had to sit down not to fall. I wasn't in any pain. Suddenly I saw everything spinning and I began shouting for help. [name] came in and I collapsed in his arms. Soon an ambulance had arrived. In the ambulance they cut my new dark blue polo shirt. At some point I must have had difficulty breathing as I was breathing with a balloon-like thingy. Eventually I got to hospital. The medics still thought I was unconscious. The ambulance medic took his balloon and left. This was my last memory. Shortly after I lost consciousness. I went into a coma soon after."*

This participant described a powerful mix of sensory experiences from the initial feelings of everything spinning and collapsing into another human being's arms. His use of the word 'new' in the description of having his dark blue polo short cut off suggests that the memory of this shirt is significant for him. Perhaps that the shirt was new and/or the last thing he was able to dress himself in. Perhaps the colour of the shirt has an emotional significance in that it was his last memory of being dressed as a man who would talk. Perhaps it was the experience of having something cut off him. His description of the 'balloon like thingy' suggests that he does not have any conscious memory of not being able to breath but that the memory of the piece of equipment fills in a gap in his memory of the events. The sentence *"the ambulance medic took his balloon and left"* creates a sense of a clear ending to the narrative of his conscious experience. As if the medic leaving the scene was the end of a performance before the curtains were closed.

The last example further illustrates gaps in the memory of being unconscious and conscious. Participant 1 has difficulty remembering everything and the gaps in his memory have been filled in with his carer's memories of the event.



**Participant 1:** *"...and I fell over. My beer went like that on the floor. How or what I don't know... [...] ...He (the paramedic) was there for a long long time to get me because I was away at one time [gesturing as if unconscious]. I was two hours.... [name of his carer] told me that... [...] ...I remember hospital when they come and seen me, they come and seen me and then they went and well I can't remember really"*

### **Sub-theme 1a: Hearing others but unable to talk**

When describing their initial experience in hospital several of the participants recalled the experience of being able to hear everything that was being said around them but being unable to talk. This created a feeling of paralysis or being in a separate world. The world carrying on around them and 'to them' but they were unable to verbally communicate or interact with the world around them.

**Participant 3:** *"I couldn't speak – so I couldn't verbalise how I was feeling. I could understand my husband and the medics perfectly – but not communicate with them".*

**Participant 4:** *"Although everyone thought I was unconscious, I could in fact hear (and understand) everything that was going on around me. When I was taken to hospital I was immobilised (I couldn't move or talk) but could hear perfectly. The doctor saw me, he said "this one's gone" ...gulp."*

These quotes illustrate a sense of powerlessness with no voice to express what they were feeling. Participant 4 uses the word 'gulp' to describe his experience of hearing the doctor refer to him with an inference that he was about to die. This one word of 'gulp' illustrates a sense of fear and paralysis. He describes being 'immobilised' and at that time perhaps the only thing he could physically do was to swallow. The word 'gulp' creates a sense of having to just swallow the fear into the body as there was no other way of responding or expressing his feelings. This quote also raises the question of whether this is a lack of awareness and

understanding of receptive language amongst healthcare staff. It suggests that there is an assumption that because the person was immobilised and unable to move or talk that he was devoid of the ability to understand, comprehend, feel and remember. Furthermore, it highlights that this participant experienced a lack of compassionate communication from the clinician. Research by McElroy and Esterhuizen (2017) highlights that the clinician-patient relationship depends upon the patient's willingness and ability to communicate. Therefore, as this participant was completely unable to communicate, he was unable to show his willingness and therefore he was unable to form a relationship with the clinician. This may have stopped him from experiencing compassionate communication which suggests the possibility that there may be a need for a greater understanding of CIs amongst emergency clinicians.

The next excerpts captured the powerlessness of the person in that they are able to hear and feel but they unable to let the doctor or nurse know what they want or need. In the process, they experienced pain but were unable to express this.

**Participant 5:** *"The doctor kept pressing here [participant pointed to left collarbone] and I hear her say 'Mrs [name] can...can...can...you feel this?'...ow....it really hurt...I felt it but...I just could...could...couldn't say anything"*

**Participant 4:** *"The oxygen mask... I remember the strap of the mask was on my ear and hurting me. I had no way of telling the nurses or moving it."*

There is a sense of 'unintended torture' playing out in these comments. The participants physically and verbally unable to express their experience of pain or that something is hurting. These participants were completely helpless in this situation. In Participant 5's case, it is likely that the clinicians were trying to check responses in line with the Glasgow Coma Scale and will have had a medical protocol to follow in terms of level of consciousness and preserving life. However, the fact that the participant could still very clearly remember and describe the experience suggests that it had a negative psychological impact. Participant

4 describing being unable to tell the nurses that his mask was hurting highlights the powerlessness and helplessness of his situation. Some research suggests that if a person experiences helplessness at the time of a trauma and the biological effects of being unable to escape can lead to profound psychological changes such as those seen in PTSD (Jones, Backman, Capuzzo, Egerod, Flaatten, Granja, Rylander and Griffiths 2010).

### **Sub-theme 1b: Feelings of fear**

All of the participants described their memory of realising that they were unable to verbally communicate and the fear they experienced:

**Participant 4:** *“When I woke up...I couldn’t move or talk. I was terrified. I was surrounded by people I don’t know, completely paralyzed and unable to talk. I was terrified because I was convinced that I was being kept alive so that they could harvest my organs. It was quite a harrowing and terrifying experience”.*

**Participant 3:** *“I couldn’t speak –.... but [husband’s name] knew me well, and he could see how much fear I felt... [...] ... I guess the underlying fear was whether I’d ever walk and talk again”*

Both of these participants make reference to their communicative and their physical limitations which emphasises the whole-body experience. Participant 4 describes his fear related to having his organs removed. This illustrates the level of fear in being unable to protect oneself in anyway i.e. unable to push someone away or run away or to tell them no. He states that he was completely paralyzed and one can only assume that his level of fear was at a high level. A stress response will trigger us to fight or flee and as he was unable to do that, suggesting he was placed into a frozen stress response both emotionally and physically. Both of the quotes highlight the intensity of the experience and suggest a feeling of having to just sit with the fear perhaps resulting in a frozen state.

The next quotes illustrate the fear activated when the participants realised their speech was not the same as before. They were able to make sounds but the words were incoherent.

**Participant 5:** *"I couldn't say...breakfast...nurse just look me blank.... I try to say tea but words come out wrong. I thought...what's wrong with me? What if she thinks I'm mad? I was so frightened. Thought I might be locked up".*

**Participant 1:** *"I scared...I couldn't speak...didn't talk [mimes opening and closing mouth] ba ba ba... I think things were coming out but I cannot remember".*

**Participant 4:** *"I was very, very scared. I could not use the buzzer and because of the trachy, I could not make noise".*

Some of the descriptions they gave about changes in their heart rate and racing thoughts suggest that due to a feeling of a potential threat, their nervous system activated a stress response. This is a physiological response to potential danger. When someone experiences a potential threat to their safety their body will excrete cortisol and adrenalin to respond to the potentially life threatening situation (Jones et al 2010).

**Participant 5:** *"Every hour doctor or nurse comes round the bed. They say "what's the year?...or "who prime minister?". I was so frightened [puts hands on chest and takes a deep breath]. Heart would beat so fast. Thought...thought...if I get wrong or can't say...then won't be allowed home...will be locked up".*

This participant later shared her experience of seeing her father sectioned in the 1960's for mental health difficulties. She had memories of his speech slurring and this childhood experience had set up a belief in her mind that being unable to speak fluently resulted in being sectioned or 'locked up'. Her sudden loss of communication had triggered some of her childhood memories and yet she was unable to express or discuss this with anyone. This

touches on the importance of considering a person in the context of a life span psychological experience, rather than just since the neurological event.

Using gesture, participant 1 also described a change in his heart rate in relation to speaking and fear of saying the wrong thing.

**Participant 1** *“because I can’t say what it is, it doesn’t work...I feel [gesture of his heart beating faster]”*

These quotes highlight the anxiety provoking nature of being unable to communicate easily. Anxiety can also impact on a person’s ability to think straight and communicate effectively and therefore it maybe that the impact is circular. Could it be that at this stage of their experience, some may have benefitted from some compassionate words such as *“I know this may be frightening but we’re going to help you find a way to say what you want to say”*. This could offer some support and/or reassurance to the individuals and potentially offer them some positive thoughts and reduce some of the fear. Furthermore, perhaps the individuals may benefit from some simple guidance on diaphragmatic breathing to reduce their physiological experience of the fear.

### **Sub-theme 1c: Weird, isolated and not knowing**

The participants were asked how it felt to be unable to communicate easily and yet still be able to hear and witness the world around them. The responses gave a sense that the participants had felt cut off from the real world perhaps in a surreal space or frozen in a space or time. Participants 3 and 5 used the word ‘weird’ which suggests a surreal, out of body or out of world experience. They were left holding their fear wrapped in uncertainty and not knowing.

**Participant 3:** *“I felt weird... [...].It was like my whole life was another life, somehow and I had reached another phase in my existence”*

**Participant 5:** *"I didn't know what was happening. Faces had like...had a mist around them...it was weird...I could see mouths moving but I was away from it".*

**Participant 4:** *"When I woke up, I had no idea where I was and why.... It is unreal"*

**Participant 2:** *"Isolated. Not knowing. Nobody sit down and say what was happening."*

**Participant 1:** *"I didn't know, I didn't know what was happening"*

All of the participants communicated a sense of the solitary feel of the experience. We need to consider the many factors that may have contributed the way in which the participants experienced the event. Some of the participants had undergone surgery and therefore there is likely to have been anaesthesia in their system. Jones et al (2010) highlight that whilst in ICU a patient's ability to process information is likely to be compromised by a number of factors such as critical illness, delirium, sleep deprivation, sedative drugs and opiates. Depending on the person's history there may have been a level of dissociating from the trauma. Furthermore, their body may have experienced a level of shock hindering their cognitive ability to process and make sense of what was occurring at the time.

## **Discussion of Super-ordinate Theme 1**

Research highlights that the fragmentary nature of the memories from the time ICU and a high proportion of delusional memories and hallucinations that are recalled afterwards make it difficult for patients to make sense of what has happened to them (Samuelson 2011). The memories are frequently described by patients as very vivid, realistic and frightening (Jones et al 2010). This is considered to prevent psychological recovery and lead to the development of PTSD (Wake and Kitchener 2013). However, there is very limited references to the perspective of a person with a CI. Sutt (2017) describes that patients in ICU have associated the inability to verbally communicate with social withdrawal, leading to

depression, lack of motivation to participate in care, poor sleep and increased anxiety and stress levels. Research in 2017 (Olsen, Nester and Hansen) highlighted that during an ICU experience *'to understand and be understood was perceived as crucial'* by patients. Whilst they did not make any reference to CIs they noted the impact of nursing staff who were deemed as 'foreign' and unable to communicate in a manner that was easily understood. The impact of this language barrier was said to impact on the patient feeling safe within the ICU.

The data gathered from the participants gives a feel of perhaps a surreal experience made up of conscious memories and part narratives from others. There is language highlighting the presence of fear and 'not knowing' during the initial stage of acquiring the CI. Some of the dialogue describing an increase in heart rate suggests that body was experiencing a threat and therefore a physiological stress response was activated. The participants were able to remember some of the specific fears such as having organs removed without the consent or being assessed as having a mental health diagnosis. Whilst these specific fears are all different, they all have a common theme: a fear of losing basic human rights related to the body and independence. The participants were unable to express this fear or ask questions and in several cases, were physically unable to move to defend themselves or flee the scene. There is a feeling of life carrying on around them as if they are in a 'bubble' and unable to talk. Simultaneously they are trying to process what has happened to them and make sense of where they are and why they are unable to function in the same way. In all of these cases, one could argue that their stress response could have been reduced by the medical or health professionals offering compassionate communication. The fact that the participants can recall dialogue that the hospital staff used suggests that there was the potential to have heard compassionate or reassuring sentences if they had been used. Of course, we need to consider and respect that the medical professionals work within a professional remit to preserve life in a fast-paced clinical environment and therefore the clinical decision making will have been focussed on working quickly to restore the human body. However, does this data suggest a need for training within emergency and hospital

wards perhaps in the compassionate use of language. This raises the questions that if compassionate language was used and this activates a soothing response in the person could this minimise the likelihood of post intensive care syndrome and PTSD symptoms in later years.

Research in Sweden into the psychological impact of spending time in ICU highlighted the need for increasing collaboration between ICU staff and staff in other units to reduce patients psychological suffering post ICU (Haraldsson, Christensson, Conlon and Henricson 2015). They note the positive impact of counselling or follow up sessions after their experience of ICU in order to process what happened. Follow up sessions are reported to have a positive effect on the individual's rehabilitation and recovery (Samuelson and Corrigan 2009). The literature makes reference to individual's experiences of being unable to communicate as a cause of stress during their time in ICU and also suggests that the follow up sessions would give them the opportunity to understand their experience and put this knowledge into words. However, again we need to consider what happens if the individual is unable to put this knowledge into words. As counselling psychologists, we need to find a way for these individuals to express this new knowledge and learning.

### **What could counselling psychologists offer in ICU?**

Counselling psychologists could model compassionate communication through their presence on ICU and when interacting with patients who are unable to verbally communicate. Counselling psychologists could provide training to a range of clinicians in the purpose of compassionate communication to create feelings of safety within ICU and hospital wards. Perhaps joint delivery of training sessions with a SLT in order to explain receptive and expressive language and consider this within the context of coming in and out of consciousness.

A randomized controlled study in 2010 concluded that the use of an ICU diary with photographs helped to fill in the gaps in patients' memories and reduce depression and anxiety in the long term (Jones et al 2010). Writing and maintenance of a diary by ICU staff



and relatives has been shown to be a valuable document to patients for helping them to gain insight into their experience and fill memory gaps, during their recovery (Haraldsson et al 2015). Counselling psychologists could play a pivotal role in introducing, explaining the purpose and modelling a consistent use of diaries within an ICU.

### **What could counselling psychologists offer after ICU?**

Research showed that many individuals who have been in ICU have psychological difficulties and a greater need for contact with a counsellor or psychologist after the ICU experience (Jones and Lyons 2003). Further research indicates that individual's memories of their time spent in ICU can change over time but that the emotional effects such as anxiety appear to remain (Haraldsson et al 2015; Rattray 2010). It is suggested that follow up sessions or counselling can assist in dispelling unpleasant memories or reinforcing pleasant memories. The counselling sessions provided them with the opportunity to process the time spent in ICU more easily and develop coping strategies. Again, there is nothing specifically related to individuals with CIs but we can consider their psychological experiences of ICU as having some similarities with the general population of ICU patients.

When working with clients with a CI, post ICU, the counselling psychologist may find it helpful to consider what the client might have experienced at the initial stage of acquiring the CI. The level of trauma and 'powerless' and 'helplessness' they experienced and whether there are any embodied sensory memories triggering flashbacks. If the client is feeling stuck it may be helpful to consider a timeline of events to chart their conscious and unconscious memories in order to help them process the experience and make sense of the memories and physical sensations. If they have a diary from ICU this may help them to process information and be a helpful tool during psychology sessions. Due the nature of them losing communicative and physical ability their stress response may have been a '*frozen*' response and therefore the fear and emotions associated to the trauma may be held in the body. This further emphasizes the needs to consider somatic based therapies rather than just a talking therapy. Furthermore, the quality that came out in the theme of '*hearing but being unable*

*to talk'* suggests that therapy needs to create a space for the individual to express their feelings and really be heard. An aim of therapy could be to focus on 'being with' the individual rather than 'doing to'; seeking to heal some of the trauma experienced in the early stages of acquiring the CI.

## **Superordinate Theme 2: Finding an alternative way to communicate**

The participants described the initial ways in which they attempted to communicate. This quote highlights the significance of competent conversation partners and an understanding of CIs within clinical environments. The success of the communication depends on the communication being received and understood by another.

**Participant 4:** *"The total lack of communication was obviously a major problem. At that stage I could not even nod for yes or move my head to the side for no. It was frustrating for both my nurses and me. Then somebody came up with the bright idea that one blink is yes and two means no. Problem was that nobody waited for the second blink! Naturally it did not work properly and it was discarded. All I wanted was to be comfortable – but had no way of saying so."*

This quote highlights the importance of healthcare staff understanding the significance of a reliable and consistent communication system. The communication system being discarded impacted on the participant's basic human right to be comfortable. It highlights the importance of finding a way for the person with the CI to indicate a consistent 'yes' or 'no' as a starting point in the communication process. This was evident in the case of Participant 3.

**Participant 3:** *"My husband provided me with cards saying 'Yes' and 'No' and that really helped me"*

It is interesting to note that the participants found themselves reverting to what can be classed as pre-verbal linguistic skills. These skills involved using movements of the body, gestures or facial expressions to get their needs and wants met. For example, turning of the head which can be seen in new born babies to indicate whether they want to feed or not (Child 2006; Sheridan 1975).

**Participant 5:** *“I ...if I didn’t want something I ...I... [mimics pursing lips] I looked away...if, if I wanted something...[laughter] I just smiled [smiles]...and put hand [gestures putting hand up]. This worked. Or...if I didn’t want something I ...I... I stayed quiet”.*

This behaviour gives the feel of perhaps a 4 or 5-year-old starting primary school and learning socially appropriate and polite ways to communicate within the environment and subsequently get her needs met. Participant 5 made several references to childhood during her interview which further evokes a question that perhaps her experience of acquiring a CI plunged her back into that developmental stage, psychologically and emotionally.

### **Sub-theme 2a: The motivation to keep communicating**

The researcher was interested to explore the reason that motivated the participants to keep communicating. Most of the participants expressed a motivating factor such as a future goal e.g getting home or getting back to work.

**Participant 3:** *“When I was in hospital having rehab, I can remember as far away as that, wanting to go back to work, so whatever [husband’s name] suggested I did”*

**Participant 5:** *“I kept smiling and nodding...you know...I I tried to look like I knew what was going on... just to get home. Every day, just keep thinking want to get home”*

Participant 5’s quote suggests that the participant was so determined to get home that she stepped into a game or presented a false self in order to achieve her goal.

Participant 4 became aware of the amount of financial and business responsibilities that needed to be addressed and the potential that his wife may suddenly be living without an income. It seems his motivation to keep communicating was to support his wife. He slowly communicated to his wife where all of the paperwork was kept and things she had to do in order to keep things going. At that moment, his focus was to be a loyal husband and support his wife.

**Participant 4:** *“I kept blinking because it was the only way to help my wife who was really in the shit... [...] ...it was mainly explaining how to tackle everyday things – paying bills, taking care of bank accounts, filling tax return forms, explaining when everything is. Before I got sick, I handled everything. Imagine – she was a young woman with an almost dead husband and two young kids who was really up shit creek and without a paddle. Blinking was the only way to help”*

This quote is also powerful representation of how the CI impacts on a whole family. The wife was thrust into a new role within the family unit which is likely to have impacted on the family as a whole; both practically and psychologically.

Participant 1 described his motivation to keep communicating was that he assumed he could keep doing things and that he would be able to get back to work and carry on with life in the same way.

**Participant 1:** *“well at first I think I can do that, I can do that...now I know...no”*

Throughout the interviews there was a feeling that in the early stages, all of the participants were seeking to restore normality. Only one participant believed that the CI was permanent. All of the others had a belief that they would recover and return to their life in the same way. Perhaps a form of denial acted as defence to the reality of the situation and served a purpose in keeping them focused and motivated during the initial stages. The sense of

motivation to keep communicating had a strong presence in the interviews, perhaps indicating an innate human instinct to communicate with others and move beyond and past the experience. One could argue that the motivation to keep communicating could be part of our survival instinct.

### **Sub-theme 2b: The experience of communicating through another person**

All of the participants described their initial experiences of communicating through another person whilst they were in hospital.

**Participant 4:** *“It was slow and frustrating. My wife would read the alphabet – letter by letter – whenever she said a letter I wanted, I would blink...then she would start again. As I selected the letters, I would gradually form a word, yes, painfully slow.”*

**Participant 3:** *“in hospital and the three weeks I spent there, I was not talking at all (I didn’t have a clue how I managed, and I was vegetarian, so [husband’s name] had to describe to the medics that I was such, and in those days there was a great deal of ignorance, especially in health authorities...[...]... as I recall it was a godsend that my husband was there and was able to articulate with them, because I couldn’t do it.”*

**Participant 5:** *“My niece is s s so patient, a dear...sh sh she would she bring letters board and wait for me to point at letters...then she write words on paper for me. She and my husband spoke to doctors and nurses.”*

**Participant 2:** *“my wife...did talking to doctors”*

Several of these quotes give a feel of a communication process that is slow and arduous. The very nature of the process gives a sense of life slowing down. It also highlights the value of having a patient and supportive communication partner, who becomes the person with the CIs voice and in a sense their thoughts and advocate.

### **Sub-theme 2c: The significance of clinicians who take time to communicate and listen**

The participants all spontaneously offered accounts of clinicians who took the time to communicate and listen to them. Again, this emphasizes the importance of compassionate communication. The time these clinicians gave was remembered vividly by the participants.

The first example describes the participant's experience of a student nurse during a night shift.

**Participant 4:** *"One night a student nurse was on duty, and she was the first person to use the letters without instruction. Obviously I appreciated this VERY much and I explained my condition and what caused it. True, nursing often just involves cleaning patients and administering their medicines but believe me, these few hours spent talking to me – bothering to communicate with me - was an example of the best kind of nursing anyone can hope to receive. I heard a nurse say nursing is not a career, but I disagree. It is not just a job where one waits for the cheque at the end of the month. It requires patience and dedication- something this student had and I appreciated very much. She was like an angel to me... and it proves that communicating with me requires common sense and mainly good will."*

**Participant 5:** *"the peeche... speech therapist took time...gave me time to find... my words and said, you know "it's ok, t t take your time. She gave me her time...very graful, grate, grateful to her."*

**Participant 2:** *"[name of SLT] she lovely. Umm speak, speak, speak, wonderful. Honestly, wonderful. Took time with me. Wonderful."*

## **Discussion of Super-ordinate Theme 2**

The quotes in this section highlight the importance of having a competent communication partner and in these particular cases, a loved one with patience and time. One might ask how these participants would have communicated if they had not had their loved ones to be their 'voice' and advocate. Sutt (2017) highlights that successful communication needs both the communicator and the communication partner to succeed in delivering and capturing the message. It would be interesting to explore whether having a competent communication partner in these early stages is a predictor of outcomes in terms of long term emotional and psychological impact. If a person is left in isolation with no communication partner does this impede their emotional processing of the event and leave them stuck in place of feeling isolated and not knowing. Research has indicated the effectiveness of conversation partners in speech and language rehabilitation (McMenamin et al 2015) but very little is written about how this may influence emotional processing of their experience.

The significance of compassionate communication from clinicians is highlighted again in this theme and the importance of clinicians that were able to offer patience and time. Previous research highlights that stroke survivors found that support was easier to receive when it communicated concern and was part of a reciprocal and caring relationship (Northcott and Hilari 2017). This again, highlights a training opportunity for counselling psychologists in that they could offer insight on the importance of compassionate communication for psychological well-being. It seems likely that compassionate communication within a clinical environment may be imperative for reducing fear and creating feelings of safety in the initial stages of acquiring the CI and subsequently reducing psychological harm in the long term.

When thinking about one to one therapy sessions, counselling psychologists may want to learn more about Supported Conversation Strategies so as to use them effectively. They may also consider the individual's pre-linguistic experience of finding an alternative way to communicate and whether this placed them back into a younger developmental stage, triggering memories from childhood. Research in 2015 reported a theme of individuals with

aphasia feeling like they 'were back at pre-school' (McMenamin et al 2015). Counselling psychologists may want to consider if an individual is still communicating in a pre-linguistic manner whether this triggers feelings of shame or inferiority. There are also implications for how transference and countertransference may play out in the therapy room. Feelings may be evoked in the counselling psychologist if the client is communicating at pre-linguistic level or with two word utterances, unable to respond to questions and groping for words. This may lead to long silences that could touch on old wounds in the counselling psychologist or evoke feelings of being unskilled and inexperienced. The counselling psychologist may need to rely mainly on their experience of transference in the room and skilfully seek to interpret what the client may be feeling or experiencing.

Finally, counselling psychologists may also want to consider the individual's initial motivations to keep communicating and whether these are helpful or unhelpful further down the road. For example – rigid beliefs may be keeping them stuck and unable to move on emotionally. Alternatively, the individual's motivating factors could serve to support the individual during therapy when defining goals and targets.

### **Superordinate Theme 3: The emotional journey**

Some of the participants chose to talk about their emotional experience and how they had 'journeyed' through some dark times to a place of acceptance. The literature review highlighted the risk of depression after stroke or head injury and mental health difficulties that can occur as a result of communication difficulties. Participant 1 shared his difficult experience of attempting suicide.

**Participant 1:** *"I mean one day I had pills one day and I was going to take all my pills and gone with it.... but that was in [name of other place] but because I had stroke nobody tell me what happened... [...] ...the doctor phone one day and said are you ok and if you're ok and I*



*said yeah but that's what I do. Now I've got a doctor there he says you got to have help now to do things like this (pointing to food preparation area). One day I sat there crying [pointing to kitchen floor] because I couldn't do that...and the doctor said 'look you can do that'. The doctor he know what to do, where the other one didn't"*

The participant indicates the importance of a GP who understands his difficulties and the help he may need. This links in further to the importance of compassionate communication within healthcare settings. There is also a positive sentiment that comes through in quote in that the doctor told the participant *"you can do that"*. Perhaps this positive encouragement and a sense of knowing provides a feeling of being 'held' and someone having confidence in him. This may have had a positive impact on his self-belief and self-esteem.

Participant 4 also described his emotional journey and the first part illustrates the darkness of his experience.

**Participant 4:** *"The only thing I could do (apart from open and close my eyes) was to cry. Unfortunately the nurses seemed to be immune to crying - they just ignored it."*

He then goes on to describe the difficulties in processing the enormity of what had happened to him:

**Participant 4:** *"Initially my wife did some research and then explained my condition, however is very hard, probably impossible to gulp it down. To go from normal to this probably can't be gulped down entirely in one big gulp....it takes time. The initial period is long – very long – years in fact. Getting round the fact that you will never move or talk again is not easy. Since initially I couldn't breathe unassisted, I had a tracheostomy and I thought I couldn't talk because of it. When it was eventually removed, I was rather disappointed that it didn't make any difference to my inability to speak"*

The participant uses the word 'gulp' again several times when talking about emotions and adjusting to the difficulties he has been presented with. Again, perhaps this is the only way he can process the enormity of the situation and emotions. He is completely Locked in and therefore has no way of moving the emotions through movement, shouting, dancing or drawing. Has he been left with a feeling that there is no-where for the emotions to go other than back down into the body. Or perhaps this has been his way of coping with emotions from a young age. Whatever the case, his quote gives a sense of the enormity of his experience and yet he has never had the opportunity to explore and discuss this with a therapist or psychologist.

The next participant alluded to a process of his wife reading his emotions.

**Participant 2:** *"frightened, no. Ummm, angry...I suppose yes...ummm yes and no...even stevens (makes a fist with hand). My wife tends to know...and says it... [...] ...depressed, yes."*

In a sense his wife has become his voice and emotional guidance system. She is able to read his emotion and then express his feeling in words. It would be interesting to explore whether this is a process that has always occurred in their marriage or has only happened since the acquisition of the CI. It would also have been interesting to explore his feelings about this and whether he finds it helpful or disempowering.

The next participant described her emotional experience within a positive frame. Whilst she makes some references to depression and staying sane, she gives a sense of feeling that her positive outlook, her husband and her work shielded her from these experiences.

**Participant 3:** *"positive and determined were words that occurred to me right through my episode of stroke rehab. Whether if [husband's name] hadn't been with me most days, I'd have felt the same – I don't know? But I am a pretty determined character..... my husband*

*was crucial. My husband is the reason that I am not locked into a care home long since...working has kept me sane. I couldn't have not gone to work – I would have got very depressed”*

### **Sub-theme 3a: The experience of loss and difficult emotions**

All of the participants had experienced loss not just of neurological processes but parts of their everyday life such as their job and driving license. They were able to express their sadness around this.

**Participant 1** – *“I don’t work anymore. I was post master. I can’t remember things. I can’t read or write so...I can’t do anything really cause it don’t work. [points to sad face on the sheet]”*.

This participant communicated a sense of hopelessness about his situation when he used the phrase *“I can’t do anything really cause it don’t work”*. This shows a change in his thinking from when he initially described his thoughts about being able to do everything just after he acquired his CI. It also shows an acknowledgement of the damage to his brain and the loss of function.

The next quote highlights the impact of a double loss on top of acquiring the CI. The CI has caused the loss of her work and at the same time she has lost permission to drive.

**Participant 5** – *“I can’t work anymore (looks down at the floor)...I need to talk to customers and can, can’t do anymore. I really miss it. Cannot drive at the moment...have lost my ind...inde...pendence”*

The next quote highlights the loss of an ability.

**Participant 3:** *“the first time I cried was when I realised that I couldn’t spell my daughter’s names. Pre-stroke I always prided myself on my ability to spell. I was a wiz about spelling pre-stroke – so it was like my whole life was another life’*

It seems that before the stroke this participant’s spelling ability has been part of her identity and to then lose this ability may have led her to question who she was and her role in the world.

### **Sub-theme 3b: The challenges of living with a CI**

As much as the participants appeared to have accepted that the CI was going to be part of their life forever, they also talked about the ongoing challenges of living with a CI.

**Participant 3:** *“I know that in a scenario with conflicting messages, my aphasia gets terrible, and without concentrating to the utmost on speech, I’m lost. This can lead to some very embarrassing circumstances... [...] ...numerical tasks...still are a challenge for me – especially when I’m tired!”*

**Participant 1:** *“I still speak, all the time, [points to head] but now it takes a long long time...to get...better. I can see what I am saying to you but sometimes I think it’s right up here (pointing to the left side of his head) but it comes out here, so it goes from there to here (pointing to head and then to mouth) and it’s sometimes not the same”*

**Participant 4:** *“What is really annoying is trying to get someone’s attention – to “talk” I need the attention of who I want to talk to and being mute and unable to make a sound makes it kind of difficult... [...] ... it happens all the time (people predicting). Unfortunately they sometimes get it wrong and I next say “let me finish”*

This again emphasizes the importance of a competent conversation partner who is patient and able to spend the time communicating in a compassionate manner. The issue of a

communication partner interrupting or not giving the person time to fully communicate their message was also highlighted by Participant 5 in the next quote. Again, this emphasizes the importance of a communication partner that can offer time and patience.

**Participant 5:** *“My husband interrupts...I say...hang on...hang on....minute...let me finish...”*

### **Sub-theme 3c – The experience living with a CI within society**

The challenges of living with a communication impairment are also impacted by the experience of living in a world with others. Participant 1 and participant 5 talked about they have to consider how many people will be in a social environment before deciding on whether they will enter the environment. There is also a level of worry that they carry about saying the wrong thing.

**Participant 1:** *“I go out to shops or pub but I won’t go in if a lot of people. If I got in there one day and it’s just like two or three people I’ll go in there but if a lot of people there I won’t go in because if a lot of people there I can hear something there (pointing to the side of him) and kkkkk (making a shaking gesture with his hands at the side of his head). If there a shop with a lot of people in I won’t go in. This works all the time now (pointing to his head). Sssss all the time, everyday. Because saying what I’m saying now, I’ve got to think about it, all the time.”*

**Participant 5:** *“If I go for meal and lots of people at the at the t table I can’t keep keep up with conversation...all voices become one noise and arrrgh [swirls index finger by head] it’s exhausting. Then people fire questions, questions at me. I worry...you know...worry I’ll say the wrong thing and loo look silly”*

**Participant 4:** *“Peoples reactions. ...they just don’t know what do to. Most people shout while talking (as if I am deaf) and often wave their hands around as if miming what they’ve*

*saying. It may be an awkward situation but I can assure you that nothing is wrong with my hearing”*

There was also reference to others assuming they are intellectually impaired because their verbal communicative ability has changed.

**Participant 4:** *“Although there is an ignorance in society, I tend to give a large leeway – people just don’t know how to handle a situation like that. What really makes me furious is when people say “tell me what you need?” ....as if I am enjoying playing mute. I don’t expect people to know instinctively how to communicate with me but then why not ask for help from someone who does? [...] there is no need to talk to me as if I am fucking retard – don’t shout and don’t mime. For Christ’s sake I am a normal person inside... [...] ...I’m locked in my body. My mental faculties; thought, reason, feeling, touch, taste, hearing, sight, smell, are unaltered...”*

This quote is powerful in illustrating the experience of this individual and the assumptions that those around him make because he is unable to verbally communicate. The sense of his frustration comes through in his choice of language. This participant’s experience of others further emphasizes an ignorance within society about CIs. It echoes experiences highlighted in an earlier theme about ICU and hospital settings. The next quote also highlights an assumption that loss of communication equals loss of intelligence.

**Participant 5:** *“I saw a lady from the village...she said to my husband ‘has she lost all her faculties then?’...I was right there next to him.... she assumed I was daft... [...] ...when I’m with my husband...if people have heard about my accident, they talk to him...assume I’m deaf or daft”*

The literature highlights that many individuals with communication difficulties report feeling self-conscious about speaking in public and take steps to hide their communication difficulties by avoiding social interaction completely or by using the bare amount of

communication required. It is thought that they do this in order to protect their identity but by doing so put themselves at risk of losing friendships and becoming socially isolated (Wray and Clarke 2018).

**Participant 1:** *"If people know me it's ok but if they don't know about me and I might say something wrong...so if there's a lot of people I won't go in because I want it right but it comes out right and I say sorry because it's not right... [...] ...people see me and I might look ok but they don't know that my brain don't work"*

### **Sub-theme 3d – Thoughts and experiences of therapists and counselling**

The participants were asked about their thoughts and experiences of therapists and counselling.

**Participant 4:** *"I dreaded weekends simply because therapists do not work in the weekends and therefore nobody came. This made time pass even more slowly..."*

**Participant 3:** *"a speech therapist, was a great help when she could get to me, which was something like every 3 days. Meanwhile, [husband's name] plodded on with me every day."*

**Researcher asked "Were you offered counselling at the time?"**

**Participant 1:** *"No. The only people that done it now are her [pointing to a letter from the speech and language therapist]. She the only one who done it. She, she a very very good."*

**Participant 2:** *"ha ha! No. Honestly you know, rare"*

**Participant 3:** *"no, they weren't available at the time. I like to think my husband was my counsellor. He did all sorts or research on the internet when he came home from me"*

**Participant 4:** *"no support at all...also, back then (year 2000) the internet in the early stages"*

**Participant 5:** *"no but there was a psych...psy...ch...gist in brain place"*

**Researcher asked:** *"Would you have accessed counselling if it had been offered?"*

**Participant 1:** *"Don't know"*

**Participant 2:** *"Counselling, no."*

**Participant 3:** *"No. I was busy with work that my husband was bringing along every day and that the rehab therapists were doing with me. Besides I didn't feel as though I needed therapy, still don't"*

**Participant 4:** *"I don't know, maybe"*

**Participant 5:** *"No, not then, just wanted to get home"*

**Researcher asked:** *"Have you accessed counselling or therapy since?"*

**Participant 5:** *"Yes. I saw lady for coun...c...coun...slin...counselling. Really super"*

**Participant 1:** *"I do...I found it better for me...it's nice somebody there to see that I'm ok and before on my own all the time but now somebody else...it better I think"*



### **Discussion of Super-ordinate - Theme 3**

Several of the participants shared some of their experiences of their emotional journey which gave a powerful feel of the mix and depth of emotions they had experienced since the change in their communication. There was some confusion over not knowing why they felt different and also a sense of the enormity of the life changing event. All of the participants made reference to a significant other who had supported them through the emotional journey whether that be a partner or an understanding GP which highlights the significance of having someone who understands their difficulties. The sadness of their many losses came through in the narrative together with a feeling of 'hopelessness' and 'powerlessness'.

The challenges of living with a CI highlighted the difficulties these individuals face when communicating with others. Fears and worries about saying the wrong thing impacted on their choice of whether to enter a social environment or not. Others interrupting, completing their sentences and a general ignorance and assumptions within society about CIs were cited as constant challenges to living with a CI. As well as some reporting a noise that accompanies their CI making it more challenging to concentrate and engage in group conversations. It is interesting to note that the participant with LIS has been asked "to show them what he needs?". This question was totally inappropriate given his condition, however this may have been an appropriate question for someone with aphasia. This leads to the question of whether generic advice for communicating with someone with stroke has been followed literally by the person without a full understanding of the type of stroke and subsequently the type of CI. This may indicate a lack of communication advice about LIS that may require further exploration.

There appeared to be mixed views about counselling or psychological therapy and a feel that several of the participants seemed closed off to the idea of counselling or psychological therapy. It was difficult to determine whether this was due to previously held assumptions about talking therapies, fears about engaging with therapy or whether they really did not feel it was something they required. During the interview, there was a sense that several of

the participants perceived a 'counsellor', 'speech therapist' and 'psychologist' as one of the same thing. There was a sense that a counsellor's purpose would have been to restore communicative function during rehabilitation. There seemed to be little awareness that a counsellor or psychologist could help them explore and process emotions relating to the massive life change event. Perhaps this illustrates what their priority was in the early stages of acquiring the CI and also suggests that acknowledging the psychological impact of the experience maybe too painful. The two participants that did eventually attend counselling did so several years after the neurological event, perhaps when the 'dust had settled' and the emotions came to the fore. Holland and Nelson (2014) suggest that counselling maybe beneficial further down the line in someone's recovery. Perhaps the role of counselling psychologist in the early stages of someone acquiring a CI is to contribute towards a feeling of being safe and contained. This may involve repetition of information and reminders of safety in a compassionate manner; taking away any pressure to communicate and reducing anxiety and fear. Perhaps their role further down the recovery is to explore aspects of their experience in a more psychotherapeutic manner to be processed.

#### **Superordinate Theme 4: Finding coping strategies and new activities as part of their recovery**

This theme highlights how the participants started to engage in activities that allowed them to find their own way through their recovery. This suggests that at this point the participants had passed through the initial fear provoking stage of acquiring the CI and were starting to pull on their inner resources and coping strategies for longer term self-management. As time passed they found new activities to focus their mind on and aid themselves further in their recovery. The first quote talks about the impact of reading.

**Participant 3:** *"Reading at first I couldn't do and then I got it all at once. I then read an article about [name of book] I loved that book with a passion, it was one of my first read novels in my teens – and I guess that was the trigger."*

Some of the participants started to use their intact cognitive ability as if perhaps attempting to re-gain some autonomy or control within their personal living environment. This may signify a stage in adjustment to the change in their communicative ability.

**Participant 4:** *Time passed, and nothing seemed to happen. I was getting very, very, bored during the day. So, being quite a “mental” sort, I began setting myself mental tasks. One of the first tasks was to learn all the names of the staff – no big deal. I relied heavily on what I heard/picked up. Obviously, I cannot ask anyone for his/her name... or for anything for that matter. Next was to learn the shift system – how it works and who is with whom. Now I know who to expect at every change of shift. It’s not the first time the nurses confirmed with me who is going to be on duty on any given day.”*

This quote illustrates how the participant started to experience boredom, a very different emotion to the one he described in one of the first themes when he described being terrified. It seems he started to utilise his cognitive skills to both occupy himself and add some structure and meaning to his everyday existence.

This was also apparent in the next quote when the participant described adding an activity into her day during her time in a rehabilitation unit. It gives a sense of her re-engaging with the world and carving out some independence whilst also finding ways to use her cognitive skills.

**Participant 5:** *“Every afternoon... after lunch I walked down to the entrance door. I sat on chair and watched the goldfish swim in the big tank. So relaxing watching the fish. Clock...clock above the tank and when it got to three o’clock I walked back....back...to my room. I felt like I... was getting back some my ind...inde...independence and practicing walking and numbers. Every day I counted the fish to check they were all there (laughter)”*

The participants also described new activities that they began to engage with that brought new forms of enjoyment for them.

**Participant 3:** *“Going for lunch and joining their art group and doing sitting down aerobics with music. I really enjoyed the art – drawing was my forte”*

### **Sub-theme 4a – The Significance of Writing**

Four of the participants spontaneously talked about the experience of writing after acquiring a CI and how it has been positive for them. It must be noted that the term writing in this context means the act of constructing words into sentences to read and therefore not just the act of using a pen and paper. It may also refer to typing and using eye blinking forms of communication. Research by James Pennebaker and colleagues have shown the positive impact of writing on health. The benefits of emotional expression are not limited to verbal expression. Research has shown that encouraging individuals to write down their thoughts and feelings about past traumatic events has a positive impact on physical and psychological health (Pennebaker 1990; Smyth and Pennebaker 2001; Lepore and Smyth 2002; Hussain 2010). One could consider that the medium of writing becomes even more vital when communication ability is impaired for both communication with others and for expressing thoughts and feelings.

The first quote illustrates the importance of the outlet of writing when one is unable to verbally communicate.

**Participant 4:** *“I write in the afternoons. The method of writing may be slow but it is my way of talking and more importantly saying the truth about the matter”.*

Writing has become part of this participant’s daily routine and an imperative part of his life and how he communicates with others. It is highly likely that the outlet of writing is positive for his psychological well-being.

The next quote also illustrates the power of writing, in this case poetry and how it appears to have been part of the healing process.

**Participant 5:** *"I like write poems now...like poems when little girl. Now I write poem, wrote poem about my head...the acc...accident. Lost speech. Poems help... me to put or....ord....order...eal...ordeal behind me now"*

Research shows that expressive writing can provide the opportunity for more cognitive processing and integration of traumatic experience in memory. It is suggested that disclosing painful memories can lead to better health and that it can lead to higher emotional awareness, foster better regulation of emotion and coping with distress (Hussain 2010).

The next quote also mentions poetry as well as the positive presence of a diary.

**Participant 3:** *"I realise now, I was a budding poet... [...] ...my diary meant a lot to me and writing it as my writing got better... [...] ...I enjoyed telling in my diary what we had done...I illustrated my diary sometimes...my diary was a challenge to me, and yet it meant a lot to me..."*

This quote touches on the research mentioned in the first theme related to the use of diaries within ICU. Jones et al (2010) suggests that diaries may help a person to change how they think about their experience of illness as they re-read the story and build an autobiographical memory.

The overall importance of writing to support communication was also evident in that two participants responded to the interview in writing. They would not have been able to participate if the interviews had been only verbal. Furthermore, during the interview Participant 1 used small amounts of writing to support his verbal language so as to be understood. For example:

**Participant 1:** *"I can't think when the next one is...it's...hang on [takes pen and paper to write down the name of the place]"*

The quotes from the participants and evolving research reporting the positive effects of writing for regulating emotions and positive health strongly suggest that this is an important therapeutic area to explore for individuals with a CI. Not only can writing support their verbal communication in a functional manner it can also support their psychological well-being during recovery and beyond. This highlights a need for further research into writing as psychological support for individuals with a CI. It seems that any research related to writing after stroke or brain injury is focused on the functional and mechanical aspect of writing. There is nothing exploring the use of expressive writing as a therapeutic tool for people with CIs.

#### **Sub-theme 4b - The Joy of Singing**

Three of the participants spontaneously talked about singing and how it had been incredibly positive for them during their recovery and beyond.

**Participant 5:** *"my husband put the radio on.... I started singing and [moves hips from side to side] ...was Cher song...I sang and sang...[laughs] oh I felt good...now I put on every day!"*

*Two of the participants talked about the positive impact of singing and also made reference to their brain. Research highlights that after stroke, individuals with speech and language difficulties are often able to sing entire pieces of text fluently (Stahl and Kitz 2014).*

**Participant 3:** *"She [a fellow patient] and I ended up having a sing-song at 7-8am every day.... I can't remember when it got established that I could sing, perfectly and in tune – when I couldn't talk! The brain is an amazing organ...as soon as I discovered that I was able to sing, in perfect pitch, [husband's name] taught me to sing 'Hey Jude' – I remember that I*

*didn't feel so bad any more, and that was the crucial point beyond which I felt positive & determined."*

**Participant 2:** *"...then we go to the choir. [name of town] music zone, lovely. Great...right...it's ruled by a different section of the brain...la la la la la [singing] see...umm fantastic..."*

There are several studies confirm the promising role of singing (Tomaino 2010). Some researchers suggest that music-based aphasia therapy maybe a promising treatment option (Stahl and Kotz 2014). More recent research into aphasia and singing showed that participating in a singing group provided the chance for individuals to establish positive and meaningful connections with other groups members (Tarrant, Warmouth, Code, Dean, Goodwin, Stein and Sigavanam 2016). However as much as this suggests a positive outcome for psychosocial well-being, as of yet it cannot be confirmed whether this is due to singing or participating in a group activity.

#### **Sub-theme 4c: The Benefits of Humour and Laughter for Psychological Well-being**

All of the participants talked about the importance of humour and laughter in keeping their mood and mental health stable.

**Participant 1:** *"sometimes I think it's right but it's not so...but we have a laugh about it actually...I have to, I have to, I got to laugh, I have to laugh, I can't else"*

**Participant 3:** *"It can lead to some very embarrassing circumstances – it's lucky I've got a sense of humour (sanity factor)!"*

**Participant 5:** *"We laughed...my husband said "oh your tickle muscle has been tweaked"  
...we laughed...laughed at funny things in hospital. We laugh now sometimes when wrong  
word comes out. Laughter keeps me sane"*

Within psychodynamic theory, humour is often discussed as a defence against anxiety or negative emotions. Freud viewed humour to be the highest and most mature form of human defence mechanism. He believed that humans mainly use humour where negative emotions such as sadness arise (Ostrower 2015). The participants showed some awareness in that the use of humour was defending against a negative psychological state. The essence of humour is that the individual creates space between themselves and the distressing and painful effects that the situation causes; thereby cancelling the emotional possibility of sorrow through humour. In this way, the humour enables the individual to cope with traumatic situations without being overwhelmed by emotions. That said, humour is also considered to be a helpful coping mechanism that can enable an individual to bear the burden of suffering and misfortune (Swaminath 2006). Scott (2018) highlights that as humans we learn to use laughter as a gauge for safety even before we are born. She suggests that hearing the rhythm of mother's laughter in the womb and as a baby hardwires us to believe laughter means 'everything is ok and I am safe'. Then, as we develop through our lifespan, laughter acts as a valid form of emotional communication; expressly linked to physiological reduction in the stressful reactions to negative emotions (e.g fear, disgust and anger) (Scott, Lavan, Chen and McGettigan 2014). Furthermore, humour can also act as a lubricant for social interaction; contributing to intensifying group cohesion, reducing tension and creating a positive environment (Ostrower 2015). Dean and Major (2008) also suggest that humour can humanise the healthcare experience and Schneider, Voracek and Ulrich (2018) note that humour and mental health are interconnected. With this in mind could it be that the participants are really valuing the use of humour in their lives as a positive coping mechanism. Once the individual realizes that the change in their communication is permanent, perhaps humour is a healthy tool for accepting the change and keeping their psychological wellbeing balanced. It's also worth noting that this use of humour maybe



considered very differently according to the context it is observed and experienced in. For example, a psychologist working psychotherapeutically may perceive the use of humour very differently to someone socializing with this individual at a social event.

#### **Sub-theme 4d – Finding the positive in their experience**

Some of the participants made reference to the circumstances when they acquired the CI and offered a positive in perspective in sharing their thoughts about how things could have been worse.

***Participant 4:** “To think of it, if this happened, say, just five years before it did, all this would have been impossible. Lasers existed but they were big, heavy, needed a high voltage and were very expensive. The invention of laser diodes changed all this – they became cheap and didn’t require high voltages to work and (more importantly) it was possible to mount one on a pair of specs.”*

***Participant 3:** “It was a walking holiday – and I went alone – having more frequent ‘migraine episodes’. I have always thought what good luck was mine not to get my stroke on holiday”*

*“I learnt to draw with my left-hand despite being a right hander from birth up to my stroke. You see with determination and a positive attitude what tasks can be done?”*

*“it’s true that I’ve become accustomed to it – I guess it’s just a case of me being positive/determined in my life”*

When the participants reflected on the overall experience and how they feel about acquiring a communication impairment years later they offered the following positive perspectives on their experiences:

**Participant 1:** *"I was ok really but I'm better now than before the stroke. I mean before, I love people and things like that but if something wrong I'd say that isn't right and...but now I won't do it now. I'm much better than I was before"*

**Participant 4:** *"Another thing I learnt since I have been in hospital is patience: everything happens so slowly. Patience and I have learnt how to listen – actually shut up and listen. Not speaking has one advantage: one does not have to make silly conversation with one's neighbour. This can be very good for me..."*

**Participant 5:** *"I found my way to counselling...never would done this if not for acc...accident with head. Feel better about my past, long long long ago, childhood. Also I realise how much my family love me... I mean really love me [smiles] it's nice"*

**Participant 2:** *"Friends we've made at choir...lovely...wonderful people. They have stroke too. New friends...lovely...fun [laughter]... [...] the model railway...brings me joy... [...] and holidays...not walking ones...cruises...3 holidays a year"*

It was interesting to note that all 5 participants offered a positive perspective to their experience. The researcher was particularly interested in this as there is an emerging interest in post-traumatic growth within the literature, in particular related to health conditions. Post traumatic growth refers to the positive changes that may arise from individuals experiencing extremely severe conditions and life events (Joseph, Murphy and Regel 2012). Tedeschi and Calhoun (1996, 2004, 2013) suggest there is a potential for people to emerge from a traumatic illness or event with an enhanced appreciation of life, a greater sense of meaning, stronger relationships and a realisation of their own potential. This is thought to be reflective of greater psychological and cognitive development, emotional adjustment and life awareness (Tedeschi and Calhoun 2005). The participants' responses indicated signs of post traumatic growth – for example – finding new friends or recognising how much your family love you could be a sign of stronger relationships.

## **Discussion of Super-ordinate Theme 4**

The final theme highlights how the participants began to develop their own activities and routines as part of the rehabilitation and perhaps to establish some control, autonomy and order in their lives. This also led to new activities which enabled them to express themselves and experience some joy. Writing served as functional means for some and as a form of psychological expression for others. It is noted that there is an absence of discussion about expressive writing and CIs within the literature and therefore this may be an area for further exploration. It is also an activity that counselling psychologists may want to incorporate into their practice when working with clients with a CI. Singing was also a new activity discovered by several of the participants and linked to positive psychological well-being. Research in this area is evolving and perhaps suggests that a collaborative approach between music therapists, SLT's and counselling psychologists could offer some fruitful therapeutic developments for individuals with CIs.

The importance of humour as a positive coping mechanism for psychological well-being. Again, the topic of humour and CIs is absent within current literature and maybe an area that warrants further exploration as the topic of humour is relevant in therapeutic work. Within a therapy room, depending on the psychologist's therapeutic orientation, humour may routinely considered to be a defence hiding some unprocessed emotions. A psychologist may think long and hard before considering whether to draw attention to the client's use of humour. Often in long term psychotherapy, breaking down defences can be considered a crucial part of positive psychological development but one always needs to consider the resources of each client and whether breaking down a defence could be harmful. It is thought that if used appropriately humour in therapy session can help put things into perspective (Swaminath 2006). However, humour and tragedy are considered to be closely linked and therefore this needs to be practiced with caution. In the matter of individuals with a CI we must keep in mind that humour may be another form of communication they can use to connect with others to compensate or augment their loss of

verbal ability. Therefore, we must consider that to tackle the use of humour from a psychodynamic framework maybe unhelpful and potentially harmful to individuals with a CI. Furthermore, depending on the type of brain injury, the person's humour maybe altered and considered inappropriate at times, thus not helping them to socialise effectively.

Finally, the theme of finding something positive from the experience came up in the interviews. Despite such distressing experiences the participants were able to find some positive aspects to reflect on. This could open further discussions within the frameworks of positive psychology and post traumatic growth. Historically, psychology has been largely consumed with symptom reduction and based on a model of disease. Seligman (2002, 2017) highlighted that for every hundred articles on sadness there was often only one on happiness. He believed that the psychology profession had made progress in understanding mental health difficulties and suffering but in the process, had neglected exploring positive emotions, personal strengths and virtues. Wray and Clarke (2018) also note there may be a possible bias towards publishing studies that highlight the difficulties of acquiring a CI as opposed to highlighting positive experiences. Scott (2018) notes that the psychology profession has established the science which appears to be entirely about negative emotions. Wray and Clarke (2018) describe the importance of the individual's belief in their own ability to improve and how they push to improve on the basis of that belief. In studies where stroke survivors living with a CI described themselves as living successfully with the condition there is reported to be a sense of taking control and actively moving forward present (Brady, Clark and Dickson 2011; Grohn, Worrall and Simmons-Mackie 2014). The literature suggests that the flexibility to adapt, adjust and take part in a meaningful activity in spite of communication difficulties is significant for positive mental health and psychological well-being (Brown, Worrall and Davidson 2011).

## Summary

To summarise, 4 themes emerged from the data that illustrate the spectrum of thoughts, feelings and experiences encountered when acquiring a CI. Theme 1 describes the unconscious and conscious aspect of their experience which highlighted the level of fear many of them experienced. This raises questions about whether memories of their time within an emergency setting may be held and stored in their body as a somatic memory and if so, this has therapeutic implications. This theme also indicated that there may be a training need with emergency clinical settings for a greater understanding of CIs. There also seems to be a greater need for clinical staff to understand the importance of compassionate communication including a reminder that patients can often hear even though they may be unable to express themselves verbally.

Theme 2 describes the experience of finding an alternative way to communicate and highlights the motivation that many demonstrated to keep communicating; often determined to reach a goal in their recovery. This theme also discusses how several of the participants instinctively found another way to communicate; often regressing or utilising pre-linguistic types of communication. The theme also highlights the significance of another person in making the communicative interchange successful. The importance of loved one to communicate 'with and through' was documented as well as the significance of clinicians who took the time to listen and communicate in an understanding and compassionate manner.

Theme 3 charted the emotional experience of these participants with some sharing some difficult times. Many of the participants described the challenges of living with a CI, including the aspects of social anxiety; subsequently becoming selective of where they go socially. They also described a level of ignorance within society and their experiences of

others assuming they are deaf or lacking IQ because they are unable to verbalise fluently. This further emphasises the need to raise awareness of CIs within society.

Finally, theme 4 illustrates how the participants found new activities in their life post acquiring the CI. Several of them began to find their own coping strategies or ways to rehabilitate themselves, suggesting an instinctive drive to adapt and/or survive. The theme highlighted new activities that enabled the participants to express themselves and connect with other people. Expressive writing, singing and laughter were discovered as other forms of communicating and all of these outlets appeared to have a positive aspect on their lives. The participants also managed to find positive aspects of their experience which perhaps indicates a form of human resilience or survival.

### **Implications for Counselling Psychology**

It is the researcher's belief that counselling psychology could bring great therapeutic value to adults with CIs. Counselling psychology as a profession has strong humanistic roots whilst also embracing the scientist-practitioner model; basing therapeutic intervention on the current evidence base and literature (Woolfe, Dryden and Strawbridge, 2011). In addition, the BPS (British Psychological Society) encourage counselling psychologists to '*utilize their artistry and creativity*' (BPS 2016), thus balancing science and art; seeking to use the evidence base creatively to meet the needs of each individual. As mentioned, each person with a CI comes with their own individual history and bundle of negative and positive experiences, thoughts, feelings and beliefs. Fairfax (2016) writes that we are all embodied beings, minds, feelings, sensations, synapses and dreams within ourselves and between each other leave emotional and neurological traces as we go forward in the process of who we are. If a person experiences neurological change it may complicate their psychological processes but it does not eradicate the person's history. Counselling psychology sees the person as a human having an individual psychological experience and the humanistic therapeutic approach makes space for an individual to bring all of their 'self' in order to

explore and process their emotional and psychological experiences. Counselling psychologists are trained in the use of the 'self' in relationship with the client and often sit in a place of an existential perspective; the underlying assumption that there are no right or universal answers. They sit with the psychological distress often seen as arising from four main areas – dying (mortality and disability), freedom (responsibility and anxiety), isolation and meaninglessness and therefore counselling psychologists are well-placed to explore all aspects of a person's experience after acquiring a CI.

The following areas are thought to be significant areas that counselling psychologists could bring therapeutic value to:

### **Compassionate communication**

Several of the participants were clearly able to remember the way in which clinicians had interacted with them during their hospital experience. During the initial stages of ICU and hospital, several issues raised about how the impaired communication had negatives complications – for example – not being able to communicate that they felt pain and not being able to communicate a fear that people would assume the person had a mental health difficulty. There was also a quote related to hearing a medic comment that the person was likely to die. These strongly highlight a need for compassionate communication within a hospital environment. Counselling psychologists may have a place within ICU and emergency care settings in order to model compassionate communication and create a feeling of safety for the patient during their initial experience of acquiring the CI. The overall aim would be to reduce psychological distress and the likelihood of PTSD and/or post intensive care syndrome.

Counselling psychologists could offer training and awareness to hospital and care staff about the importance of compassionate communication when working with a person with a CI. This could be delivered jointly with speech and language therapy. The subject may need to be approached from two angles:

- 1) to explain receptive and expressive language and how a person may still hear and understand even when unable to verbally communicate.
- 2) to consider the psychological experience and implications of being unable to communicate and raise awareness of how clinicians can offer compassionate communication in the early stages of the individual's clinical experience.

CFT (Compassion Focussed Therapy) (Gilbert 2009) framework could support this initiative in terms of an evidence based approach. CFT offers a psychological framework for understanding the different physiological responses we experience in different situations. It conceptualises the brain's responses into 3 systems; drive, threat and soothing. Clinicians who are able to offer compassionate communication may be in a position to activate the person's soothing system so as to reduce the activation of the threat system i.e. a stress response. In terms of rationale; providing this clinical input at the time of acquiring the CI could potentially reduce GP's visits post hospital discharge and therefore reduce costs and the need for longer term clinical resourcing. Counselling psychologists could also be instrumental in offering training about the psychological needs of individuals with a CI to GP's.

### **Writing as a psychological and therapeutic tool**

This study highlighted the importance of expressive writing in terms of being able to express their beliefs, express difficult feelings creatively and to support their memory and language, during recovery and throughout their lives. Subsequently this highlighted an absence in the literature about expressive writing and individuals with a CI. To date there is no research into this area and how it may have beneficial effects for psychological well-being. Again, counselling psychologists may have a place within ICU's and hospital wards to promote the use of diaries and journals to support gaps in memory and then later in the person's journey offer writing as an outlet for expressing emotions and psychological experiences. Perhaps



the use of expressive writing could be used to assist long term psychotherapy for the person with a CI.

### **Therapy sessions**

As mentioned, Freud introduced the concept of catharsis as a form of therapy. The aim being to heal emotional blockages by uninhibited talking. Talking therapies, often named the talking cure are often the go to therapeutic approach, however, we have discussed the complications of this for a person with a CI. Their reduced verbal ability may impact on their ability to access a talking therapy. This suggests the need for psychologists to consider other therapeutic approaches. Furthermore, findings from this study suggest that individuals may have embodied some of their experiences of ICU and hospital settings. With both factors in mind, counselling psychologists can offer their therapeutic use of 'self' to sit with the individual and explore their experiences alongside them. Counselling psychologists approach will be mindful of the somatic memories the individual maybe experiencing and offer the time and space for these memories to be felt and processed. This could have a positive effect of reducing anxiety and improving communicative ability. Counselling psychologists will also consider the person's attachment history and how this may impact on willingness to engage with a clinician. There will also be an awareness that the CI may have triggered emotional and psychological aspects of the person's developmental history. Additionally, counselling psychologists can seek to integrate their therapeutic skills alongside other therapeutic approaches such as dance, movement, drama, music and arts therapies. Somatic based approaches are emerging in terms of voice yoga, laughter yoga, movement medicine and 5 Rhythms dance. Perhaps counselling psychologists, alongside SLTs could explore ways to merge some of these approaches, to enable adults with CIs to express themselves and experience positive psychological results.

## **The Limitations of the Research Project**

In some cases, the CI did impact on the complexity of narrative that a participant was able to verbally express and therefore this may have impeded the depth of the discussion. This was also compounded by each participant meeting the researcher for the first time and therefore there maybe have been some ambivalence or reluctance in revealing all psychological thoughts and processes to a stranger. The researcher would have been interested to explore how the participants had found meaning in their near-death experience. There was some discussion around this with Participant 4 but it is likely that this was because the interview took place via email over the course of several weeks and therefore this time and space allowed for greater depth as well as perhaps not being face to face.

It is also worth noting that all of the participants were 3 or more years' post acquiring the CI. Whilst this factors lends itself well to the aim of this study (i.e. the overall psychological experience) it may be that the participants agreed to take part in the study because they had reached a 'good place' psychologically. That is, they may have reached a place of acceptance of their CI and therefore felt able to talk about it.

Furthermore, all of the participants had a level of receptive language intact that enabled them to understand the questions. With this in mind, adults with severe receptive language difficulties have not been captured in this study.

### **Evaluation of IPA as a method for this study**

The researcher deemed IPA to be a relevant approach for this study, however some limitations were noted. One of the participants with aphasia who participated in a face to face interview offered minimum amounts of language and words. Out of context, this level of narrative could be perceived as meaningless. Furthermore, after analysis, when some of these quotes were documented in this thesis, there was a risk of the quotes appearing

‘empty in their content’ and lacking depth of meaning. This posed a small challenge, as IPA is an approach that encourages the researcher to interpret the data. Therefore, if the participants’ comments are limited in language, then interpretation could become challenging. The researcher felt it was important to report quotes from all of the participants and where language may have lacked content or meaning, the researcher attempted to report this in context in order to give it meaning. To not have done this would have further silenced these individuals and repeated a pattern of excluding participants with CIs from qualitative research. IPA as an approach supported these quotes as the researcher was able to add her interpretation.

In contrast, several of the participants, in particular the ones that were interviewed by email, offered a rich and colourful amount of language, with much to be analysed and interpreted. This also support the use of IPA and the researcher believes that conducting some of the interviews by email was a worthwhile exercise. The email interviews took place over the course of days and weeks and allowed space for the participants to really think about the questions, consider their psychological experience and formulate a response, without the pressure of an interviewer being opposite them in real time. The researcher believes that conducting interviews by email, not only gave some of the participants a mode of communication to participate but that it also allowed for rich and colourful narrative to emerge in its own time.

The interview questions (Appendix E) were planned in order to guide a structured interview and gather the data that the researcher was attempting to explore. In reality, the interview unfolded organically and although the researcher covered the areas set out in the interview schedule, it was not a rigid session of ‘firing’ a list of questions. The researcher aimed to engage each participant in a conversation about their psychological experience and allow topics to emerge in their own time. The researcher felt it was important for the participant to feel that they were part of a two-way equal conversation, rather than an interviewer and

interviewee dynamic. With this in mind, the interview structure was used as a guidance sheet during the interviews.

### **Suggestions for Further Research**

As part of this study, the literature review highlighted some areas that may warrant further research. There is an absence of research exploring attachment history and how this may influence the experience of acquiring a CI. This may be important to research in terms of whether there are any relationships between acquiring a CI, pre-linguistic communication, attachment history and psychological/emotional processes. The literature review also highlighted a lack of research into how a diagnosis of a CI is given and what might be best practice for delivering this news. There is also room for exploration of how acquiring a CI may impact on the family homeostasis.

In terms of data, as mentioned previously, there is no research into the use of writing as a therapeutic tool for adults with a CI. This maybe because a CI is often the result of a stroke and therefore it may be assumed that their CI is accompanied by a physical limitation or cognitive impairment, limiting their writing ability. However, we do not know if this is the case for all and therefore it's conceivable to consider that writing may well be an effective therapeutic tool for many with a CI. Overall, the research into expressive writing suggests that it could provide a simple and cost effective therapeutic intervention for clinical populations (Hussain 2010). Some sources suggest that expressive writing could assist psychotherapy (Pennebaker and Susman 1988) as it provides an opportunity to express emotions without having to speak to others about deeper emotional experiences to others (Hussain 2010). This may have significant therapeutic implications for individuals with a CI and is worth further exploration.

There is also room to explore many therapeutic approaches that are emerging and consider whether these may have value when working with individuals with a CI. For example - arts

and music based therapies that allow for expression in other ways other than speech. EMDR that can focus on traumatic memories without needing the verbal narrative. Mindfulness that does not require verbal expression and guides the person to focus on their breath or images. Compassion Focussed Therapy that offers concepts of how to recognise feelings in the body. Acceptance and Commitment Therapy that offers metaphors and analogies that may help the person to accept the change in their communication. Furthermore, the place of humour, laughter and positive psychology may be an area for further exploration for people with CI in the context of how this may support recovery and longer term psychological well-being.

Future research could include large scale studies comparing different approaches and measuring how standard psychological interventions may be appropriate for this client group. This could also involve evaluating services that already offer psychological intervention for adults with CIs. This may enhance therapeutic knowledge of how to tailor an approach to an individual, according to the type of CI and their psychological profile.

Finally, there is very little attention giving to what therapy and counselling may be suitable for adults with Locked-in syndrome. This absence in the literature strongly indicates a need for more research into this area.

## **Conclusion**

The aim of the study was to gather data about peoples' psychological experiences of acquiring a CI in adulthood. Five adults were interviewed about their experiences and the data gathered charted their experiences from the initial time of acquiring the CI to the present day. The literature review highlighted gaps in research that may benefit from further study such as attachment history and acquiring a CI, best practice for delivering a diagnosis of a CI and the impact of acquiring a CI on the family homeostasis. It also raised concerns

about a lack of psychological provision for adults with CIs and a lack of awareness within society about CIs

The interviews gleaned a range of information about the psychological experiences of the participants. The importance of compassionate communication within an ICU and hospital environment was identified. The participants were able to remember hearing others speak, even though they were unable to verbally respond. This coupled with sensory memories signifies the psychological impact of their initial time in hospital. This raises the question of whether psychological support in the early stages of acquiring the CI could reduce psychological distress both at the time and in the future, post discharge. The positive impact of clinicians who take the time to communicate was also acknowledged; further emphasising the need to ensure communication and care is compassionate at all times (even if a person appears unconscious or unresponsive). This indicates a training need for medical and care staff to enhance their knowledge and understanding of CIs and the importance of compassionate communication.

The interview data also described the experience of finding an alternative way to communicate and the importance of having a conversation partner with patience and time. The experience of having to communicate in an alternative way was also discussed, aspects of regressing to pre-linguistic communication were noted and a question raised about communicating with others being a survival instinct. The participants' thoughts, feelings and experiences of counselling were explored with mixed results. None of them were offered counselling at the time of acquiring their CI. Some chose to access counselling several years after acquiring their CI and some expressed no need or desire to access counselling. There was a sense that several of the participants did not fully understand what counselling might be able to offer them, which may be a point for further exploration in the future.

When discussing activities that the participants had discovered during their recovery most of them described a positive use of expressive writing. Several also described the positive

impact of singing on their mood and how it enabled them to connect with others and make friends. In addition, all of the participants described how the use of humour and laughter was helpful in connecting them with others during their recovery, and supporting their psychological well-being in the long term. In a sense, writing, singing and humour are all forms of communication that can allow the person to express their thoughts, share their creativity, be heard and subsequently socially interact and bond with others to share and experience life. This in turn supports healthy psychological well-being and positive quality of life.

It is interesting to note that despite all of the evolving research exploring neuroscience and different clinical interventions for brain injury and CI, very little is written about the value and positive effects of human connection and compassion for people who have acquired a CI. The interview data highlighted how that people with a CI really valued and remembered others who were compassionate and took the time to communicate with them. In this current day society of fast paced technology and speed, are we at risk of de-humanizing healthcare by seeking to 'fix the person', rather than 'be with the person'. As clinicians, are we overlooking the basic human need to feel seen and heard. Furthermore, the participants gained therapeutic value and healing from activities that enabled them to express and communicate through another mode i.e. writing, singing and humour. This would support a proposal for more arts based health initiatives to encourage these other forms of expression; perhaps based in spaces away from clinical environments and free from rigid agendas and outcomes measures. The overall aim being to reduce psychological distress, allow processing of difficult emotions, enable expression of thoughts, nurture creativity and encourage social interaction and connection with others.

It is anticipated that the counselling psychologist could bring their humanistic approach to this client group. The counselling psychologist can create a therapeutic space for the person to feel safe and held should they choose to explore their psychological experience. The counselling psychologist also brings artistry and creativity to identify when and how other

activities may provide an outlet for expression. Finally, the counselling psychologist's training and understanding of evidence based practice ensures they are well-placed to provide a clinical rationale for their approach and continue to contribute towards research. Research is evolving in the area of psychotherapy for brain injury and therefore maybe now is the time for counselling psychologists to carve out a new pathway within a neuropsychology; bringing an understanding of human relationships, existential enquiry and compassion focussed approaches to the table.

## **References**

American Psychiatry Association [www.psychiatry.org](http://www.psychiatry.org) accessed 2017

Arrowsmith-Young, B. (2013). *The Woman Who Changed Her Brain*. Simon and Schuster, New York

Ayerbe, L. Ayis, S. Rudd, A G. Heuschmann, P U. and Wolfe, C D. (2011). Natural history, predictors, and associations of depressions 5 years after stroke: The South London Stroke Register. *Stroke*, Vol 42, Issue 7, Pages 1907 - 11

Baker, C. Worrall, L. Rose, M. Hudson, K. Ryan, B. and O'Byrne, L. (2018). A systematic review of rehabilitation interventions to prevent and treat depression in post stroke aphasia. *Journal of Disability and Rehabilitation*. Vol 40, Issue 2016

Bara, G B. Cutica, I. and Tirassa, M. (2001). Neuropragmatics: extralinguistic communication after closed head injury. *Brain and Language*. Vol 77, Issue 1, pp 72 – 94



Bauer, G. Gerstenbrand, F. and Rimpl, E. (1979.) Varieties of the locked in syndrome, *Journal of Neurology*. Vol 221, Issue 2, pp 77 - 91

Baylor, C, Burns, M, Eadie, T, Britton, D, and Yorkston, K. (2011). A qualitative study of interference with communicative participation across communication disorders in adults. *American Journal Speech Language Pathology*. Vol 20, Issue 4, pp 69-87.

Beck, A. T. (1976). *Cognitive therapy and the emotional disorders*. Oxford, England: International Universities Press.

Black, R. Busby, M. and Hitch, C. (2018). Different questions needs different answers: a response to recent concerns over qualitative research. *British Psychological Society. The Psychologist*. Vol 31, pp 3 -4

Brady, M C. Clark, AM and Dickson, S. (2011). The impact of stroke related dysarthria on social participation and implications of rehabilitation. *Disability Rehabilitation*. Vol 33, pp 178 - 186

Brady, M C. Kelly, H. Godwin, J. and Enderby, P. (2012). Speech and Language Therapy for aphasia following stroke. *Cochrane Database Systematic Review*. 16/5

Braun, C M. Lussier, F. Baribeau, J M. and Ethier, M. (1989). Does severe traumatic closed head injury impair sense of humour?. *Brain Injury*. Vol 3, Issue 4, pp 345 - 54

Breaking Through, [www.Breakingthroughwithyou.co.uk](http://www.Breakingthroughwithyou.co.uk).counselling service for people with speech and communication difficulties. accessed 2015

British Psychological Society, [www.bps.org.uk](http://www.bps.org.uk) accessed 2017 and 2018

Bronken, Kirkevold, Martinsen, Wyller and Kvigne (2012). Psychosocial Well-Being in Persons with Aphasia Participating in a Nursing Intervention after Stroke. *Nursing Research and Practice*. Article ID 568242

Brown, K. Davidson, B. Worrall, L E. and Howe, T. (2013). "Making a good time": the role of friendship in living successfully with aphasia. *International Journal of Speech Language Pathology*. Vol 15, Issue 2, pp 165 – 175

Brown, K. Worrall, L E. and Davidson, B. (2011). Living successfully with aphasia: family members share their views. *Top Stroke Rehabilitation*. Vol 18, pp 536 - 548

Brumfitt, S. (1998). The measurement of psychological well-being in the person with aphasia. *International Journal of Language and Communication Disorders*. Vol 33, Issue S1, pp 116 – 120

Brumfitt, S. (2006). Psychosocial aspects of aphasia: speech and language therapists' views on professional practice. *Disability and Rehabilitation*. Vol 28, Issue 8, pp 523 – 534

Brumfitt, S. and Sheeran, P. (1998). The development and validation of the Visual Analogue Self Esteem Scale (VASES) 1. *British Journal of Clinical Psychology*. Vol 38. Issue 4. pp 387 – 400

Brumfitt, S. (ed) (2010). *Psychological well being and acquired communication impairment*. Wiley-Blackwell. West Sussex.

Bugental, J F T. (1992). *The art of the psychotherapist*. WW Norton, USA.

Cairncross, M., Peterson, A., Lazosky, A., Gofton, T., and Weijer, C. (2016). Assessing Decision-Making Capacity in Patients with Communication Impairments: A Case Study, *Cambridge Quarterly of Healthcare Ethics*. New York. Vol. 25, Issue 4, pp 691 - 699

Charland-Verville, V, Lugo, Z, Jourdan, JP, Donneau, AF and Laureys, S, (2015). Near-death experiences in patients with locked-in syndrome: Not always a blissful journey. *Consciousness and Cognition*. Vol 34, pp 28 -32

Charlick, S, Pincombe, J, Mckellar, L, and Fielder, A, (2016). Making Sense of Participant Experiences: Interpretative Phenomenological Analysis in Midwifery Research. *International Journal of Doctoral Studies*. Volume 11

Chaudhary, U., Xia, B., Silvoni, S., Cohen, LG., and Birbaumer, N., (2017). Brain-Computer Interface-Based Communication in the Completely Locked-In State. *PLOS Biology*. Vol 15, Issue 1

Child, C. (2006). *Communication Development Profile*, Speechmark Publishing, UK

Coetzer, R. (2007). Psychotherapy following traumatic brain injury: integrating theory and practice. *Journal of Head Trauma Rehabilitation*. Vol 22, Issue 1, pp 39 – 47

Coetzer, R. (2014). Psychotherapy after acquired brain injury: Is less more?, *Review, Neuropsychology*. Vol 9, Issue 1E, pp 8 - 13

Coetzer, R. and Balchin, R. (2014). *Working with brain injury: a primer for psychologists working in under-resourced settings*. Psychology Press. UK

Collin, C, Benson, N, Ginsburg, J, Grand, V, Lazyan, M, Weeks, M, and Tomley, S, (2012). *The Psychology Book*. DK, UK

Cruice, M., Worrall, L. & Hickson, L. (2011). Reporting on psychological well-being of older adults with chronic aphasia in the context of unaffected peers. *Disability and Rehabilitation*. Vol 33, Issue 3, 219-228

Cunningham, R (1998). Counselling someone with severe aphasia: an explorative case study. *Disability and Rehabilitation*. Volume 20, Issue 9

Cunningham, R and Ward, C. (2003). Evaluation of a training programme to facilitate conversation between people with aphasia and their partners. *Aphasiology*. Vol 17, Issue 8, pp 687-707

Dalton, P. (1994). *Counselling People and Communication Problems*. 1<sup>st</sup> Ed. Sage. UK

Danivas, V., Bharmal, M., Keenan, P. (2016). An interpretative phenomenological analysis (IPA) of coercion towards community dwelling older adults with dementia: findings from Mysore studies of natal effects on aging and health. *Social Psychiatry and Psychiatric Epidemiology*. Vol 51, Issue 12, pp 1659 – 1664

Darcy, S. Taylor, T and Green, J. (2016). 'But I do the job': examining disability employment practice through human rights complaint cases. *Disability and Society*. Vol 31, Issue 9

Davies, R. (2016). Chapter 29 'Journeying through physical health', pages 479 – 495. *Handbook of Counselling Psychology*. Sage Publication, UK (Douglas, B, Woolfe, R, Strawbridge, S, Kaskat, E, and Galbraith, V.)

Dean, R A. and Major, J E. (2008). From critical care to comfort care: the sustaining value of humour. *Journal of Clinical Nursing*. Vol 17, pp 1088 – 1095

Dickson, S. Barbour, R S. Brady, M. Clark, A M. and Paton, G. (2008). Patients' experiences of disruption associated with post-stroke dysarthria. *International Journal Language and Communication Disorders*. Vol 43, Issue 2, pp 135 – 153

Dickinson, J. Friary, P. & McCann, C. M. (2016). The influence of mindfulness meditation on communication and anxiety: A case study of a person with aphasia. *Aphasiology*. Pp 1-15.

Dimitris, A. and Kauffman, J M. (2013). The social model of disability: dichotomy between impairment and disability. *The Journal of Medicine and Philosophy*. Vol 38, Issue 4, pp 441 – 459

Docking, K. Murdoch, B E, and Jordan, F M. (2000). Interpretation and comprehension of linguistic humour by adolescents with head injury: a group analysis. *Brain Injury*. Vol 14, Issue 1, pp 89 – 108

Doughty Horn, E A. Crews, J A. Guryan, B A. and Katsilometes, B M. (2016). Identifying and addressing grief and loss issues in a person with aphasia: A single case study. *Journal of Counselling and Development*. Vol 94, Issue 2

Ellis, A. (1962). *Reason and Emotion in Psychotherapy*. Stuart. New York

Fairfax, H, (2016). 'Neuropsychology and counselling psychology'. *Handbook of Counselling Psychology*. Sage Publication, UK

Farrell, D. Keenan, P. and Keubbs, L. (2013). An interpretative phenomenological analysis (IPA) of EMDR clinicians experiences of bullying. *Sociology Science Direct*. Vol 2, pp 6 – 25

Flynn, L. Cumberland, A. and Marshall, J. (2009). Public knowledge about aphasia: a survey with comparative date. *Aphasiology*. Vol 23, Issue 3, pp 393 – 401

Fotiadou, D., Northcott, S., Chatzidaki, A. and Hilari, K. (2014). Aphasia blog talk: How does stroke and aphasia affect a person's social relationships?. *Aphasiology*, doi: 10.1080/02687038.2014.928664

Fredrickson, B L. (2001). The role of positive emotions in positive psychology: the broaden and build theory of positive emotions. *American Psychologist*. Vol 56, Issue 3, pp 218 – 226

Fridriksson, J. (2011). Measuring and inducing brain plasticity in chronic aphasia. *Journal of Communication Disorders*. Vol 44, Issue 5, pp 557 – 563

Galletta, E E. and Barrett, A M. (2014). Impairment and functional interventions for aphasia: having it all. *Current Physical Medical Rehabilitation*. Vol 2, Issue 2, pp 114 – 120

Garcia, L J. Barrette, J. and Laroche, C. (2000). Perceptions of the obstacles to work reintegration for persons with aphasia. *Aphasiology*. Vol 14, No 3, pp 269 – 290

Gilbert, P. (2009). Introducing compassion-focussed therapy. *Advances in Psychiatric Treatment*. Vol 15, Issue 3, pp 199 – 2-8

Glaser, BG. (1967) The Discovery of Grounded Theory: Strategies for Qualitative Research, *Nursing Research* 3 (2). January.

Greenberg, V D. (1997). Freud and His Aphasia Book: *Language and the Sources of Psychoanalysis*. Cornell Studies in the History of Psychiatry. Ithaca: Cornell University Press. USA

- Grohn, B. Worrall, L. Simmons-Mackie, N. and Hudson, K. (2014). Living successfully with aphasia during the first year post-stroke: a longitudinal qualitative study. *Aphasiology*. Vol 28, Issue 12, pp 1405 - 1425
- Guina, J. and Guina, C. (2018). Wants talk psychotherapy but cannot talk: EMDR for post stroke depression with expressive aphasia. *Innovations in Clinical Neuroscience*. Vol 15, Issue 1-2, pp 45 – 48
- Gyorfi, A. and Rebek-Nagy, G. (2015). Aphasia and interdisciplinarity. *Social and Behavioural Sciences*. Vol 205, pp 671 - 675
- Hackett, M L. Anderson, C S. House, A. and Halteh, C. (2008). Interventions for preventing depression after stroke. *Cochrane Database Systematic Review*. 3):CD003689. doi: 10.1002/14651858.CD003689.pub3.
- Haley KL, Womack JL, Harmon TG, and Williams, SW (2015). Visual analog rating of mood by people with aphasia. *Top Stroke Rehabilitation*. Vol 4, pp 239-45
- Haraldsson, L. Christensson, L. Conlon, L. and Henrikson, M. (2015). The experiences of ICU patients during follow up sessions – A qualitative study. *Intensive and Critical Care Nursing*. Vol 31, Issue 4, pp 223 – 231
- Headway Brain Association, [www.headway.org.uk](http://www.headway.org.uk) accessed 2017
- Heidegger, M. (1962). *Being and Time*. Blackwell, Oxford.
- Hilari, K. Needle, J J. and Harrison, K L. (2012). What are the important factors in health related quality of life for people with aphasia? A systematic review. *Archives Physical Medical Rehabilitation*. Vol 93, pp 86 – 95

Hilari, K. and Northcott, S. (2006). Social support in people with chronic aphasia. *Aphasiology*. 20(1), pp. 17-36. doi: 10.1080/02687030500279982

Hildrebrand, M W. (2015). Effectiveness of interventions for adults with psychological and emotional impairment after stroke: An evidence base review. *The American Journal of Occupational Therapy*. Vol 69, Issue 1

Holland, A L and Nelson, R L (2014). *Counselling in Communication Disorders: A Wellness Perspective*. 2<sup>nd</sup> Ed. Plural Publishing, USA

Huejung, K. and Rose, K M. (2014). Concept analysis of family homeostasis. *Jan Leading Global Nursing Research*. Vol 70, Issue 11, pp 2450 – 2468

Hussein, D. (2010). Healing through writing. *The International Journal of mental health*. Vol 12, Issue 2, pp 19 - 23

Hyland, T. (2009). Mindfulness and the therapeutic function of education. *Journal of Philosophy of Education*. Vol 43, Issue 1, pp 119 - 131

James, I A. Southam, L. and Blackburn, I M. (2004) Schemas Revisited. *Clinical Psychology and Psychotherapy*. Vol 11, pp 369 - 377

Johansson, V. Soekadar, S R. and Clausen, J. (2017). Locked Out: Ignorance and Responsibility in Brain-Computer interface communication in Locked-in syndrome. *Clinical Neuroethics*. Vol 26, Issue 4, pp 555-576

Jones, C. and Lyons, C. (2003). Researching the experience of being critically ill: some methodological difficulties. *Intensive and Critical Care Nursing*. Vol 19, Issue 6, pp 365 – 369



Jones, C. Backman, C. Capuzzo, M. Egerod, I. Flaatten, H. Granja, C. Rylander, C. and Griffiths, R D. The RACHEL group. (2010) Intensive care diaries reduce new onset post traumatic stress disorder following critical illness: a randomised, controlled trial. *Critical Care*. Vol 15, Issue 5

Joseph, S, Murphy, D and Regel, S (2012). An Affective-Cognitive Processing Model of Post Traumatic Growth. *Clinical Psychology and Psychotherapy*. Vol 19, Issue 4, pp 316 - 325

Karkou, V. and Meekums, B. (2017). Is dance movement therapy an effective intervention for dementia? A review of the evidence, Dementia and Cognitive Improvement Group. *Cochrane Library*

Lepore, S. J. & Smyth, J. M. (Eds.). (2002). *The writing cure: How expressive writing promotes health and emotional well-being*. American Psychological Association. Washington, DC, US.

Levine, P A. (2010). *In an unspoken voice: how the body releases trauma and restores goodness*. North Atlantic Books, USA

Lugo, Z. Pella, F. Blandin, V. Laureys, S. and Gosseries, O. (2017). Assessment of needs, psychological impact and quality of life in families of patients with Locked in syndrome. *Journal of Brain Injury*. Vol 31, Issue 12, pp 1590 - 1595

Magee, W L. Brumfitt, S M. Freeman, M. and Davidson, J W. (2006). The role of music therapy in an interdisciplinary approach to address functional communication in complex neuro-communication disorders: a case report. *Disability Rehabilitation*. Vol 28, Issue 19, pp 1221 - 9

Mandelstam, M. (2011). *How we treat the sick: Neglect and abuse in our health services*. Jessica Kingsley Publishers, UK

Mannion, R. and Braithwaite, J. (2012). Unintended consequences of performance measurement in healthcare: 20 salutary lessons from the English National Health Service. *International Journal of Medicine*. Vol 42, Issue 5, pp 569 - 574

Marcotte, K. Androver-Roig, D. Damien, B. de Preaumont, M. Genereux, S. Hubert, M. and Ansaldo, A I. (2012). Therapy-induced neuroplasticity in chronic aphasia. *Neuropsychologia*. Vol 50, Issue 8, pp 1776 - 86

Marshall, J. (2010). Classification of aphasia: are there benefits for practice?. *Journal Aphasiology*. Vol 24, Issue 3, pp 408 - 412

McDonald, S. and Pearce, S. (1996). Clinical insights into pragmatic theory: frontal lobe deficits and sarcasm. *Brain Language*. Vol 53, Issue 1, pp 81 - 104

McElroy, C. and Esterhuizen, P. (2017). Compassionate communication in acute healthcare: establishing the face and content validity of a questionnaire. *Journal of Research in Nursing*. Vol 22, Issue 1 -2, pp 72 – 88

McGrath, J. (2004). Beyond restoration to transformation: positive outcomes in the rehabilitation of acquired brain injury. *Clinical Rehabilitation*. Vol 18, Issue 7, pp 767-775

McNemanin, R. Tierney, E. and MacFarlane, A. (2015). Addressing the long term impact of aphasia: how far does the conversation partner programme go?. *Aphasiology*. Vol 29, Issue 8, pp 889 – 913

Meershoek, A. Krumeich, A. and Vos, R. (2007). Judging without criteria? Sickness certification in Dutch disability schemes. *Sociology Health Illness*. Vol 29, Issue 4, pp 497 -514

Michallet, B. Le Dorze, G. Tetreault, S. (2003). The needs of spouses caring for severely aphasic persons. *Aphasiology*. Vol 15, pp 731–47

Miller, N. and Campbell, D. T. (1959). Recency and primacy in persuasion as a function of the timing of speeches and measurements. *Journal of Abnormal and Social Psychology*. Vol 59, pp 1-9

Miller, E L. Murray, L. Richards, L. Zorowitz, R D. Bakas, T. Clark, P. and Billinger, S A. (2010). Comprehensive Overview of Nursing and Interdisciplinary Rehabilitation Care of the Stroke Patient. *Stroke*. Vol 41, pp2402 – 2448

Morris, R. Eccles, A. Ryan, B and Kneebone, I I. (2017). Prevalence of anxiety in people with aphasia after stroke. *Aphasiology*. Vol 31, Issue 12, pp 1410 – 1415

Morris, Z S. Wooding, S. and Grant, J. (2011). The answer is 17 years, what is the questions: understanding time lags in translational research. *Journal Research Society Medicine*. Vol 104, Issue 12. pp 510 - 520

Murray, M. and Chamberlain, K. (1999). *Qualitative health psychology: theories and methods*. Sage, UK

Murray, L L. and Ray, H A. (2001). A comparison of relaxation training and syntax stimulation for chronic nonfluent aphasia. *Journal Communication Disorders*. Vol 34, Issue 1 – 2, pp 87-113

Musser, B. Wilkinson, J. Gilbert, T. and Bokhour, B G. (2015). Changes in identity after aphasic stroke: implications for primary care. *International Journal of Family Medicine*. Epub 2015 Jan 21

National Health Service. [www.nhs.uk](http://www.nhs.uk) accessed 2017

National Institute for Clinical Excellence (NICE). [www.nice.org.uk](http://www.nice.org.uk) accessed 2017

Newdick, C. and Danbury, C. (2013). Culture, Compassion and Clinical Neglect: Probity in the NHS after Mid Staffordshire. *Journal of Medical Ethics*. Published Online. <http://dx.doi.org/10.1136/medethics-2012-101048>

Nicholl, D. Aojula, A. Hassan-Smith, G. Ben Amer, H. and Nightingale, P. (2017). *The impact of brief neurological examination on neurophobia*. Presentation – Association of British Neurologists Annual Meeting 2017, Liverpool

Northcott, S. and Hilari, K. (2011). Why do people lose their friends after a stroke?. *International Journal of Language and Communication Disorders*. Vol 46, Issue 5, pp. 524 - 534

Northcott, S. and Hilari, K. (2018). “I’ve got somebody there who cares”: what support is most valued following stroke?. *Journal of Disability and Rehabilitation*. 40 (20), pp 2439 – 2448

Northcott, S. Marshall, J, and Hilari, K. (2016). What factors predict who will have a strong social network following a stroke? *Journal of Speech Language and Hearing Research*. Doi: 10.1044/2016\_JSLHR-L-15-0201

Northcott, S, Simpson, A, Moss, B, Ahmed, N, and Hilari, K, (2016). How do speech and language therapists address the psychosocial well-being of people with aphasia?. Results of online survey. *International Journal of Communication Disorders*. 2016 Sept 4

Northcott, S, Simpson, A, Moss, B, Ahmed, N, and Hilari, K, (2017). Supporting people with aphasia to settle into a new way to be: speech and language therapists views on providing psychosocial support. *International Journal of Language and Communication Disorders*. Vol 53, Issue 1, pp 16 – 29

Nystrom, M. (2006). Aphasia: an existential loneliness: A study on the loss of the world of symbols. *International Journal of Qualitative Studies on Health and Well-being*. Vol 1, Issue 1, pp 38- 49

Obholzer, A. and Roberts, V Z. (1994). *The unconscious at work: individual organizational stress in the human services*. Routledge, UK

O'Brien, E. (2016). Talking about aphasia: The Two Voices of Insight, *Insight, Communication Disorders*. UK

Oliver, M. (1990). *The politics of disablement*. Macmillan. Basingstoke

Olsen, K D. Nester, M. and Hansen, S B. (2017). Evaluating the past to improve the future: a qualitative study of ICU patients experiences. *Intensive and Critical Care Nursing*. Vol 43, pp 61 - 67

O Malley-Keighran, MO, and Coleman, M. (2014). 'I am not a tragedy. I am full of hope': communication impairment narratives in newspapers. *International Journal of Language Communication Disorders*. Vol 49, Issue 2, pp 174 - 88

Onnis, L. (2017). Caregiver communication to the child as moderator and mediator of genes of language. *Behavioural Brain Research*. Vol 32, pp 197 - 2002

Orbach, S. (2000). *The Impossibility of Sex*. Touchstone, New York, USA

Ostrower, C. (2015). Humour as a defense mechanism during the Holocaust, Interpretation: *A Journal of Bible and Theology*. Vol 69, Issue 2, pp 183 - 195

Owensworth, T. (2014). *Self Identity After Brain Injury*. Psychology Press, UK

Pakhomov, S. Marino, S. Birnbaum, A. Hawkins-Taylir, C. and Leppik, I. (2010). Measuring speech and language characteristics of effects of medications on cognition, *The Journal of the Acoustical Society of America*. Vol 127, Issue 3

Pearce, S. McDonald, S. and Coltheart, M. (1998). Interpreting ambiguous advertisements: the effect of frontal lobe damage. *Brain Cognition*. Vol 38, Issue 2, pp 150 – 164

Pennebaker, J W. (1990). *Opening up: The healing power of confiding in others*. William Morrow, New York.

Pennebaker, J. W., & Susman, J. R. (1988). Disclosure of traumas and psychosomatic processes. *Social Science & Medicine*. Vol 26, Issue 3, pp 327-332

Pinker, S. (1994). *The Language Instinct*. Penguin, UK

Pope, R. (2017). The NHS: Sticking fingers in its ears, humming loudly. *Journal of Business Ethics*. Vol 145, Issue 3, pp 577 - 598

Rankin, L. (2013). *Mind over medicine*. Hay House Publishing, USA

Rattray, J. (2010). Life after critical illness: 'known knowns' and 'known unknowns'. *Australian Critical Care*. Vol 23, Issue 4, pp 174 - 175

Robinson, R G. and Spalletta, G. (2010). Poststroke depression: a review. *Canadian Journal of Psychiatry*. Vol 55, Issue 6, pp 341 – 349

Rogers, C. (1951). *Client-centered therapy: Its current practice, implications and theory*. Constable. London

Ross, A. Winslow, I. Marchant, P. and Brumfitt, S. (2006). Evaluation of communication, life participation and psychological well-being in chronic aphasia: the influence of group intervention. *Aphasiology*. Vol 20, Issue 5, pp 427 – 448

Rousseau, MC, Baumstarck, K, Allesandrini, M, Blandin, V, Billette de Villermeur, T, and Auquier, P. (2015). Quality of Life in patients with locked-in syndrome: Evolution over a 6 year period. *Orphanet Journal of Rare Diseases*. 19.10.88

Rousseaux, M. Verogneaux, C. and Kozlowski, O. (2010). An analysis of communication in conversation after severe brain injury. *European Journal of Neurology*. Vol 17, Issue 7

Royal College of Speech and Language Therapists (2017 and 2017). [www.rcslt.org](http://www.rcslt.org)

Samuelson, K. (2011). Adult intensive care patients' perception of endotracheal tube related discomforts: a prospective evaluation. *Heart and Lung*. Vol July 1, Page 49

Samuelson, K A. and Corrigan, I. (2009.) A nurse-led intensive care after-care programme – development, experiences and preliminary evaluation. *Nursing Critical Care*. Vol 14, Issue 5. Pp 254 - 263

Scase, R. (1992) *Class*. Open University Press, UK

- Scneider, M. and Voracek, M. (2018). A joke a day keeps the doctor away: meta-analytical evidence of differential associations of habitual humour styles with mental health. *Scandinavian Journal of Psychiatry*. Vol 59, Issue 3
- Scott, S. (2018). The language of laughter. *Manor*. Summer 2018. pp 45 - 47
- Scott, S. Lavan, N. Chen, S. and McGettigan, C. (2014). The social life of laughter. *Trends in Cognitive Sciences*. Vol 18, No 12
- Seeto, R. Scruby, K. and Greenhill, T. (2017). 'Your whole life becomes a recovery': Experiences of young adults following acquired brain injury. *Counselling Psychology Review*. Vol 32, Issue 4, pp 39-48
- Sekhon, J K. Douglas, J. and Rose, M L. (2015). Pathology practice in addressing psychological well-being in people with aphasia after stroke. *International Journal of Speech and Language Pathology*. Vol 17, pp 252 – 262
- Seligman, M. E. P., & Beagley, G. (1975). Learned helplessness in the rat. *Journal of Comparative and Physiological Psychology*. 88, 534-541. doi:10.1037/h0076430
- Seligman, M.E.P. (2002). *Authentic Happiness: Using the New Positive Psychology to Realize Your Potential for Lasting Fulfillment*. Free Press, New York, USA
- Seligman, M (2017). *Authentic Happiness*, Nicholas Brealey Publishing. London
- Sellars, C., Hughes, T., & Langthorne, P. 2005. Speech and Language Therapy for Dysarthria due to non-progressive brain damage. *The Cochrane database of systematic reviews*. Issue 3. Pages: CD002088.



Sharp, K. and Hewitt, J. (2014). Dance as an intervention for people with Parkinson's disease: a systematic review and meta-analysis. *Neuroscience and Biobehavioural Reviews*. Volume 47, pp 445-456

Sheridan, M D. (1973). *From birth to five years: children's developmental progress*. NFER Publishing, London

Sheratt, S. (2011). Written media coverage of aphasia: a review. *Aphasiology*. Vol 25, Issue 11, Pages 1132 - 1152

Shisler-Marshall, R. Laures , J L. and Love, K. (2018). Brief Mindfulness group training in aphasia: exploring attention, language and psychophysiological outcomes. *International Journal Language Communication Disorders*. Vol 53, Issue 1, pp 40- 54

Shrubsole, K. Worrall, L. Power, E. and O'Connor, D A. (2016). Recommendations for post-stroke aphasia rehabilitation: an updated systematic review and evaluation of clinical practice guidelines. *Aphasiology*. Vol 31, Issue 1, pp 1 24 1

Simmons-Mackie, N. and Damico, J. (2011). Counselling and Aphasia Treatment: Missed Opportunities. *Topics in Language Disorders*. Vol 31, Issue 4, pp 336-351

Smith, JA, Flowers, P, and Larkin, M, (2009). *Interpretative Phenomenological Analysis*. SAGE, UK

Smyth, J M. and Pennebaker, J W. (2001). What are the health defects of disclosure? In A Baum, A. Revenson, T A. and Singer, J E. *Handbook of Health Psychology*. Lawrence Erlbaum, Mahwah, NJ

Stahl, B. and Kotz, S A. (2014). Facing the music: three issues in current research in signing and aphasia. *Frontiers in Psychology: Cognitive Science*

Stein-Rubin, C and Adler, BT (2017). *Counseling in Communication Disorders*. Slack Incorporated, USA

Sutt, Anna-Liisa (2017). Towards an improved understanding of the effect of a speaking valve on lung volumes and communication in the critically ill tracheostomised patient. *PhD Thesis, Medicine Faculty, The University of Queensland*

Swaminath, G. (2006). 'Joke's a Part: in defence of humour. Indian Journal of Psychiatry. Vol 43, Issue 3, pp 177 – 180

Syder, D. (1998). *Wanting to Talk: Counselling Case Studies in Communication Disorders*, 1<sup>st</sup> Ed, Wiley, UK

Tanner, D C. (2010). *Exploring the psychology, diagnosis and treatment of Neurogenic Communication Disorders*. I Universe, UK

Tanner, D C. and Gerstenberger, D L. (1988). The grief response in neuropathologies of speech and language. *Aphasiology*. Vol 2, Issue 1, pp 79 -84

Tarrant, M. Warmoth, K. Code, C. Dean, S. Goodwin, V A. Stein, K. and Sugavanam, T. (2016). Creating psychological connections between intervention recipients: development and focus group evaluation of group singing session for people with aphasia. *British Medical Journal*. Vol 6, Issue 2

Taormina-Weiss, W (2013). Psychological intervention can help a person with a disability progress through stages of disability and assist them resolving difficulties experiences. *Psychology and Social Aspects of Disability*. Disability Information. Rev 12.05.2012

Tedeschi, R. G., & Calhoun, L. G. (1996). The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress*. Vol 9, Issue 3, pp 455-472.

Tedeschi, R G. and Calhoun, L G. (2004). *Post-traumatic growth: conceptual foundation and empirical evidence*. Lawrence Erlbaum Associates, Philadelphia, USA

Tedeschi, R.G., & Calhoun, L.G. (2007). Grief as a transformative struggle. In K.J. Doka (Ed.): *Living with Grief: Before and After the Death*. (pp. 107-122). Hospice Foundation of America. Washington DC

Tedeschi, R.G., & Calhoun, L.G. (2013). Working as an expert companion to facilitate posttraumatic growth. In D. Murphy & S. Joseph (Eds.). *Trauma and the therapeutic relationship: Approaches to process and practice*. (pp. 96-110). Palgrave Macmillan. New York

The Stroke Association (2014, 2016, 2017). [www.stroke.org.uk](http://www.stroke.org.uk) accessed

The Stroke Association (2013). *'Feeling Overwhelmed': the emotional impact of stroke*. Life After Stroke Campaign Report

Thomas, E. J., Levack, W. M. M., & Taylor, W. J. (2014). Self-reflective meaning-making in troubled times: Change in self-identity after traumatic brain injury. *Qualitative Health Research*. Vol 24, Issue 8, pp, 1033–1047.

Tikofsky, R. (2012). Freud's Theories of Aphasia and their Relevance to Contemporary Neuroscience: An historical analysis. *Procedia – Social and Behavioural Sciences*. Vol 61, pp 246 - 247

Theisen Simanke, R. (2017). Meaning and object in Freud's theory of language. *International Journal of Psychoanalysis*. Vol 96. Issue 6

Van der Kolk, B. (2006). Clinical implications of neuroscience research in PTSD. *Annals of the New York Academy of Sciences*. pp. 1-17

Van Dijk, M J. de Man-van Ginkel, J M. and Hafsteinsdóttir, T B and Schuurmans. (2017). Psychometric evaluation of the Signs of Depression Scale with a revised scoring mechanism in stroke patients with communicative impairment. *Clinical Rehabilitation*. Vol 31, Issue 12

Wake, S. and Kitchiner, D. (2013). Post-traumatic stress disorder after intensive care. *British Medical Journal*. Vol 346

Ward, T. and Fairfax, H. (2017). Neuroscience. *Counselling Psychology Review*. Vol 32, Number 4, Pages 1 -3

Wilkinson, B. (2013). *Beyond Words: a counselling services for clients with a communication disability*. Nottingham NHS Speech and Language Therapy Service

Wilkinson, S. (1988). The role of reflexivity in feminist psychology. *Women's Studies International Forum*. Vol 11, Issue 5, pp 493-502

Willig, C. (2001). *Introducing Qualitative Research in Psychology: Adventures in Theory and Method*. Open University Press, Buckingham.

Winner, E. and Gardner, H. (1977). The comprehension of metaphor in brain-damaged patients. *Brain: A Journal of Neurology*. Vol 100, Issue 4, pp 717 - 729

Woolfe, R. (1990). 'Counselling psychology in Britain: an idea whose time has come'. *The Psychologist*. Vol 12, pp 531–535

Woolfe, R. Strawbridge, S. Douglas, D. and Dryden, W. (2011). *Handbook of Counselling Psychology*. 3<sup>rd</sup> Edition, Sage Publications, London

World Health Organisation for ICF and ICD 10 [www.who.int](http://www.who.int) accessed 2017 and 2018

Worrall, L. Brown, K. Cruice, M. Davidson, B. Hersh, D. and Howe, T. (2009). The evidence for a life-coaching approach to aphasia. *Aphasiology*. Vol. 24, Issue 4

Worrall, L. and Frattali, C. (2000). *Neurogenic Communication Disorders*. Theime Publishers, UK

Worrall, L. and Wallace, S. (2015). The ICF, Relationship-Centred Care and Research Outcome Measurement: Carol Frattali's Impact on Aphasia Research. *SIG 2 Perspectives on Neuropsychology and Neurogenic Speech and Language Disorders*, Vol 25, Issue 3, pp 107-113

Wotton, G. (2016). Aphasia therapy: a case study. *International Journal of Therapy and Rehabilitation*. Vol 23, Issue 11.

Wray, F. and Clarke, D. (2018). Longer-term needs of stroke survivors with communication difficulties living in the community: a systematic review and thematic synthesis of qualitative studies. *BMJ Open*. Vol 7, Issue 10

## **Appendices**

|          |  |
|----------|--|
| <b>A</b> | Participant Information Sheet                                  |
| <b>B</b> | Consent Form   |
| <b>C</b> | Aphasia Friendly Participant Information Sheet (Email Version) |
| <b>D</b> | Aphasia Friendly Consent form                                  |
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| <b>F</b> | Demographic Form   |

## Appendix A – Participant Information Sheet



### Participant Information Sheet

#### The psychological experience of acquiring a communication impairment in adulthood.

##### Who is the researcher and what is the research about?

Thank you for your interest in my research. The research aims to explore adults' individual experiences of acquiring a communication impairment. There is very little research into this area and therefore I would like to capture the voice of adults who have experienced this change in their life.

My name is Rachel Adams and I am a Trainee Counselling Psychologist in the Department of Health and Social Sciences, University of the West of England, Bristol. I am completing this research for my doctoral thesis. My research is supervised by Dr Tony Ward. I am also a qualified Speech and Language Therapist.

##### What does participation involve?

**An interview** - You are invited to participate in a semi structured interview. There are no right or wrong answers – I am interested in the range of opinions, thoughts and experiences. The interview will be recorded and transcribed as part of the research. All transcriptions will be kept anonymous and confidential.

**A demographic tick box sheet** – after the interview you are kindly asked to answer some demographic questions. This is for me to gain a sense of who is taking part in the research.

**Consent form** - you will need to confirm that you agree to participate, before beginning the interview. A consent form has been included at the end of this form and will need to be completed prior to the interview.

##### Who can participate?



Any adults who have been diagnosed with a communication impairment in adult life. All participants must be over 20 years of age and have been living with their communication impairment for over 2 years.

The communication impairment maybe the result of a head injury, stroke or other neurological condition. The communication impairment might have been diagnosed as aphasia, dysarthria and/or dyspraxia.

### **How will the data be used?**

The data will be anonymised (i.e. any information that can identify you will be removed) and analysed for my research project. This means extracts from your interview responses may be quoted in my thesis and in any publications and presentations arising from the research. The demographic data for all of the participants will be compiled into a table and included in my thesis and in any publications or presentations arising from the research. The information you provide will be treated confidentially and personally identifiable details will be stored separately from the data. My marking tutors may ask to view the confidential data but will also be bound by confidentiality and will not share the information with anyone else.

### **What are the benefits of taking part?**

You will get the opportunity to participate in a research project on an important counselling and psychological issue. It is hoped that the research can contribute towards raising awareness of communication difficulties and highlight gaps in services and provision.

### **How do I withdraw from the research?**

If you decide you want to withdraw from the research please contact me via email. Please note that there are certain points beyond which it will be impossible to withdraw from the research – for instance, when I have submitted my thesis. Therefore, I strongly encourage you to contact me within 3 weeks of participation if you wish to withdraw your data. I'd like to emphasise that participation in this research is voluntary and all information provided is anonymous where possible.

### **Are there any risks involved?**

We don't anticipate any particular risks to you with participating in this research; however, there is always the potential for research participation to raise uncomfortable and distressing issues. For this reason I would signpost you to make contact with some counselling services should this occur.

If you have any questions about this research please contact my research supervisor

:Dr Tony Ward, Department of Health and Social Sciences, Frenchay Campus,  
Coldharbour Lane, Bristol BS16 1QY

Email: [tony.ward@uwe.ac.uk](mailto:tony.ward@uwe.ac.uk)

Should you wish to discuss specific concerns related to the topic in the questionnaire,  
please contact the researcher on [Rachel4.Adams@live.uwe.ac.uk](mailto:Rachel4.Adams@live.uwe.ac.uk)

This research has been approved by the Faculty Research Ethics Committee  
(FREC)

## Appendix B – Consent Form



### **The psychological experience of acquiring a communication impairment in adulthood.**

#### **Consent Form**

Thank you for agreeing to take part in this research.

My name is Rachel Adams and I am a Trainee Counselling Psychologist in the Department of Health and Social Sciences, University of the West of England, Bristol. I am collecting this data collection for my doctoral thesis. I am also a qualified Speech and Language Therapist.

My research is supervised by Dr Tony Ward, Assistant Professor and Counselling Psychologist. Should you have any queries about the research he can be contacted at the Department of Health and Social Sciences, University of the West of England, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY [Tel: (0117) 3281234; Email: [tony.ward@uwe.ac.uk](mailto:tony.ward@uwe.ac.uk)]

Before we begin I would like to emphasize that:

- your participation is entirely voluntary
- you are free to refuse to answer any question
- you are free to withdraw at any time [within the limits specified on the information sheet – 3 weeks after the interview].

There are no right or wrong answers and I am interested in everything you have to say.

Please tick the 1st box below to confirm that you have read the contents of this form and the participant information sheet, and that you consent to participate in the research. Please tick the second box to confirm that you are a have been diagnosed with a communication impairment.

1<sup>st</sup> ☐

2<sup>nd</sup> ☐

\_\_\_\_\_ (Date)

*This research has been approved by the Faculty Research Ethics Committee (FREC)*

## Appendix C – Aphasia Friendly Participant Information Sheet



### INFORMATION SHEET

#### Information about the research

##### What is the research about?

The **research** is about **living with aphasia**.

PICTURE

PICTURE

Rachel is **interviewing adults with aphasia**.

PICTURE

PICTURE

Rachel wants to know **thoughts and feelings about aphasia.**

PICTURE

**Rachel is interested in your experience of aphasia.**

**PICTURES**

Rachel **wants to hear your story.**

The **research is not speech and language therapy.** PICTURE

**Taking part in the research**

**You will be asked to sign a consent form.**

PICTURE

Rachel will **visit you at an arranged time.**

PICTURE

Rachel will **ask you questions about your experience.**

**Rachel and you will have a conversation.**

PICTURE

You can take your time.

There is no rush.

You can respond in anyway.

PICTURE

Rachel will record the conversation.

PICTURE

The **conversation** will last between **45 minutes and 1 hour.**

**PICTURE**

## **After the research**

**Rachel will type up the conversation.**

PICTURE

**Your name will not be typed up.**

The **typed conversation is confidential and anonymous.**

PICTURE

The **recording of the conversation** will **be deleted**.

PICTURE

Two **university staff** mark **Rachel's work**.

Two **university staff** will **read parts** of the **conversation**.

**University staff** and **Rachel follow** confidentiality **rules**.

PICTURE

### **Reason for taking part?**

Chance to share your experience.

Chance to share your views.

PICTURE

Contributing towards psychological research.

PICTURE

**Research** that **aims to raise awareness** in **society**.

PICTURE



## **What if I change my mind?**

**Taking part** in the **research is voluntary**.

You do not have to take part.

**You can withdraw** from the research **up to 3 weeks after the interview**.

**You can withdraw** from the research **by contacting Rachel**.

## **Are there any risks involved?**

There are no particular risks to you.

Talking about your experience may feel uncomfortable and upsetting.

PICTURE

If you feel very upset afterwards Rachel can signpost you to counselling services.

PICTURE

## **Do you have any questions?**

**You can contact Rachel (the researcher) at**

**PHOTO**

[Rachel4.Adams@live.uwe.ac.uk](mailto:Rachel4.Adams@live.uwe.ac.uk)

**You can contact Rachel's supervisor Dr Tony Ward at**

**PHOTO**

[Tony.ward@uwe.ac.uk](mailto:Tony.ward@uwe.ac.uk)

Dr Tony Ward,

Department of Health and Social Sciences,

Frenchay Campus,

Coldharbour Lane,

Bristol BS16 1QY

This research has been approved by the Faculty Research Ethics Committee

(FREC)

PICTURE

## Appendix D – Aphasia Friendly Consent Form

Thank you for taking part in the research.

My name is Rachel Adams.

PHOTO

I am a Trainee Psychologist at university.

PICTURE

I am a qualified Speech and Language Therapist.

PICTURE

**Psychological Research: Aphasia**

### Consent Form

The research is for a doctoral thesis. PICTURE

The research is supervised by Dr Tony Ward. PHOTO

Any queries, contact Dr Tony Ward at  
Department of Health and Social Sciences,  
University of the West of England,  
Frenchay Campus, Coldharbour Lane,  
Bristol BS16 1QY  
Tel: (0117) 3281234  
Email: [tony.ward@uwe.ac.uk](mailto:tony.ward@uwe.ac.uk)

PHOTO

Before we begin I would like to emphasize that:  
- your participation is entirely voluntary.

- you are free to refuse to answer any question.
- you are free to withdraw at any time up to 3 weeks after the interview.
- You are also the 'expert'.
- There are no right or wrong answers.
- I am interested in everything you have to say.

Please tick the 1st box below to confirm that you have read the contents of this form and the information sheet.

This means you consent to being in the research.

Please tick the second box to confirm that you have been diagnosed with a communication impairment.

1<sup>st</sup> ☐

2<sup>nd</sup> ☐

\_\_\_\_\_ (Date)

*This research has been approved by the Faculty Research Ethics Committee (FREC)*

## Appendix E - Interview Guide

My name is Rachel. Thank you for taking part in this research.

Have you read the information sent in the post (have copies in hand)

Just to remind you:-

- I will be recording our conversation.
- You can refuse to answer any questions.
- There are no right or wrong answers.
- I am interested in your story.

Confirm consent

Establish a consistent Yes and No

If this gets too difficult at any time, please just raise your arm or let me know and we can take a break, pause the interview or stop completely.

I have some set questions which I will work through but please feel free to add anything else you feel you would like me to know.

We can take our time.

- **How many years have you had aphasia/communication impairment?**
- **How did your communication change? What happened?**
- **Do you remember when you first realised that you were unable to communicate in the same way?**
- **What was your first thought? How did you feel? How did you react?**
- **How did other people react? Family? Friends? Others?**
- **How did that make you feel?**
- **What did you think about this?**
- **Did a doctor or health professional talk to you about your communication?**
- **Can you remember your thoughts when they spoke to you about it?**
- **Can you remember how you reacted?**

- **What were your feelings about it?**
- **Did you share your feelings with anyone?**
- **What support was offered?**
- **What are your thoughts about this experience now?**
- **Did the feelings change over time?**
- **What did you do to make yourself feel better? Did this help?**
- **Did anybody in particular help you to feel understood? If so, who was this, what did they do that was helpful?**
- **Did you have any professional counselling or psychological support?**
- **If so, how many sessions? Did this help?**
- **What has aphasia/communication impairment changed for you?**
- **What's the most difficult thing for you about aphasia/CI?**
- **Have you noticed anything positive since aphasia/CI?**
- **Have your thoughts and feelings about aphasia/CI changed over the years?**
- **Did you know what aphasia/CI was before?**
- **If you met someone today who had just got aphasia what advice would you offer them?**
- **If you were to give advice to health professionals about adults with communication difficulties what would you say?**
- **If you were to raise awareness in society about communication difficulties what would be your biggest issue to raise?**
- **Is there anything else you would like to offer?**

## Appendix F – Demographics Form



### The psychological experience of acquiring a communication impairment in adulthood – Rachel Adams

#### Demographics Sheet

The following questions ask for information about your personal circumstances. You do not need to provide this information as it is entirely voluntary. All data you provide will be kept confidentially and securely.

NAME: \_\_\_\_\_

Sex: Are you?

|                          |
|--------------------------|
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |

Male

Female

Prefer not to say

(NB: If transgender, indicate your preferred sex role)

Sexual Orientation: Are you?

|                          |
|--------------------------|
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |

Heterosexual

Gay/Lesbian

Bisexual

Prefer not to say

Your Ethnicity: (Please tick)

White:

|                          |
|--------------------------|
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |

British

Irish

Other White Background (Please specify \_\_\_\_\_)

Prefer not to say

Black or Black British:

|                          |
|--------------------------|
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |

African

Caribbean

Other Black background (Please specify \_\_\_\_\_)

Prefer not to say

Asian or Asian British:

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Other Asian Background (Please specify \_\_\_\_\_)
- ☐ Prefer not to say

Chinese or Other Ethnic Group:

- ☐ Chinese
- ☐ Other Ethnic Group (Please specify \_\_\_\_\_)
- ☐ Prefer not to say

Mixed Ethnic Background:

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Other mixed background (Please specify \_\_\_\_\_)
- ☐ Prefer not to say

Age: (Please tick which age group you are in)

- ☐ Under 25
- ☐ 25 - 34
- ☐ 35 - 44
- ☐ 45 - 54
- ☐ 55 +
- ☐ Prefer not to say

What is your religious affiliation? (Please tick which group you are in)

- ☐ Protestant Christian
- ☐ Roman Catholic
- ☐ Evangelical Christian
- ☐ Jewish
- ☐ Muslim
- ☐ Hindu
- ☐ Buddhist
- ☐ Atheist
- ☐ Other, (Please specify \_\_\_\_\_)
- ☐ Prefer not to say