The Mental Health Impact of Aphasia: Risk Factors and Moderating Factors

Submitted by Aoife Murtagh for the completion of the degree Master of Science by Research in Psychology, 2019. Supervised by Dr Paul Dockree.
Declaration

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Summary

For some individuals who have suffered an acquired brain injury, aphasia can be a lasting and life-altering disability. Previous studies have found associations between aphasia and reduced mood and quality of life outcomes, however little research has explored this relationship and the possible risk and protective factors at play. This study aimed to examine the effects of aphasia type and severity on mood and anxiety levels, and assess the impact of social support, quality of life, cognitive reserve, time and change since onset, support group attendance, and age and gender.

In Chapter 1, the introduction provides a brief epidemiological overview of aphasia. The literature review opens with the neurological and cognitive background of aphasia, along with briefly discussing treatment and prognosis. The focus then shifts to the mental health impact of acquired disability, and the mental health implications of reduced communication and socialization (as potential consequences of language deficit). Finally, previous research on mental health in acquired brain injury and aphasia is discussed. The chapter concludes with the presentation of the research questions.

Chapter 2 deals with the quantitative study. Participant selection and the choice of scales and measures is discussed. The methodology is laid out, and the research protocol and special measures taken in working with an aphasic population are reviewed. The results section lays out the quantitative analyses of the primary research questions, followed by additional quantitative analyses which were carried out on the data. It was found that 60.9% of participants had PHQ-9 scores suggestive of possible depression, however aphasia subtype and severity did not have a significant impact on these findings. The degree of improvement in symptoms since onset was found to have a significant negative correlation with depression scores, and the level of social support received was found to be greater for those with more severe aphasia. The findings are then discussed, along with the implications of the null hypotheses.

Chapter 3 is based on the qualitative component of the study. Methodology is laid out, and the analysis of the semi-structured interview is presented under the categories of
practical and emotional difficulties, and helpful and adaptive strategies. The results are preliminarily discussed.

Chapter 4 consists of overall discussion and conclusions. The study findings are put in context with regard to previous research on mental health in acquired brain injury and aphasia, and particularly with regard to previous research on psychosocial risk and protective factors. Finally, strengths and weaknesses of the study are discussed and recommendations are made for future research.
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Chapter 1: Background and Introduction
1.1 Introduction and Epidemiology:

Aphasia is the term for cognitive language deficits due to brain damage. It can be caused by either acquired brain injury (ABI) or, less commonly, degenerative neurological conditions such as Primary Progressive Aphasia (PPA), a form of frontotemporal dementia.

The most common cause of aphasia is ischemic stroke, followed by haemorrhagic stroke (Bohme, 1984), which combined were estimated to affect approximately 55.8 million people globally in 2010. Of these, 16.9m experienced a first stroke, 33m were dealing with disability from a previous stroke, and 5.9m died from stroke-related causes (Feigin et al., 2014). Some degree of aphasia is estimated to occur in approximately one third of stroke patients (NAA, 2018), and The National Institute of Neurological Disorders and Stroke in the USA estimates that approximately one million people in America currently deal with aphasia or have suffered from it at some point (ASHA, 2017). This would translate to approximately 18,000 people in Ireland if rates of aphasia are similar. The annual stroke rate in the US has been measured as roughly 0.24% (Benjamin et al., 2017) versus 0.43% in Ireland (Timmins et al., 2018), which may indicate a higher incidence of post-stroke aphasia also, however this is uncertain.

Prevalence and epidemiology figures for all-cause aphasia are not generally recorded, but the average age of a stroke sufferer in Ireland is 73 (McElwaine, McCormack & Harbison, 2015), which may be similar to the average age of an aphasia sufferer, given the high percentage of aphasia cases which are caused by stroke (measured as approximately 84% of cases by Bohme (1984)). The average age for aphasia patients may be slightly younger when other relatively common causes such as traumatic brain injury (TBI) are included, which has a mean age of approximately 43 at onset of injury in Ireland (Philips, 2008). It is unclear how age or gender may impact the likelihood of developing aphasia following a stroke or other brain injury.

1.2 Neurological and Cognitive Background of Aphasia:

Aphasia is divided into two main categories, expressive and receptive, based on the linguistic effects of the damage sustained.
Receptive aphasia is the term for deficits in language comprehension abilities. It is also known as semantic aphasia, fluent aphasia or Wernicke’s aphasia, and is usually caused by temporal lobe damage. In receptive aphasia, a person has some degree of difficulty in understanding the meanings of words, both spoken and written. In milder cases, a person may only have difficulty with long, unbroken sentences or particularly fast speech, or with words they don’t encounter often; while in more severe cases, a person may have only basic language comprehension abilities and require much repetition or the use of gestures or visual aids to understand concepts communicated verbally. A person with severe receptive aphasia may be able to understand simple phrases which are commonly said to them, but struggle with more complex communication or in unfamiliar contexts. In addition, due to the loss of semantic information, those with receptive aphasia also have difficulties in producing meaningful speech. They may find that they struggle to find the word with the correct meaning for what they wish to say, or they may say an incorrect word without being aware that it is incorrect. In extreme cases, this can lead to the nonsensical yet non-halting speech that gave rise to the characterisation of receptive aphasia as ‘fluent’ aphasia, however in reality this degree of receptive aphasia without any degree of expressive aphasia is uncommon (Bhatnagar et al., 2002; Kang et al., 2010).

Expressive aphasia causes difficulty in producing language, while comprehension may be left largely undamaged. It is also known as productive aphasia, non-fluent aphasia, agrammatic aphasia, or Broca’s aphasia, and it is usually caused by frontal lobe damage. Expressive aphasia is characterised by a loss of fluency in speech; sufferers will struggle to find the correct word or to form grammatically correct sentences. In more minor cases, this may result in only slightly halting speech, while in severe cases, a person may be almost completely non-verbal. It is common for aphasia patients to have some degree of both expressive and receptive aphasia. In cases where both expressive and receptive deficits are severe, the term global aphasia is often used.

Aphasia occurs most commonly due to damage to the left hemisphere of the brain, which is language-dominant in approximately 94% of people (Coon, 2006). The most common areas of damage that lead to aphasia are in the inferior frontal gyrus towards the posterior of the frontal lobe (traditionally known as Broca’s area) and the posterior portion of the superior temporal gyrus (known as Wernicke’s area). Broca’s area is normally responsible for language
production, and damage leads to the expressive aphasia symptoms outlined in the previous paragraph, while Wernicke’s area is responsible for semantic information and damage leads to receptive aphasia. However, other nearby regions also have roles in language processing, and damage to any of these areas could theoretically lead to some degree of aphasia in certain individuals. These include the arcuate fasciculus, a bundle of axons which plays a large role in the connection of Broca’s and Wernicke’s areas. Damage to this area also leads to expressive aphasia, including a characteristic difficulty with repeating words and phrases which are spoken to the individual (sometimes termed conduction aphasia), as semantic information received and processed in Wernicke’s area cannot reach the production centre in Broca’s area. Recent research has also implicated the supramarginal gyrus in the parietal lobe, the left dorsal superior temporal gyrus, and the temporo-parietal junction as also being occasionally responsible for conductive deficits (Yourganov et al., 2015). See Fig.1.1 for lesion findings in their sample.

Figure 1.1: Yourganov et al. (2015) heatmap of MRI lesions sites in aphasia types, with red indicating least prevalence and yellow indicating highest prevalence. Source: Yourganov et al., 2015, p. 210
The supramarginal gyrus has also been implicated in visual word recognition when reading (Stoeckel et al., 2009) and in phonological word choice when simulating a lesion using transcranial magnetic stimulation (Hartwigsen, 2010), suggesting that, though the parietal lobe is not commonly thought of in association to aphasia, damage to this region may have the potential to cause both expressive and receptive deficits.

Both Broca’s and Wernicke’s areas and the arcuate fasciculus (and many surrounding areas of the cortex) are supplied by the same artery, the Middle Cerebral Artery, but different branches serve the frontal and temporal lobes (Hillis, 2007). This means that, in the case of cerebrovascular accident (CVA), a large determining factor in whether an individual develops expressive, receptive or global aphasia is how far deep in the artery the point of occlusion or damage occurs. This is also the reason why right-side weakness quite commonly co-occurs with aphasia, if the ischemia of the Middle Cerebral Artery has affected nearby motor regions (Hillis, 2007). It is also possible for damage to the right hemisphere of the brain to lead to aphasia, particularly in left-handed individuals, for whom approximately 19% have been found to have a language-dominant right hemisphere (Coon, 2006), and who generally show a much more bilateral pattern of language representation than right-handers (Knecht et al., 2000). Using transcranial Doppler sonography on 326 participants, Knecht et al. (2000) also found that language representation correlated with the spectrum of handedness, with only a 4% rate of right hemisphere language dominance in strongly right-handed individuals, a 15% rate in ambidextrous participants and a 27% rate in strong left-handers.

For some individuals who develop aphasia following an ABI, aphasia is a short-term complication and resolves in the first weeks or months following the injury, often with the aid of speech and language therapy, while for others, aphasia becomes a long-term complication which doesn’t resolve in response to treatment. A large study in 2010 found that, of 669 people who presented to hospital with stroke, 30% experienced aphasia in the immediate aftermath. Of these, aphasia had resolved in 38% by the time of discharge (a median time of 5 days). After six months, the percentage of the sample whose aphasia had resolved had increased to 74%, and symptoms had improved in a further 12%, leaving 14% of the aphasic sample with unchanged symptoms (Maas et al., 2010). The degree of aphasia an individual is left with long-term varies widely and depends on many factors, some of which are as yet
unclear. Factors affecting recovery from brain injury have been widely researched in recent years, as it became clear that the degree of recovery a person can hope to experience does not correlate as strongly as might be expected with the total area of damage sustained, or with age. For example, Forkel et al. (2014) found in a longitudinal study that that only 30% of the variance in recovery in a sample of post-stroke aphasia patients was possible to attribute to these factors. However, theirs was one of an increasing amount of recent studies which suggest that the integrity of the right hemisphere may play a large role in language recovery. When accounting for the volume of the right arcuate fasciculus, Forkel et al (2014) found they could predict 60% of the variance in recovery at six months post-onset, though it is notable that this finding could not be repeated in a later study (Forkel & Catani, 2018). A 2017 systematic review of the literature on the role of the right hemisphere in language recovery found that:

Although many gaps remain in the knowledge on the role of the right hemisphere, there is some evidence of a facilitation of spontaneous language recovery in the acute and subacute phase. In the subacute and chronic phase, the right hemisphere homologous language areas, along with memory and attention-related areas, facilitate treatment related improvement. (Cocquyt et al., 2017, p. 68.)

However, in treatment-free phases of chronic aphasia, the review found no evidence that right hemisphere structures encouraged recovery, and indeed some evidence was found which suggested that increased right hemisphere activity may play an inhibitory role in recovery at these times. This emphasises the importance of continued treatment in chronic aphasia.

The language deficits of aphasia are normally assessed and treated by speech and language therapists (SLTs). Assessment is usually carried out using a battery of tests which include sections on naming, word repetition and comprehension. Commonly used examples include the Boston Diagnostic Aphasia Examination (BDAE) and the Western Aphasia Battery (WAB). These tests do not include measures of functional impairment, which may be carried out separately (ASHA, 2019a). Treatment consists of language exercises designed to practice and improve on the specific deficits a patient has. For example, a person with trouble naming
objects will often work on naming flashcards, and may also work on compensatory strategies for working around deficits (ASHA, 2019b). In terms of efficacy, speech and language therapy has been shown to approximately double improvement in language during the acute phase, and to have even greater gains over baseline in the chronic phase (over a year post-injury) (Raymer et al., 2008), as spontaneous improvement generally slows after the acute/sub-acute phases. This fact has given rise to the myth that there is less to gain from treatment in the chronic phase or that no further improvements can be made, which is not supported by research (Galletta, Goral & Conner, 2018) and may thus be harmful to outcomes if considered in treatment plans. SLT treatment works best at increasing competency in the language of instruction, and is of highly variable benefit to bilingual individuals trying to regain skills in an additional language (Faroqi-Shah et al., 2010).

1.3 Acquired Disability and Mental Health:

As aphasia can constitute a long-term, disabling condition and has received relatively little detailed research from a psychosocial perspective, it may be helpful to examine the mental health effects of other types of long-term acquired disabilities for context. Aphasia caused by ABI may follow a static or improving course, but does not generally become worse over time, meaning that it may be more helpful to examine the psychological effects of conditions that follow a similar pattern, rather than degenerative conditions. This is because conditions which do not fluctuate unpredictably or follow a negative course may theoretically allow for more effective psychosocial adaptation by the individual affected.

One such condition which has received considerable study from a psychosocial context is spinal injury causing partial paralysis. For example, a large 2011 study examined 947 participants with spinal cord injury (SCI) and found that 23% had Patient Health Questionnaire 9 scores suggestive of depression, and 29% were on antidepressant medication (Fann et al., 2011). The authors also noted that only 6% were receiving adequate psychotherapy according to treatment guidelines. A 2008 study compared 33 participants with SCI living in the community to healthy controls matched for age and gender, and found that the SCI group had elevated negative psychological scores across all domains examined, and that their
depression scores were over twice those of the control group (Craig et al., 2008). The authors stated that their findings of depression levels were fairly typical of the literature, citing studies which ranged from findings of 20%-43% of participants with SCI having possible depression according to standardised measures. A study in 2012 sought to examine trajectories in mental health following SCI, and interviewed 206 adults with SCI at six time points, starting at the beginning of rehab and ending at 5 years post-injury. The 5-item Mental Health Index was used, and a general upward trend was found over time, though around a third of participants still experienced mental health difficulty at five years post-injury. Five different trajectories were identified, “...(1) high scores (above 80) at all time-points (52%), (2) low scores (≤60) at all time-points (4%), (3) early recovery from 40 to scores above 70 (13%), (4) intermediate scores from 60 to scores above 70 (29%), and (5) severe deterioration of scores above 70 to scores below 30 (2%).” (van Leeuwen & Hoekstra et al., 2012, p. 2170). Pain level, gender and education level were found to have minor effects on the results, while other demographic factors such as age, marital level and number of children had no significant effect. Interestingly, degree of physical disability was also not found to significantly impact results.

Other studies have sought to examine the external and internal factors which may impact mental health and quality of life in this group in more detail. For example, a 2017 study examined the quantity and quality of social relationships among 133 participants with SCI and their romantic partners, and how these interacted with mental and physical health. It was found that the subjective quality of relationships was more strongly associated with better mental and physical health than the size of the social network, and that loneliness was associated with poorer scores in both domains (Tough et al., 2017). (The complex nature of relationships between social interaction, loneliness and mental health is discussed further in section 1.5.) Another study examined mental health, life satisfaction and participation in activities in 143 adults with SCI, and how internal constructs such as self-efficacy and neuroticism impacted these domains. Their participants were interviewed five years after the onset of injury. It was found that lower self-efficacy, higher neuroticism and a number of internal cognitive appraisals negatively impacted participation and mental health, which in turn impacted life satisfaction (van Leeuwen & Post et al., 2012).

A 2009 systematic review of 18 studies on mental health and quality of life in persons with SCI provides a quite comprehensive overview of mental health and related factors in this
population. It found that roughly 30% of participants had elevated depression levels according to standardised items, and that this rate was similar in rehab and community settings (Craig, Tran & Middleton, 2009). A similar percentage of participants exhibited raised anxiety levels, which were not observed to decrease up to two years post-onset. Perhaps unsurprisingly, given the often violent nature of SCI onset, there was also evidence for Post-Traumatic Stress Disorder in the population, with different studies finding rates between 14 and 44 percent. The analysis also found lowered quality of life in the population, and that those dealing with an SCI exhibited a belief in a more external locus of control and had increased feelings of helplessness. Once again, demographic factors and degree of disability were not found to affect quality of life as greatly as internal psychological factors and level of pain, “Although factors, such as level of lesion, age, age at the time of injury, sex, time at injury and completeness of the lesion have not been consistently found to be associated with lower QOL, negative psychological states (such as low levels of self-efficacy, that is, perceiving that one has little control over one’s life and behavior) and pain intensity have been found to lower QOL.” (Craig, Tran & Middleton, 2009, p. 112.)

Other types of acquired conditions which have received some psychosocial study include sudden-onset sight and hearing difficulties. A 2008 study examined quality of life and psychological adjustment in 163 participants who had recently experienced retinal detachment (a sudden-onset cause of sight loss) and compared them to matched participants with less serious and more gradual vision defects. The mean time since detachment and partial surgical repair was five weeks. The group who experienced retinal detachment had significantly poorer quality of life scores, and this was most pronounced in the psychological adjustment subscale (Zou et al., 2008). Another study examined the mental health effects of the same retinal detachment condition over time, with mood and anxiety measured immediately after injury, at three months post surgery, and again at six months and twelve months post surgery. Amongst their 113 participants, both mood and anxiety scores improved on average during each of the intervals, though depression scores improved markedly while anxiety scores showed only minor improvement. Vision scores also improved in the majority of participants over the duration of the study. Interestingly, visual deficit severity was strongly positively correlated with depression and anxiety scores at zero months and three months post-onset, but the correlation declined thereafter. A moderate correlation
remained between deficit severity and anxiety scores, but the correlation between deficit and depression scores was no longer statistically significant at six months and twelve months post-onset (Mozaffarieh et al., 2007). This may suggest a degree of psychological adaptation, and may also be related to the improvement in vision amongst the majority of participants (though most retained some deficit).

In terms of causes of hearing loss, the cause that would most mirror the sudden onset of an ABI may be sudden sensorineural hearing loss (SSNHL). This accounts for 99% of cases of sudden organic unilateral hearing loss (not including psychogenic causes), and is caused by damage to the nerves of the inner ear, which is often idiopathic. A study in Japan compared quality of life in those who had experienced idiopathic sensorineural hearing loss (ISSHL) at least 30 days prior versus those who had other types of hearing loss, and found that QoL was reduced in both groups compared to Japanese averages (Sano et al., 2013). The ISSHL group in particular scored poorly on the mental health subscale. A number of potential moderating factors were investigated using multiple regression, and it was found that age and time since onset both had a minor impact on results, with higher age and longer time since onset predicting slightly higher QoL scores. Gender did not have an impact, and notably, neither did the degree of hearing loss. A very large Taiwanese study using anonymised public health records retrospectively followed 1717 patients who had been diagnosed with SSNHL and compared their rates of depression diagnosis against a matched control group over a nine year period. When adjusting for factors such as comorbid physical conditions, the SSNHL group were still found to have a depression diagnosis rate 2.18 times that of the control group, and this was especially pronounced in participants under 60 years old (Tseng et al., 2016). Gender, income, and a variety of comorbidities such as hypertension and diabetes were not found to be significantly predictive of depression diagnoses in the SSNHL group (degree of hearing deficit was not analysed as a risk factor). A longitudinal study of 147 participants with SSNHL investigated the association between recovery and depressive symptoms, and found that those who had largely recovered showed significantly better mental health scores than those who still had remaining symptoms at one year post onset (Chen et al., 2013). Tinnitus (ringing in the ear) was a particular risk factor for poorer scores.

Overall from the literature, we see a number of factors emerging across conditions in terms of how the sudden acquisition of disability affects mental health and quality of life. We
see that the different disabilities discussed cause lower average QOL amongst those affected, and raise depression scores significantly compared to control groups and the general population. However, we also see that the degree of physical or sensory injury is not a reliable correlate to these results, and that internal psychological factors, recovery or lack thereof, and possibly the quality of social support have a larger impact. Age sometimes has an impact, but this is not universal across conditions, and gender had no impact in any of the studies. The acquisition of one of these disabilities is similar, in some ways, to the acquisition of aphasia following an ABI, in that they occur suddenly and require significant psychosocial adaptation. However there are clearly also significant differences between the limitations and challenges posed by these conditions, in that paralysis is a physical disability, vision and hearing loss are sensory disabilities, and aphasia is a cognitive disability. Hence it will be interesting to see how results from this study and other aphasia and ABI studies compare to those of studies on other acquired disabilities, and whether any broad themes related to disability, coping or adaptation emerge.

1.5 Communication, Socialisation and Mental Health:

In studying the mental health effects of a long-term disability, it makes sense to consider the specific limitations of the condition and how they may interact with mental health. For aphasia, this means considering previous research on the topic of social interaction and language-based communication, and their impacts on psychological wellbeing.

Socialisation and communication through language are some of the key evolutionary features of humans, and research has shown the important and often complex role these aspects of our lives play in maintaining good mental health, and treating mental illness. Social isolation has been identified as a seeming key risk factor in the development of a variety of mental illnesses (Comer, 2011), and depression and anxiety have both received a large amount of study in relation to this risk factor. Certain groups in particular have received the most research focus in this regard, namely disabled groups, the elderly, and school-age children and adolescents.
One of the earlier studies to examine the correlation of social isolation to poor mental health in all-cause disability found that degree of social isolation (as measured by self-reported frequency of visitors) correlated with poorer mental health scores on a previously validated 6-item measure, amongst 486 Disability Benefit claimants in the US (Ludwig, 1970). This effect was independent of degree of physical limitation and dependence, which were also found to correlate with poorer mental health scores.

Since then, more specific research has been carried out on loneliness, social support and mental health in many different long-term conditions, and in particular amongst older populations. This is because loneliness has been identified as an issue amongst many groups of older adults in residential care or living independently, due to factors such as retirement from the workforce, loss of a spouse, or poor health and/or mobility difficulties (Ogden, 2007). A fairly typical example of such research would be a 2004 study of 234 older adults with an average age of 81 living in residential care in the US, which examined loneliness and a number of other social and health factors in relation to depressive symptoms, and found:

*Depression was predicted by being older, number of chronic health conditions, grieving a recent loss, fewer neighbor visitors, less participation in organized social activities and less church attendance. Grieving a recent loss, receiving fewer visits from friends, and having a less extensive social network predicted loneliness. In addition, loneliness scores explained about 8% of the unique variance in depression scores, suggesting it is an independent risk factor for depressive symptoms. (Adams, Sanders & Auth, 2004, p. 475.)*

While there has been regrettably little research on the topic, anecdotally, receiving fewer visits from friends and a narrowing social circle is a common complaint from those with moderate or severe aphasia.

While 8% of depression score variance accounted for by loneliness is not insignificant, other studies have found a stronger relationship. A very large 2009 study of 2910 older adults living at home found a significant correlation of moderate effect size (.359) between social disconnectedness (as measured by frequency of visits, size of social circle and other similar
factors) and lower self-reported mental health scores, however they found a strong correlation (.8) between perceived social isolation and reduced mental health scores (Cornwell & Waite, 2009). In addition, ‘objective’ social disconnectedness and perceived social isolation were only moderately correlated, with perceived social isolation accounting for a large part of the effect size of social disconnectedness. This led the authors to suggest that the relationship was largely mediated by mental health, with poorer mental health leading to a greater feeling of social isolation (though social disconnectedness did remain a significant independent correlate with lower mental health scores). However, it could be argued that the measures of social disconnectedness were capturing quantity of social interaction as opposed to ‘quality’, and this may account for some of the variance. Similar findings to the 2009 study were replicated in a cross-ethnicity analysis using data taken from the same dataset, the National Social Life, Health, and Aging Project (Miyawaki, 2015).

The debate about the nature of the correlation between loneliness, social isolation and mental health has been ongoing in the literature, as it of course the case that depression in particular will often lead to withdrawal from social activities, and a more negative perception of life in general (Carr, 2006), which may in theory include a more negative perception of what social support a person does have. Anxiety, the other most commonly included measure in studies of this nature (including this study), can also lead to avoidance of social situations and leaving the house less frequently (Comer, 2011). Different methodologies have been proposed to try to better establish the causality of the relationship. These include more ‘objective’ measures that a person has less control over, and longitudinal studies. In the first category, some studies have examined the mental health of people who have recently moved to a new location due to work, education, etc. For example, an Australian study examined the loneliness and mental health of those who had relocated for work, education, or due to their rental lease becoming unavailable for renewal (Rohde et al., 2016). They found that relocation was significantly correlated with loneliness, and with decreased scores on the two mental health items they used, suggesting again that social isolation in and of itself is a risk factor for poorer mental health, even if it is not as strongly predictive as subjective loneliness. Their findings were strongest in the elderly and women.

In the longitudinal category of studies, a study of 6105 adults over age 50 using data from the Irish Longitudinal Study on Ageing examined factors such as spousal and family
relationships, social network integration and support from friends, and examined depression and anxiety symptoms after a two year interval. It found that, “Social support from friends and children was protective against depressive symptoms in both genders.” (Santini et al., 2016, p59.) They also found a number of gender differences in the associations between different social factors and mental health scores, for example that spousal support appeared to be a significant protective factor for men, and strained relationships with children correlated significantly with depressive symptoms in women. They found that subjective loneliness was a significant mediator in the majority of associations.

In a discussion of socialisation, mental health and how they relate to aphasia, it is fitting to ask how much of an impact aphasia typically has on socialisation and social support. It would seem intuitive that a damaged ability to produce or comprehend language would have a profound social impact, and while this is likely true in many cases, the reality may be quite nuanced. One way to examine the impact of communication difficulties on social support and feelings of loneliness in aphasia would be to compare data from post-stroke aphasia studies with similar studies on general post-stroke populations. Unfortunately, there has not been a large amount of research thus far on this aspect of aphasia, with social measurements often being part of a larger Quality of Life index and not separated out for analysis. However a recent study published in the journal Aphasiology compared the social networks and perceived quality of social support of stroke patients with aphasia, without aphasia, and healthy older adults. They found that those with aphasia had significantly reduced social networks and less support from friends, but there was no significant difference in perceived social support (Hilari & Northcott, 2017). The generalisability of the findings of this study are limited by two factors: firstly, that their aphasia sample size was very small with only 11 participants. And secondly, their interviews were conducted at only 6 months post-onset, which is a time when symptoms may still be improving relatively rapidly (Goldstein & McNeil, 2015), and when a person’s social contacts may still be adapting to their condition, along with the individual themselves. Studies analysing social support and loneliness in a general post-stroke population have been slightly more numerous. A recent meta-analysis of 22 qualitative and 48 quantitative post-stroke studies found some very interesting results:
The qualitative studies described a contraction of the social network, with non-kin contact being vulnerable. Although family were more robust network members, significant strain was observed within the family unit. In the quantitative studies, poor functional social support was associated with depression (13/14 studies), reduced quality of life (6/6 studies) and worse physical recovery (2/2 studies). Reduced social network was associated with depression (7/8 studies), severity of disability (2/2 studies) and aphasia (2/2 studies). Although most indicators of social network reduced post stroke (for example, contact with friends, 5/5 studies), the perception of feeling supported remained relatively stable (4/4 studies). (Northcott et al., 2016, p. 811.)

A number of these findings are notable, for example that the direct association between reduced social network and depression appears to be more prevalent than in similar studies on the general non-ABI population, that aphasia was significantly associated with reduced social network in the two studies that analysed it, and that we again see friends and non-family relationships appearing as a ‘weak link’ in the social network. However there are many variables in the symptoms and functional disabilities people will have post-stroke, and it is likely that these individual factors need to be studied in more detail. Within aphasia, factors such as the education of family and friends on effective communication methods for people with aphasia may play a role, along with the symptom type and severity variability that this study seeks to analyse.

Finally, another vital way that communication interacts with mental health is in the treatment and management of mental illnesses, and psychosocial support for other long-term disabilities. A variety of talk-therapies are used to treat psychological disorders (such as depression and anxiety disorders), either in conjunction with medication or on their own, or to help manage disorders that are treated with medication (such as bipolar disorder or schizophrenia) (Carr, 2006). While it is certainly possible to employ a method such as CBT with a person with moderate or even severe aphasia, it requires a practitioner versed in supported conversation techniques, and wait times to see such a practitioner (who is normally a clinical neuropsychologist) can be long. While there are regrettably no recent wait time figures, Dr Niall Pender stated in the Irish Medical Times in 2009 that wait times in Ireland could be up to a year (Culliton, 2009). Highly-used services such as distress support phone lines would be
extremely difficult for a person with severe or moderate aphasia to derive benefit from, particularly those services that rely primarily on ‘listening’.

In addition, it is common for those who have suffered an acquired brain injury to attend a support group for psychosocial support and to aid in staying mentally healthy. There has been surprisingly little research on the effects of these groups on mental health in stroke patients, with more research focused on support groups for carers, however the research that has been conducted shows positive psychosocial effects for groups. For example, a 2014 study of a support group for those under 65 who had had a stroke found that, “Participants demonstrated improved socialization,” and improved, “healthy coping,” as measured by standardised scales (Muller, Toth-Cohen & Mulcahey, 2014, p. 277). A 2015 thesis project with somewhat larger participant numbers also found significantly improved social integration in those who attended a stroke support group over stroke patients who did not (White, 2015). Clearly more research is needed on this topic, however this is another support avenue that may be more difficult to avail of for those with significant linguistic communication difficulties. Anecdotally, feelings of alienation at support groups not geared towards aphasia are often expressed by aphasia sufferers, but no papers could be found currently that investigated this so no conclusions on the benefits of stroke groups for aphasia patients can be drawn.

1.4 Mental Health following an Acquired Brain Injury:

Mental health following ABI is a complex topic for a number of reasons. Each brain injury is different and results in different levels and types of functional disability. Some individuals experience total or almost total recovery following an ABI, while for others, the consequences are permanent.

The prevalence of depression and anxiety (at least according to standardised items) following ABI is fairly well-established, though many studies focus on one particular cause of ABI. A 2014 meta-analysis of depression following stroke analysed 61 studies covering 25,488 participants, and found rates of approximately 31% at time points less than one year post-
stroke (Hackett & Pickles, 2014), and these rates are typical of other similar studies (Jones & Jorge, 2018). The study also analysed depression rates at different points over time, and found a rate of 25% between one to five years post-stroke, and 23% at five years post-stroke; this decline was statistically significant. Another 2014 meta-analysis conducted a similar review of TBI studies, and looked at rates of diagnosed depression and rates according to self-report measures. The analysis included 99 studies, and found that 27% of participants had diagnoses of depression, ranging from 16% amongst those whose injury was classified as mild to 30% amongst those whose injury was classified as severe. When using self-report measures, estimates varied between 32% when using the Hospital Anxiety and Depression Scale (HADS) and 48% when using the Centre for Epidemiologic Studies Depression Scale (CED-S). It was also found that the depression rate declined over time, and that rates when using self-report measures were strikingly higher amongst those whose injury was classified as mild (64%) versus severe (39%) (Osborn, Mathias & Fairweather-Schmidt, 2014).

In studies that focused more on anxiety, results have also been relatively consistent, and generally show a slightly lower prevalence of anxiety disorders than depression, but still higher than what would usually be observed amongst the general population (analysis of research on 150,000 participants estimated a 12 month prevalence rate of all anxiety disorders of approximately 11-13% in the general adult population in Europe (Wittchen & Jacobi, 2005)). A meta-analysis covering 44 studies on post-stroke anxiety found rates of 18% when using clinical interview, and 25% when using standardised rating scales (Burton et al., 2013). The analysis looked at rates over time in the months following stroke and found a very slight upward trend, but grouped together all studies which took place six months or more post-stroke. A 2009 Australian study conducted the Structured Clinical Interview for DSM-IV Disorders on 100 participants with TBI (time since onset: 0.5 - 5.5 years), and compared results to their preinjury psychiatric history, obtained through medical records and retrospective self-report. Preinjury, 17% of participants had a diagnosis of major depressive disorder and 13% suffered from an anxiety disorder, while at the time of interview, these rates were found to be 45% and 38% respectively, and this difference was statistically significant (Whelan-Goodinson et al., 2009). In terms of specific disorders, higher rates of depression, generalized anxiety disorder, posttraumatic stress disorder and panic disorder were found postinjury, and a lower rate of substance use disorder. All other disorders had the
same prevalence as prior to injury (though it should be noted that the relative prevalence of many rarer disorders would not be accurately measured in a sample this size). Overall, there is a lack of research on TBI and anxiety in comparison to anxiety and stroke or ABI in general, however a 2015 review examined the existing literature and drew a number of tentative conclusions. Rates of anxiety disorders were found to be roughly 13-28% in various studies (Mallya et al., 2015). In some studies, GAD was the most prevalent disorder, and in others, PTSD was more prevalent (though the review reports widely varying PTSD figures between studies, samples and time-points, anywhere between 3-50%, with the majority being somewhere in the middle). A number of consistent factors were found, including that rates of anxiety seemed to increase during the first year, that rates of PTSD were higher in women, and that PTSD was most prevalent in those with mild injury. It is proposed in the review that this may be because those with mild injury are more likely to have memories of the incident. So to sum up the literature on prevalence, we see depression rates somewhere in the 25-40% range in most studies, with a decline sometimes noted at time points after one year post-onset, and TBI and stroke having similar figures. Anxiety rates also seem to be similar regardless of cause, with estimates varying more widely and being more in the 15-35% range, with the possibility of higher PTSD rates amongst TBI sufferers. In spite of the uncertain relationship to symptom severity, rates of depression and anxiety are consistently significantly higher than those in the general population.

Many studies have further investigated the myriad factors that may affect the course of mental health following brain injury. On the physical side of things, studies have investigated the relationship between lesion location and size and the likelihood of poor mental health. A recent longitudinal study of 100 participants at time points between six months and two years post-stroke looked at the association between stroke hemisphere and depression. They found that, although left hemisphere stroke was significantly more associated with cognitive impairment in their sample, laterality of stroke did not predict depression (Baccaro et al., 2019). However it is notable that the rate of depression in their sample was relatively low in ABI terms (19% at two years according to the PHQ-9), and this may be because much of their sample seemed to be quite well recovered from their ABI symptoms by that point in time, with only 38% still experiencing impairment. Another study of 70 participants with mixed causes of ABI examined the relationship between apathy, depression and lesion location, and
found that while apathy was associated with subcortical and right hemisphere lesions, depression was not predicted by lesion location (Finset & Andersson, 2000). In terms of the degree to which ABI severity or the severity of cognitive impairment predict poor mental health outcomes, the data is mixed, as was partially discussed in the previous paragraph. For example, a 2013 review and meta-analysis reported that cognitive impairment (as measured by standardised items) was associated with worse mood scores in the two studies which analysed it as a factor, however stroke severity (as measured by items such as the National Institute of Health Stroke Scale (NIHSS)) was analysed in three studies and was not found to be a predictor of poorer mood (Ayerbe et al., 2013). A recent Egyptian study of 102 stroke patients also found that cognitive impairment predicted poorer depression scores at three months post-stroke (Mohammed et al., 2019). This is somewhat contradictory, and implies either that some of these findings are due to confounding variables or statistical anomalies, or that cognitive impairment correlates poorly with measures of stroke severity, as it is true that bedside measures such as the NIHSS mostly do not include measures of non-linguistic cognitive domains such as memory or executive functioning. It is also worth noting that many studies use impairment cut-offs when analysing cognitive impairment, rather than ordinal data. Certain types of ABI-related disability and other physical health conditions have been found in some studies to be associated with poorer mental health in this population, including greater physical disability and physical dependence, hypertension, cardiovascular disease, smoking, arthritis, and diabetes (Mohammed et al., 2019; Ellis, Grubaugh & Egede, 2013; Jones & Jorge, 2018). In terms of demographic factors, age is not generally found to be associated with depression or anxiety, and while some studies find that females with ABI have slightly higher rates of anxiety or depression, most do not find significant gender differences (Ayerbe et al., 2013). This is in itself notable, as most research on the general population finds a roughly two-to-one female predominance in depression and anxiety symptoms (Comer, 2011).

In terms of psychosocial factors relating to mental health vulnerability or resilience in the ABI population, the research is somewhat disjointed. A variety of studies have looked at a variety of factors and found interesting results, but it is difficult to identify individual factors which have received enough study to draw firm conclusions. A number of studies have found that a history of having mental health difficulties prior to ABI is a risk factor for poorer mental
health following ABI (Ayerbe et al., 2013), which makes some sense, as the individual vulnerabilities a person had prior to ABI are unlikely to disappear afterwards. We may also guess that many of the predisposing factors found for anxiety and depression in the general population (including genetics and adverse childhood experiences) hold true for the ABI population too, though to what degree is uncertain, as we have already seen that the normally well-established gender ratios of common mental illnesses are different for those with ABI. A recent study in the UK investigated the relationship between dimensions of self-esteem and depression and anxiety symptoms in a sample of 65 participants with ABI under the age of 57. Their findings were summarised thus:

57.5% of the sample had clinically low self-esteem... and factor analysis identified four factors, which differed from those found previously in other populations. Multiple regression analysis revealed anxiety was differentially predicted by “Self-Worth” and “Self-Efficacy”...and depression by “Self-Regard”... A fourth factor, “Confidence”, did not predict depression or anxiety... Self-esteem after ABI is multidimensional and differs in structure from self-esteem in the general population. (Longworth et al., 2018, p. 1078)

Though their sample size was too small and their findings too preliminary to draw such confident conclusions, it is another indication that the nature of mental health issues post-ABI differ from those in the general population. The high rate of clinically low self-esteem is also striking, though perhaps not surprising given the high depression rates in the ABI population. The question of course then becomes, is low self-esteem causing depression or vice versa? However, it is easy to speculate that feelings of low ‘self-worth, self-efficacy and self-regard’ may at least sometimes be triggered by the acquisition of disability, which may then lead to a heightened likelihood of depression. A Canadian study which is currently in press analysed psychosocial factors from the opposite perspective, by determining which factors were associated with ‘complete mental health’ (CMH), defined as the absence of mental illness within the past year, almost daily happiness and satisfaction, and psychological and social well-being, amongst a very large national study of adults over 50. 300 of these participants who had previously had a stroke were separated out for analysis. It was found that 68% of the sample was in CMH, and that, “Among stroke survivors, the odds of CMH were higher among those with at least one confidant, those without disabling chronic pain, and those without a history of childhood maltreatment, depression, or generalized anxiety
disorders.” (Fuller-Thompson & Jensen, 2019, in press). In these results, we see factors that are often associated with poor mental health amongst the general population. A study discussed in the previous paragraph in reference to its analysis of depression, apathy and lesion location also analysed coping style with the well-known COPE scale, and found that a lack of ‘active approach-oriented’ coping was associated with apathy, while avoidant coping was associated with depression (Finset & Anderson, 2000). Coping style was not found to be associated with lesion location, and coping styles did not differ significantly between their ABI sample and their control sample.

A large recent study analysed a variety of social and psychological factors affecting life satisfaction in an online sample of 592 individuals with ABI. High rates of depression (48%) and suicidal ideation (41%) were found, and, “Increased engagement in leisure activities, higher emotional stability (p <.001) and sociability (p <.01) coupled with lower depression (p <.001) and romantic loneliness (p <.001) significantly predicted satisfaction with life.” (Proctor & Best, 2019, p. 387). These variables accounted for 50% of the variance in life satisfaction. Some of these factors are likely to have significant cross-over (those with depression, for example, are likely to be less engaged in leisure activities, less social, and quite possibly score lower in emotional stability), which is often an issue in studies trying to separate out psychosocial risk factors, however the romantic loneliness risk factor is a novel finding. It is also of course worth noting that their sample would have been relatively self-selecting, particularly in terms of aphasia, as those with any receptive aphasia would mostly be unable to fill out online questionnaires without assistance. This is an issue in any ABI study which asks participants to fill out questionnaires on their own. A smaller study took a qualitative approach to analysing psychosocial factors associated with depression and functional independence two years post discharge from hospital for ABI, and found that participants perceived family relations, returning to work, waiting lists, psychological support, fatigue and ‘personal competencies’ as being important factors to their mental health and quality of life (Glintborg, Thomsen & Hansen, 2018). Factors such as returning to work or an individual’s opinion of their own competencies may relate to aspects of self-esteem such as those identified in the previously discussed Longworth et al. (2018) study. Finally, here in Ireland, a study conducted last year sought to delve into the relationship between increased social activity and social group membership and decreased depression in ABI populations. They
hypothesized that membership of multiple social groups was the factor which increased self-regulation and thereby decreased depression. Using a mediation analysis of data from 50 participants who had completed self-report measures on these components, they concluded, “multiple group belonging predicted lowered depression symptoms, by providing a basis for enhancing self-regulation.” (Kinsella et al., 2018, in press). Though this is not an implausible hypothesis, a mediation analysis cannot really be used to establish causation from a correlational study – it merely elaborates on the correlation.

There are two additional specific factors which may be useful to discuss in relation to mental health and ABI, one of which is reported frequently by patients themselves, and the other which is discussed more by rehabilitation workers. The factor frequently reported by patients – perhaps more frequently than any other ABI sequela – is fatigue. Increased fatigue (generally defined as an undue feeling of exhaustion after physical or mental effort) has been found to affect up to 85% of people who have had a stroke, according to meta-analysis (Cumming et al., 2016), with similar figures seeming likely for other causes of ABI. A Swedish study investigated fatigue in ABI (as measured by a standardised fatigue scale) in relation to cause of ABI, lesion location and depression symptoms. They found that only depression had a statistically significant association with fatigue, but that not all participants who had fatigue were depressed, nor vice-versa (Holmqvist, Berthold-Lindstedt & Moller, 2018). Another recent study from Denmark analysed the relationship between fatigue and depression in 105 young people with ABI, between the ages of 15 and 30. Unsurprisingly, they found elevated levels of both fatigue and depression in comparison to a control group, and when analysing different components from the Multidimensional Fatigue Inventory, they found that, “...the predominantly mental dimensions of fatigue, General Fatigue, Mental Fatigue, and Reduced Motivation, were independently associated with MDI [Major Depression Inventory], all p’s <.01, while the physical dimensions, Physical Fatigue and Reduced Activity, were not.” (Dornonville-de la Cour et al., 2018, in press.) The exact cause of fatigue in ABI remains unclear in most cases (Jones & Jorge (2018) suggest that the high rate of untreated sleep apnoea post-ABI may be partly to blame, but this is just one hypothesis), however it is clear that it is an extremely prevalent problem with a significant and complex relationship to mental health.

The second factor is the question of ‘insight’, or in more clinical terms anosognosia, i.e. the patient’s awareness of their own deficits. The question of insight is sometimes raised by
rehab professionals in relation to individuals with more severe aphasia or other deficits, however it is not extensively studied, either on its own or in relation to mental health. A small American study analysed the relationship between clinician-rated anosognosia and ‘denial’, coping style and depression in 27 participants with ABI at a post-acute rehab centre. Though anosognosia and denial were correlated, only denial was associated with greater use of avoidant coping, which was in turn associated with depression (Kortte, Wegener & Chwalisz, 2003). A larger 2014 study analysed awareness of deficits in relation to depressive symptoms and treatment motivation in 93 ABI outpatients. In this study, patients were divided into three groups: those who underestimated their deficits in comparison to their partner or clinician, those whose estimates were similar, and those who overestimated their deficits. Their results were interesting, though perhaps not surprising, and discovered that those who underestimated their deficits (i.e. had a more positive view of their abilities) had the least depressive symptoms, and those who underestimated their abilities had the highest levels of depression (Smeets et al., 2014). No effect was found on treatment motivation. A study from the following year took a relational approach to researching discrepancies between ABI survivors’ self-assessment and the assessments of others, and analysed the disability assessment of 35 stroke survivors and their spouses, this time in relation to spousal mental health. They found that, “Quantitative data indicated that spouses rated survivor cognitive functioning as significantly worse than survivors rated their own and that survivor-spouse discrepancy scores for physical functioning were significantly associated with spouse depressive symptoms.” (McCarthy & Lyons, 2015, p. 46). This finding is interesting, as though it may be the case that this discrepancy contributed to depressive symptoms in partners, it may also be the case that depressive symptoms contributed to a more negative appraisal of their spouse’s condition.

This ambiguity highlights the fact that, overall, we must examine the concept and assumptions of ‘insight’ carefully, as it is a difficult thing to define and quantify. From a measurement perspective, the idea that outsiders (and particularly non-clinician outsiders) usually have a more accurate perception of deficits than the individual affected is inherently problematic and open to scrutiny. All individuals with ABI who have a full level of consciousness and a functioning memory are aware that they've experienced a brain injury, and that their lives and abilities are now different. It may be easy to label an individual as
lacking insight if they appear less emotionally affected by their condition than it seems like they ‘should’ be, or if they sometimes seem to have an overly optimistic assessment of their own abilities. However this risks using the standards of non-disabled individuals to judge and label the lived experience of those with ABI. It seems possible that large psychological adjustment is necessary for many people post-ABI in order to avoid depression, and this may result in what could be regarded as a ‘blasé’ type of attitude from the outside. After all, if the effects of the injury can’t be readily healed, then the only options are to adapt or succumb to negative emotions. It also seems possible that those with long-term moderate or severe ABI symptoms may not be judging their abilities through the same lens as rehab workers or family members, and have likewise had to adjust their expectations for the sake of their self-concept and mental health. It is worth remembering that research suggests most people, with the exception of those with depression, may tend to overestimate their own abilities (Vasquez, 1987). And indeed, the Smeets et al. (2014) study above illustrates the potentially psychologically protective effects that ‘overestimation’ of abilities can have in the ABI population also. Additionally, it is possible that apathy directly caused by brain damage may be misdiagnosed as anosognosia. Severe aphasia or aprosodia (problems with normal speech intonation) may also lead to this impression. This is not to say that the concept of anosognosia is invalid, and it unquestionably applies in some severe cases involving memory damage or a lowered level of consciousness, but it may need more robust research and careful application than is commonly the case currently.

The final aspects to consider are how poor mental health affects outcomes in ABI, and what treatments are most successful. In terms of pure mortality risk, a large study using the South London Stroke Register tracked over 2000 participants for ten years, and administered the Hospital Anxiety and Depression Scale annually. Their aim was to identify trajectories in mood, and analyse how these interacted with overall mortality and gender. They identified slightly different trajectories in men and women, with women having a greater prevalence of severe depression symptoms, and found that men in the ‘severe’ trajectory group had a 2.6 times greater annual mortality risk than men in the low symptoms trajectory, while women in the most severe trajectory group had a 2.8 times greater mortality risk than women in the low symptoms group (Ayis et al., 2019). Meanwhile, a large 2013 meta-analysis of the effect of post-stroke depression on mortality found a 52% increased risk of death (Bartoli et al.,
While estimates vary somewhat, the vast majority of studies seem to agree that depression following ABI does significantly increase mortality risk (there has been less study of other mental health issues in this regard).

In terms of degree of disability, the experience of a mental illness has a potential to add an additional disability on top of ABI. A thorough meta-analysis of post-stroke depression studies found that depression was associated with significantly poorer functional outcomes (Kutlubaev & Hackett, 2014). However, this review also found depression to be associated with increased neurological and physical disability in the acute phase and beyond, leaving the causation of the poorer functional outcomes somewhat ambiguous. A 2013 study on anxiety in 54 ABI outpatients found some evidence of anxiety levels being an independent contributor to impairment, with regression analysis revealing that, “Anxiety predicted a significant proportion of the variance in caregiver-assessed real-life affective/behavioral and cognitive functioning.” (Bertisch et al., 2013, p. 429). Meanwhile, neuropsychological test scores did not correlate with any domain of functioning, suggesting that anxiety on its own was having a significant effect. Overall, it is not surprising that many studies cannot draw such clear-cut conclusions, as the relationship between disability and mental health post ABI is assumed by most to be complex and bi-directional (Jones & Jorge, 2018). Further research, including perhaps different types of study designs and longitudinal cohort analysis, is needed to give a clearer picture of the specific impact of mental health issues. However, given the well-established disability burden of depression and anxiety in otherwise healthy individuals (see e.g. Comer, 2011), it would be very surprising if these conditions didn’t also increase disability burden in the ABI population.

Treatment for mental illness, as in the general population, can be psychological or pharmacological, or a combination of the two. There are also more psychosocial interventions designed specifically for ABI, which may include peer-support (some of which were discussed on page 16). Jones and Jorge (2018) approach treatment from a very psychiatric perspective, and give an in-depth overview of the research on drug efficacy. To summarise their report: as in the general population, placebo-controlled trials of SSRIs for the treatment of depression post-stroke appear to have mixed results, with the drugs potentially showing greater efficacy for anxiety than depression. Jones and Jorge advocate for more research into the use of SSRIs prophylactically post-stroke, given the high rate of depression in this population and some
research which suggests SSRIs may be more effective at preventing depression in this group rather than curing it. However, this is an unusual view, given that it is extremely rare for any type of psychiatric medication to be given long-term on a solely preventative basis. Another 2018 review is somewhat ambivalent on the use of SSRIs for post-stroke depression, given the inconsistent evidence of efficacy and the possibility of SSRIs causing an increased cerebral haemorrhage risk in this population (Villa, Ferrari & Moretti, 2018). Most research appears to focus on post-stroke depression rather than other psychiatric conditions or causes of ABI. When it comes to psychotherapy, CBT is the most researched treatment for mental health issues post-ABI, presumably because it is currently the most well-researched form of therapy for common conditions like depression and anxiety amongst the general population, and has a very strong evidence base (see e.g. Carr, 2006). A recent meta-analysis conducted here in Ireland (by a group which includes one of the facilitators of this project) reviewed data from 24 studies covering 507 participants who received CBT for depression or anxiety following a brain injury. Some studies used a pre-post design while others had no-treatment control groups. They found large effect sizes of over 1 for both depression and anxiety treatment, with the effect size amongst depression patients being slightly larger. They also concluded:

“Additionally, it is clear that CBT is not a panacea, as studies frequently indicate only partial reduction in anxiety and depression symptoms. This review suggests that if CBT is aimed at, for example, anger management or coping, it can be effective for anger or coping, but will not generalise to have an effect on anxiety or depression. CBT interventions that target anxiety and depression specifically appear to generate better therapeutic effects on anxiety and depression.” (Waldron, Casserly & O’Sullivan, 2013, p. 64).

Overall, we can conclude that the issue of mental health post-ABI is very complex with many factors that are not yet clearly understood, however the research is clear that those with an ABI are certainly an at-risk group for common mental illnesses, and that there is clear statistical benefit to psychotherapeutic intervention. Of course, it is worth bearing in mind that the ABI population is heterogenous in terms of the cognitive and/or physical disabilities they experience following their injury, and most studies treat the group as homogenous, which may or may not be contributing to the relative opacity of the factors which are most contributing to poor mental health in this population. Degree of disability may be an important factor, along with fatigue, coping style and self-esteem. It is unclear to what degree
this remains true for those whose primary disability is aphasia, as they are a minority of the ABI population (as discussed on page 5).

1.6 Mental Health and Quality of Life in Aphasia:

To date, there has been a limited amount of research on the topic of aphasia and mental health, with much more research being focused on mental health in the overall ABI population. Additionally, sample sizes in aphasia studies are often small, owing to inherent difficulties in recruiting a population with communication challenges, and the necessarily longer and more complicated interview process. Possibly for these reasons, aphasia could be considered a very under-researched area from a psychosocial perspective. However the research which does exist suggests that aphasia can have a significant effect on mental health and quality of life.

In terms of the prevalence of depression and anxiety in aphasia, research is generally agreed that it is significantly higher than in the general population, however it is unclear to what extent rates differ from the overall ABI population. A relatively large, recent study of 144 people with aphasia following stroke found that approximately 42% had elevated depression symptoms according to the Centre for Epidemiologic Studies Depression Scale (Ashaie, Hurwitz & Cherney, 2019). 19% of these reached the scale's threshold for depression, while 22% had elevated 'subthreshold' symptoms. Another, longitudinal study of 24 people who developed long-term aphasia after ischaemic stroke found that 33% met the DSM-III diagnostic criteria for major depression at 12 months following the stroke (Kauhanen et al., 2000). One study was identified which did compare 30 participants with post-stroke aphasia to 31 participants similar in demographics who had experienced a stroke but had no aphasia symptoms. At three months post-stroke, it was found that the group with aphasia had significantly higher levels of anxiety and depression, with mean depression scores being over twice as high in the aphasia group (Shehata et al., 2015). These results provide perhaps the clearest evidence that aphasia may be a significant risk factor for poor mental health in the ABI population. Only one study was identified which assessed the prevalence of anxiety in aphasia, and it relied on proxy assessments from carers. In their sample of 111, they found a 41% rate of anxiety using a modified Hospital Anxiety and Depression Scale, and a slight association with lower age and
more severe aphasia symptoms (Morris et al., 2017). However the findings of any proxy measure which hasn't been validated against a sample of self-reports need to be regarded sceptically.

In terms of quality of life and factors affecting mental health in this population, there have been a number of small investigations. A study of 30 people suffering with mild to moderate aphasia examined symptom severity in relation to quality of life and found that a negative correlation existed between symptom severity and QoL scores (Cruice et al., 2003). A qualitative study of seven participants examining the subjective experience of aphasia found themes such as a lack of confidence to communicate, and an increased desire to communicate despite decreased ability (Arnesveen-Bronken et al., 2012). Additionally, a very recent study explored factors affecting quality of life in 32 participants with aphasia following stroke, and found: “The relative importance in predicting the variance [of QoL] was 32% for limitations on activities of daily life, 21% fatigue, 23% depression and 24% communication activity limitations.” (Bullier et al., 2019, in press). However, no studies have been found which analysed the impact of potential factors such as the type of aphasia, the course of aphasia symptoms, time since onset or attendance at a support group. Research tentatively suggests that symptom severity may contribute to poorer mental health or quality of life, but this is also not certain.

Language is one of our most basic skills, and communication and social interaction are complex, key factors in good mental health. This study hopes to contribute to our academic understanding of the emotional impact that impairment of these vital abilities could have, and help to identify risk factors and inform future research or treatment for this group of people.

1.7 The Current Study:

The current study aims to analyse the effect of aphasia, aphasia symptom severity and aphasia subtype on mental health, social support and quality of life, and to assess which psychosocial factors interact significantly with mental health. The main research questions are:

1. Does aphasia have a significant impact on mood or anxiety levels?

2. Does the type of aphasia (expressive/receptive) have an impact on this potential link?

3. Does the severity of symptoms mediate the link?
4. Does the degree of symptom improvement since onset moderate the link?

5. Do gender or age have an effect?

6. Do the factors of social support, quality of life, cognitive reserve or attendance at a support group moderate the link?

A mixed-methods approach will be used to examine these questions, comprising of a quantitative correlational analysis, and a smaller qualitative component to gain additional insight.
Chapter 2:
Quantitative Study
Methods

Participants:

The participants were drawn from two national acquired brain injury non-profit support services, and interviews were conducted primarily at the day service centres of these organisations, with the approval and clinical oversight of on-site clinical psychologists. One interview was conducted at a participant’s home, in the presence of a rehab worker from the organisation. 23 participants in total took part in the quantitative interviews, with an average age of 50.5 years \((SD = 10.7\) years\) and an age range of 31-67 years. There was a roughly equal gender split, with 12 males and 11 females.

Recruitment was carried out through organisation staff, who distributed study leaflets at the day centres and contacted potential participants via telephone to ask if they might be interested in participating, and if they consented to their contact details being shared with the researcher. The contact details of those interested were then passed on to the researcher, and interview times were arranged. In cases of severe aphasia, a family member sometimes assisted in this arrangement, however the agreement of the participant was always obtained, and no participant was unaware of the purpose of the appointment. Some participants were current regular users of the day services and others were past attendees who no longer attended very frequently; exact service usage figures were not recorded.

Inclusion criteria specified participants who were over 18, suffered from aphasia, and had been experiencing symptoms for at least six months following an acquired brain injury. Individuals who did not feel that aphasia was their most serious disability were excluded (however it was not feasible to exclude all participants with any additional ABI symptoms). 18 participants had suffered from a neurovascular accident (i.e. ischemic or haemorrhagic stroke), three had suffered from a traumatic brain injury, one had suffered from an anoxic injury, and one had experienced brain damage from tumour removal. The mean time since injury was 78.3 months \((SD = 48.3, range: 19-246)\).

A majority of participants reported experiencing fatigue more often since their ABI, and some described minor memory issues. A number of participants experienced degrees of right
side weakness, however all except one were ambulatory. Most participants lived in the community, either independently or with support from family or employed carers, while two lived in supported housing for people with an ABI. No participants had been in paid employment following their ABI.

As it was uncertain whether proxy reports would have to be relied on for certain scales for individuals with very severe aphasia, and for the purpose of linking quantitative and qualitative study data, each participant was given a participant number. The identification key for these numbers was stored on the researcher’s computer and encrypted using AxCrypt software, and was deleted once data collection was complete. These measures were fully detailed in the consent form, which was read out to the participants (who also had their own copy) and any questions they had were discussed using supported conversation.

It may be worth noting that it was initially hoped that the sample size would be larger (approximately 60) to give greater statistical power to the results. However the rehab organisations found that they had fewer eligible individuals than they had expected, and time constraints prevented the recruitment of additional samples. One participant did not complete all scales, as a follow-up interview was required due to running over time, and this did not prove possible to arrange (this is noted in the \( n \) of analyses).

Scales and Measures:

Initial Questions: A short set of initial information was collected, including age, gender, and month and year of aphasia onset. See Appendix A for the full list.

Language assessment scale: It was decided that a traditional aphasia test (such as the Western Aphasia Battery) was not the best choice for the study due to time constraints, and the wish to get a measure more of functional expressive and receptive impairment in day-to-day life, rather than information on very specific linguistic elements. As individuals with aphasia sometimes
anecdotally opine that their performance in assessments doesn’t accurately reflect their usual communicative ability, it was decided that the questions would be split between items asking about usual communicative ability, and a number of objective assessment items based on comprehension and communication ability on that particular day. Feedback on the content of the scale was sought from a senior speech and language therapist with considerable experience in aphasia assessment and treatment, who believed it was a sound approach and the scale ‘captured a good range of information’. Possible scores ranged from 13-65 for the expressive and receptive subscales and 26-130 for the overall language score, with lower scores indicating greater impairment, and possible scores ranged from -26 to 26 for the ‘change since onset’ component, with higher scores indicating more aphasia symptom improvement. See Appendix B for the full measure and scoring scheme.

Overall, the internal reliability of the scale was high, with a Cronbach’s Alpha of .876 for the expressive component and .823 for the receptive component. It was indeed observed that some individuals with good conversational ability during interview performed much more poorly on the objective items than would have been expected, but overall the self-report and objective items had a high degree of agreement, and having both types of items did not detract from internal reliability values. Due to time constraints, it was not possible to test external reliability or quantitatively examine validity.

**Patient Health Questionnaire 9 (PHQ-9):** The Patient Health Questionnaire 9 (Kroenke, Spitzer & Williams, 2001) was chosen as the measure of depressive symptoms, as it is brief, well-validated, has been used in other studies on the mental health effects of disabilities, and uses straightforward language. Validity was assessed by the scale originators against an independent structured mental health professional (MHP) interview. It was found that PHQ-9 score ≥10 had a sensitivity of 88% and a specificity of 88% for major depression. Higher scores indicate higher levels of depression symptoms.

**Beck Anxiety Inventory (BAI):** The Beck Anxiety Inventory (Beck et al., 1988) was chosen as the anxiety measure primarily because it has been extensively tested and its format and language appeared very aphasia-friendly. The BAI was found to have a Cronbach’s alpha of .92, and test-
retest reliability (over 1 week) for the BAI was found to be .75. The BAI is moderately correlated with the revised Hamilton Anxiety Rating Scale (.51). Higher scores indicate higher levels of anxiety symptoms.

**The Inventory of Socially Supportive Behaviours (ISSB):** The Inventory of Socially Supportive Behaviours (Barrera, Sandler & Ramsay, 1981) was chosen because of its emphasis on non-verbal social support. It was considered that those with more severe aphasia would be very likely to score lower on most other scales measuring socialization, and that this may not be a true reflection of the quality of social support received. The internal reliability for this scale is .84. Over a 2-day interval, the test-retest reliability was found to be .88 by the scale designers. Few other scales have been designed to measure exactly the same construct as the ISSB, however it shows moderate correlations with measures of network size, and family cohesion. Higher scores indicate greater social support.

**Quality of Life Scale (QOLS):** The Quality of Life Scale (Flanagan, 1978) 16-item version (Burckhardt & Anderson, 2003) was chosen due to its aphasia-friendly format and use in many previous studies on chronic illness and disability. Test-retest reliability has been measured as .83 and Cronbach’s alpha as .86. The scale creators also found high correlations between the QOLS and the Life Satisfaction Index-Z (LSI-Z) (r = 0.67 to 0.75). Lower scores indicate poorer quality of life.

**Cognitive Reserve Index questionnaire (CRIq):** The Cognitive Reserve Index (Nucci, Mapelli & Mondini, 2012) was chosen as it measures a relatively newly-defined concept which seemed interesting to assess in relation to aphasia and mental health. Cognitive reserve groups together a number of domains which have shown evidence of being protective against cognitive decline in old age and to correlate with less cognitive damage following brain injury. These domains cover engagement with hobbies, working life and family responsibilities. As this scale simply asks what activities have been undertaken and the amount of time they have been undertaken for,
conventional reliability information is not available. Higher scores indicate greater cognitive reserve.

**Methodological Adaptations for Conducting Research with People with Aphasia:**

Conducting research with participants with aphasia presents a number of challenges in regards to effectively conveying written and verbal information and collecting accurate responses. To help with these challenges, standard aphasia communication techniques were employed, and in particular Supported Conversation for Adults with Aphasia (SCA; Kagan et al., 2001) techniques. The researcher had previously made use of the online training resources made available by the developers of the method, the Toronto Aphasia Institute, and had been employing these techniques for two years in work with individuals with aphasia. To further prepare, a day of aphasia Conversation Partner training with undergraduate SLT students was also attended.

In keeping with SCA practice, participants were encouraged to take their time and not to worry about making any mistakes. Written material made use of bolded words, helpful colours, and illustrative pictures where possible. See Appendix C for the appearance-altered PHQ-9 scale, and Appendix D for the Debriefing Form which was used. Other techniques used are outlined in the Research Protocol below.

**Research protocol:**

- The participants were greeted and presented with the consent form. The purpose of the study, right to withdraw, and Supported Conversation for Adults with Aphasia™ (SCA) techniques were outlined.

- The participant’s aphasia history and severity were assessed using a short questionnaire.

- The standardised scales for mood, anxiety, social support, QoL and cognitive reserve were administered.
- For those with reading or spoken comprehension difficulties, all written material was read aloud and clarified using supported conversation techniques. This involved the use of synonyms, writing things down, asking verifying questions, drawing brief pictures, and where practical, the use of pre-prepared flashcards to help illustrate certain items. For those with difficulties verbally answering questions and who did not like to use a pen, there was an enlarged answer scale available which they could use to indicate their responses, as well as yes, no, and ‘sort of’ indicators. Answers were verified in keeping with SCA practice, by rephrasing the question and asking again. The degree of use of these techniques was based on the person’s individual language strengths and deficits as established in the aphasia assessment questionnaire and during the course of the interview. All participants required some degree of supported conversation.

- If the session lasted more than 45 minutes, a break and a beverage were offered. Most interviews lasted approximately 90 minutes, depending on the individual’s level of aphasia and other factors.
Results

Outcome statistics of all scales are presented in Table 2.1 for reference. Where present, score classifications and impairment cut-offs are discussed in the relevant analysis sections.

Table 2.1: Outcome statistics of all scales

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expressive language</td>
<td>46.35</td>
<td>10.73</td>
<td>17-61</td>
<td>23</td>
</tr>
<tr>
<td>Receptive language</td>
<td>53.61</td>
<td>9.53</td>
<td>22-65</td>
<td>23</td>
</tr>
<tr>
<td>Overall language</td>
<td>99.91</td>
<td>18.73</td>
<td>39-124</td>
<td>23</td>
</tr>
<tr>
<td>Language change since onset</td>
<td>13.57</td>
<td>4.32</td>
<td>8-22</td>
<td>23</td>
</tr>
<tr>
<td>PHQ-9 depression</td>
<td>7.70</td>
<td>5.78</td>
<td>0-20</td>
<td>23</td>
</tr>
<tr>
<td>Beck Anxiety Inventory</td>
<td>10.73</td>
<td>10.17</td>
<td>0-32</td>
<td>22</td>
</tr>
<tr>
<td>Quality of Life Scale</td>
<td>84.82</td>
<td>10.07</td>
<td>65-104</td>
<td>22</td>
</tr>
<tr>
<td>Inventory of Socially Supportive Behaviours</td>
<td>56.14</td>
<td>15.23</td>
<td>20-79</td>
<td>22</td>
</tr>
<tr>
<td>Cognitive Reserve Index</td>
<td>114.05</td>
<td>14.97</td>
<td>93-148</td>
<td>22</td>
</tr>
</tbody>
</table>
Analyses of Primary Research Questions:

1. Does aphasia have a significant impact on mood or anxiety levels?

The mean score on the PHQ-9 depression scale was 7.7 ($SD = 5.78$, $n = 23$). A total of 60.9% of participants had scores suggestive of some degree of depression symptoms. Scores were distributed as follows, according to the parameters of the scale:

<table>
<thead>
<tr>
<th>Classification:</th>
<th>Minimal or none (0-4)</th>
<th>Mild (5-9)</th>
<th>Moderate (10-14)</th>
<th>Moderately Severe (15-19)</th>
<th>Severe (20-27)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of Participants:</td>
<td>9</td>
<td>6</td>
<td>5</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

The PHQ-9 also includes a supplementary functional impairment (FI) item. In this, 11 out of 23 participants indicated some degree of functional impairment due to low mood. 9 participants indicated mild FI, while 2 indicated severe FI.

The mean score on the BAI was 10.73 ($SD = 10.17; n = 22$). A total of 18.2% of participants had scores indicative of ‘moderate anxiety’ or higher. Scores were distributed as follows, according to the parameters of the scale:

<table>
<thead>
<tr>
<th>Classification</th>
<th>Mild (0-21)</th>
<th>Moderate (22-35)</th>
<th>Severe (36-63)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of Participants</td>
<td>18</td>
<td>4</td>
<td>0</td>
</tr>
</tbody>
</table>
2. **Does the type of aphasia (expressive/receptive) have an impact on this potential link?**

Only 3 participants were found to have receptive language scores significantly lower than expressive scores, meaning that the receptive aphasia group was not large enough for independent analysis. However expressive and receptive scores were individually compared to the mood and anxiety scales, to analyse whether a trend emerged for poorer mood or anxiety scores which correlated to the level of impairment in one language domain over the other. Neither expressive nor receptive scores were found to correlate significantly to mood or anxiety scores. Expressive and receptive scores correlated strongly to each other, $r(21) = .714, p = .001$; as did anxiety and depression scores, $r(20) = .768, p = .001$.

*Table 2.4: Expressive, receptive, depression and anxiety score correlation table*

<table>
<thead>
<tr>
<th></th>
<th>Expressive Language</th>
<th>Receptive Language</th>
<th>Depression</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Expressive Language</strong></td>
<td>$r = .714$</td>
<td>$r = -.198$</td>
<td>$r = -.075$</td>
<td></td>
</tr>
<tr>
<td><strong>Receptive Language</strong></td>
<td>$p = .000$</td>
<td>$p = .194$</td>
<td>$p = .369$</td>
<td></td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td>$r = -.198$</td>
<td>$r = .063$</td>
<td>$r = .248$</td>
<td></td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
<td>$p = .194$</td>
<td>$p = .338$</td>
<td>$p = .133$</td>
<td></td>
</tr>
</tbody>
</table>

3. **Does the severity of symptoms mediate the link?**

To assess whether the severity of aphasia symptoms correlated with mood or anxiety scores, the overall language score (combined expressive and receptive) was compared to the PHQ-9 and BAI scores. No significant correlation was observed with mood scores, $r(21) = -.075, p = .367$, or anxiety scores, $r(20) = .073, p = .373$.
4. Do the degree of symptom improvement or time elapsed since onset moderate the link?

As no direct correlation between aphasia symptom severity and mood or anxiety was found, a moderation analysis was not performed. Instead, the ‘change’ component of the scale was compared directly to mood and anxiety scores. A significant, moderate, negative correlation was observed between degree of improvement since onset and PHQ-9 depression scores, \( r(21) = -0.353, p = .049 \).

*Figure 2.1: Scatterplot and trendline of PHQ-9 scores against ‘change since onset’ scores*

No significant correlation was observed between change scores and BAI anxiety scores, \( r(20) = -0.260, p = .121 \). However, when using linear regression, a significant interaction was observed with anxiety scores (for figures, see p. 48).
Time since onset in months was compared against depression \( r(21) = -.038, p = .859 \) and anxiety scores \( r(20) = .052, p = .818 \), however no significant correlations were found.

5. **Do gender or age have an effect?**

Once again, due to the lack of a direct correlation between language scores and mood or anxiety scores, a moderation analysis was not possible. Instead, age and gender were each analysed against mood and anxiety scores for the sample. No significant results were found. The correlation results for age and mood were \( r(21) = -.100, p = .650 \), and for age and anxiety were \( r(20) = -.124, p = .582 \). Independent t-tests were conducted to test whether gender had an influence on mood or anxiety scores. The results for mood were \( t(21) = -.166, p = .870 \), and for anxiety were \( t(20) = -.368, p = .716 \).

6. **Do the factors of social support, quality of life, cognitive reserve or attendance at a support group moderate the link?**

As moderation analysis was not possible, other types of analyses were used to examine the potential effects of these factors on mood and anxiety in the sample, and their interactions with aphasia severity.

First, one-way ANOVAs were conducted to examine whether attendance at a support group for brain injury, for aphasia, or having never attended a support group had an impact on mood or anxiety in the sample. Results were not significant (mood: \( F(2, 20) = 1.02, p = .378 \); anxiety: \( F(2, 20) = .01, p = .995 \)). Independent t-tests were conducted to assess whether having attended a brain injury or aphasia support group in the past six months had an impact on mood or anxiety (versus no attendance in the past six
months). Results were also not significant (mood: \( t(21) = .15, p = .885 \); anxiety: \( t(20) = .03, p = .977 \)).

Next, linear regression and correlation were used to examine the relationships between overall language scores and social support, quality of life and cognitive reserve. A significant, moderate, negative correlation was observed between overall language scores and social support, \( r(20) = -.365, p = .047 \), meaning that those with more severe aphasia received more socially supportive behaviours. A correlation between quality of life and social support approached significance, as well as between overall language score and cognitive reserve.

**Table 2.5: Correlations between language score, social support, quality of life and cognitive reserve**

<table>
<thead>
<tr>
<th></th>
<th>Language Score</th>
<th>Social support</th>
<th>Quality of life</th>
<th>Cognitive reserve</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language score</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>r</strong></td>
<td>(-.365)</td>
<td>(-.108)</td>
<td>(.313)</td>
<td></td>
</tr>
<tr>
<td><strong>p</strong></td>
<td>.047</td>
<td>.316</td>
<td>.078</td>
<td></td>
</tr>
<tr>
<td>Social support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>r</strong></td>
<td>(-.365)</td>
<td></td>
<td>(-.092)</td>
<td></td>
</tr>
<tr>
<td><strong>p</strong></td>
<td>.047</td>
<td></td>
<td>.342</td>
<td></td>
</tr>
<tr>
<td>Quality of life</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>r</strong></td>
<td>(-.108)</td>
<td>(.334)</td>
<td>(.134)</td>
<td></td>
</tr>
<tr>
<td><strong>p</strong></td>
<td>.316</td>
<td>.064</td>
<td>.276</td>
<td></td>
</tr>
<tr>
<td>Cognitive Reserve</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>r</strong></td>
<td>(.313)</td>
<td>(-.092)</td>
<td>(.134)</td>
<td></td>
</tr>
<tr>
<td><strong>p</strong></td>
<td>.078</td>
<td>.342</td>
<td>.276</td>
<td></td>
</tr>
</tbody>
</table>
A simultaneous multiple regression analysis was then conducted on the variables to assess their combined interaction with aphasia scores. Though the predictive power of the variables was not significant individually, there was a modest but highly statistically significant combined interaction with the overall language ability score.

Table 2.6: Regression table for overall language score and predictor variables

<table>
<thead>
<tr>
<th></th>
<th>Unstandardized B</th>
<th>Standard Error</th>
<th>t statistic</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>93.60</td>
<td>30.76</td>
<td>3.04</td>
<td>.007</td>
</tr>
<tr>
<td>Quality of life</td>
<td>-.05</td>
<td>.30</td>
<td>-.17</td>
<td>.868</td>
</tr>
<tr>
<td>Social support</td>
<td>-.29</td>
<td>.20</td>
<td>-1.46</td>
<td>.163</td>
</tr>
<tr>
<td>Cognitive reserve</td>
<td>.26</td>
<td>.19</td>
<td>1.35</td>
<td>.194</td>
</tr>
</tbody>
</table>

To investigate this relationship further, the regression analysis was repeated on the expressive and receptive components of the language scale separately. Significant relationships were found between the combined predictor variables and both
components of the scale, however the effect was larger and of higher significance in the receptive scale. Expressive results: \( B = 44.96, t(18) = 2.14, p = .046 \). Receptive results: \( B = 48.88, t(18) = 3.17, p = .005 \).

As shown above in Table 2.6, cognitive reserve was not found to fit the model well, as though it was expected that all variables may trend in the same direction against language scores, in fact social support and quality of life behaved in the opposite fashion to cognitive reserve. When cognitive reserve was excluded from the model, predictive power was significantly stronger, and the effect remained strongest in the receptive scale. Overall language score: \( B = 119.39, t(19) = 4.85, p < .001 \); expressive score: \( B = 58.6, t(19) = 3.55, p = .002 \); receptive score: \( B = 61.14, t(19) = 4.97, p < .001 \).

Similarly, correlation and linear regression were used to assess the relationships between the variables of social support, quality of life and cognitive reserve, and mood and anxiety in the sample. No significant correlations were observed between mood or anxiety and the predictor variables, though correlations with quality of life approached significance (mood: \( r(20) = -.310, p = .080 \); anxiety: \( r(20) = -.295, p = .091 \)). Simultaneous regression analyses were conducted with the grouped predictor variables for both mood and anxiety, which yielded non-significant results (mood: unstandardized \( B = 16.77, t(18) = 1.22, p = .237 \); anxiety: \( B = 32.91, t = 1.33, p = .200 \)). However, it was noted that quality of life alone had a significant interaction with the depression scale, \( B = 22.26, t = 2.17, p = .042 \).
**Additional Analyses:**

**Investigating the relationship between the change since onset variable and depression scores:**

As change since onset (CSO) proved to be a significant correlate of PHQ-9 depression scores ($r(21) = -.353$, $p = .49$), with a greater degree of improvement in aphasia predicting lower depression scores, it seemed prudent to investigate the properties of the CSO construct further, to reduce the possibility of mood-related bias in self-report responses interfering with results.

The change since onset component of the language assessment scale was made up of two related subcomponents (see Appendix B for full scale). The first subcomponent repeated two basic questions the participants had been asked about their language functioning at the start of the scale, but asked them to answer based on their abilities directly following their injury, to the best of their recollection. The difference between these sets of scores and was taken as the first half of the change component. The second subcomponent asked participants to simply rate their perception of their symptom improvement on a scale from 0-10. While it seemed best to include this question for a number of reasons, there was also an acknowledgement that this type of direct question may be more open to bias based on mood, with those of a more optimistic persuasion assessing their improvements more favourably, and vice versa.

To investigate this possibility, the scores from the second subcomponent were compared separately against depression scores. Results were less powerful than the combined component, did not reach significance ($r(21) = -.300$, $p = .082$) and were very similar to the depression correlation of the first subcomponent ($r(21) = -.273$, $p = .103$). Though this does not entirely rule out the possibility of some bias in the change component, it does make it less likely that bias alone accounts for the relationship.
Further investigations of change since onset as a predictor variable:

As ‘change since onset’ proved to be a significant predictor of depression scores, it was decided to investigate this variable further as a predictor of mental health and quality of life using correlation and linear regression. Though correlation with anxiety scores was not significant (see page 38), a significant interaction was found when using regression. Highly significant interactions were also found with the depression scale and QOL scale. Greater improvement in aphasia predicted lower depression and anxiety scores and higher quality of life scores. Results below in Table 2.7:

Table 2.7: Regression results with ‘change since onset’ as the predictor variable and PHQ-9, BAI and QOL scores as dependent variables.

<table>
<thead>
<tr>
<th></th>
<th>Unstandardized B</th>
<th>Standard Error</th>
<th>t statistic</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mood</td>
<td>14.12</td>
<td>3.9</td>
<td>3.63</td>
<td>.002</td>
</tr>
<tr>
<td>Anxiety</td>
<td>19.1</td>
<td>7.26</td>
<td>2.63</td>
<td>.016</td>
</tr>
<tr>
<td>Quality of life</td>
<td>75.68</td>
<td>7.13</td>
<td>10.62</td>
<td>.000</td>
</tr>
</tbody>
</table>

Figure 2.3: Scatterplot and trendline of ‘change since onset’ and BAI anxiety scores.
Predictors of ‘change since onset’:

Factors which may impact ‘change since onset’ were analysed using linear regression and independent t-tests, including cognitive reserve, age and gender, social support, marital status, and support group attendance. When using regression, significant interactions were found with both social support and cognitive reserve (see Table 2.8). In regard to social support, it is not possible to say whether improvement in aphasia predicts greater social support or whether social support predicts greater improvement in aphasia. In regard to cognitive reserve, the direction of the interaction is difficult to explain, as there is no obvious reason why greater cognitive reserve would lead to less improvement in aphasia. The relationship was very weak and the statistical significance was considerably lower than the interaction with social support, so it seems likely that the finding is a statistical anomaly.
**Table 2.8**: Regression results with ISSB social support and CRIq as the predictor variables and ‘change since onset’ as dependent variable.

<table>
<thead>
<tr>
<th></th>
<th>Unstandardized B (of CSO score)</th>
<th>Standard Error</th>
<th>t statistic</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social support</td>
<td>11.84</td>
<td>3.68</td>
<td>3.29</td>
<td>.004</td>
</tr>
<tr>
<td>Cognitive reserve</td>
<td>17.02</td>
<td>7.42</td>
<td>2.3</td>
<td>.033</td>
</tr>
</tbody>
</table>

**Figure 2.5**: Scatterplot and trendline of ‘change since onset’ and ISSB social support scores.

**Figure 2.6**: Scatterplot and trendline of ‘change since onset’ and CRIq cognitive reserve scores.
Age ($r(21) = -0.124, p = 0.574$), gender ($t(21) = 0.26, p = 0.795$) or marital status ($t(21) = -0.21, p = 0.836$) were not found to affect CSO scores. Having attended a brain injury or aphasia support group in the past was also not found to affect CSO scores ($t(21) = -0.11, p = 0.917$), and neither was having attended a group in the past six months ($t(21) = -1.91, p = 0.070$).

**Controlling for social support:**

Partial correlation analyses were conducted to investigate whether the increased social support received by those with more severe aphasia may be compensating for a relationship that would otherwise exist between mood or anxiety and language scores. However no significant relationship was found when controlling for the effect of social support. Mood: $r(19) = 0.133, p = 0.283$; anxiety: $r(19) = 0.081, p = 0.363$.

The reverse analysis was also conducted, to assess whether aphasia severity may be masking a relationship that would otherwise exist between social support and mood or anxiety scores. Relationships with social support when controlling for language score were similarly insignificant. Mood: $r(19) = -0.094, p = 0.343$; anxiety: $r(19) = 0.035, p = 0.439$.

**Quality of life as an outcome variable:**

Quality of life indices are commonly included in studies of chronic illness or disability as an outcome measure. However as the QOLS index includes items which could be both influenced by aphasia, and items which may be independent moderators impacting the link between aphasia and mental health, it was treated as a moderator variable in the main analysis. To investigate QOL as an outcome measure, correlations and t-tests were conducted with relevant potential predictor variables.

Severity of aphasia was not found to correlate significantly with quality of life (see Table 2.5), and neither were the expressive ($r(20) = -0.118, p = 0.301$) or receptive ($r(20) = -0.069, p = 0.381$)
subscales. However, when using linear regression, an association was found with overall language score ($B = 93.09$, $t = 5.43$, $p = <.001$) with poorer language scores slightly predicting higher QOL scores (accounting for approximately 9.75% of variance). ‘Time since onset’ of aphasia did not correlate significantly with QOL scores ($r(20) = .152$, $p = .249$), and a correlation with ‘change since onset’ approached but did not reach significance ($r(20) = .287$, $p = .097$).

As noted in Section 6 of the analyses of primary research questions, moderate correlations between QOL and depression and anxiety scores approached but did not reach significance. However, when using regression, a significant interaction was observed between PHQ-9 and QOL scores, showing that low mood was significantly associated with poorer quality of life in this sample. For exact figures, see page 42.

Having previously attended an ABI or aphasia support group was not found to affect QOL scores ($t(20) = .09$, $p = .928$), nor was attendance within the last six months ($t(20) = .03$, $p = .977$).

Finally, age ($r(20) = .067$, $p = .766$) or gender ($t(20) = -.50$, $p = .623$) were not found to affect QOL scores in this sample.

**Impact of prior mental illness:**

To ensure a representative sample, information was collected on the mental health of participants prior to their ABI. It was found that 17 participants had never been diagnosed with a mental illness, and 5 had been diagnosed with depression. To assess the impact of this on the mental health outcome variables, the means of this group were compared against those of the remainder of the group. The group who had dealt with depression did not show higher PHQ-9 ($M = 5.6$ vs $M = 8.3$) or BAI scores ($M = 7.6$ vs $M = 11.7$).
Further demographic and family status investigations:

The CRIq index collected information on marital status, and presence and number of children. Given the literature discussed in Chapter 1.5 suggesting that family relationships may be a more robust source of social support in disability than other relationships, it was decided to analyse these factors with relation to social support, mood and anxiety.

Marital status (currently married \((n = 11)\) versus currently not married \((n = 12)\)) was not found to have a significant effect with regards to mood \((t(21) = .74, p = .468)\), anxiety \((t(15.7) = 1.71, p = .107)\) or social support \((t(20) = .12, p = .903)\).

It was not possible to compare results of participants with children against those without, as the group without was too small for analysis \((n = 5)\). However number of children \((M: 1.5, SD: 1.1, \text{range: } 0-3)\) was not found to correlate with social support, \(r(20) = -.111, p = .311\).

Investigation of proxy measures:

Initially, the use of proxy measures given to a caregiver was planned for any participant with receptive aphasia too severe to complete the measures themselves, however this did not ultimately prove necessary. In order to validate and assess the use of proxy measures, proxy scales were also given to a number of family members who accompanied participants, so that results could be compared to the participants’ own responses. Ultimately, 6 family members completed the Stroke Aphasic Depression Questionnaire (SADQ-21) designed for caregivers, and 5 also completed the Hamilton Anxiety Inventory (HamA) and the Quality of Life Scale (QOLS; the same index completed by the aphasic participants). The results of the SADQ-21 and HamA were compared against the results of the PHQ-9 and BAI, respectively. Results from the proxy and first-person measures have been adjusted to the same numerical scale and are displayed below in Table 2.9. The possible range of the depression scores is 0-27, the possible range of the anxiety scores is 0-63, and the QOLS has a possible range of 16-112.
Table 2.9: Results of self-report and proxy scales.

<table>
<thead>
<tr>
<th>Participant</th>
<th>PHQ-9</th>
<th>SADQ-21* (proxy)</th>
<th>BAI</th>
<th>HamA* (proxy)</th>
<th>QOLS</th>
<th>QOLS (proxy)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>7</td>
<td>17.2</td>
<td>1</td>
<td>35.1</td>
<td>77</td>
<td>58</td>
</tr>
<tr>
<td>2</td>
<td>0</td>
<td>8.2</td>
<td>1</td>
<td>8.5</td>
<td>91</td>
<td>102</td>
</tr>
<tr>
<td>3</td>
<td>7</td>
<td>10.3</td>
<td>8</td>
<td>27.8</td>
<td>86</td>
<td>57</td>
</tr>
<tr>
<td>4</td>
<td>14</td>
<td>7.3</td>
<td>29</td>
<td>23</td>
<td>75</td>
<td>87</td>
</tr>
<tr>
<td>5</td>
<td>11</td>
<td>6.4</td>
<td>14</td>
<td>16.9</td>
<td>100</td>
<td>82</td>
</tr>
<tr>
<td>6</td>
<td>0</td>
<td>5.2</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Mean</td>
<td>6.5</td>
<td>9.1</td>
<td>10.6</td>
<td>22.26</td>
<td>85.8</td>
<td>77.2</td>
</tr>
</tbody>
</table>

* SADQ-21 scores have been divided by 2.33 to scale with PHQ-9 scores. HamA scores were multiplied by 1.21 to scale with BAI scores.

Though the sample size was very small for meaningful statistical analysis, correlations were conducted which did not indicate significant relationships between the self-reports and proxy reports in these particular cases. Depression scales: $r(4) = .089, p = .433$; anxiety scales: $r(3) = -.021, p = .487$; QOLS: $r(3) = .321, p = .299$. On average, the family members assessed the participants as having poorer mental health and a lower quality of life than the participants’ own reports. This was true in 4 out of 6 cases for the depression scales, 4 out of 5 cases in the anxiety scales, and 3 out of 5 for the QOLS.

The Question of Multiple Comparisons:

Given the relatively large number of analyses conducted on a small sample size, statistical correction for multiple comparisons was considered. While many of the linear associations would have survived Bonferroni correction, a correlation would have to be overwhelmingly strong to survive correction in a sample of this size. Given the exploratory nature of this study,
it was decided to err on the side of potential false positives rather than potential false negatives, and that the limitations of the sample size and statistics would be clearly discussed.
Discussion

The quantitative study produced some very interesting findings, some which were predicted and some which were not. There were also some expected findings which did not appear. It goes without saying that the reproducibility and generalisability of many of these findings is unknown, given the small amount of existing research on the topic of aphasia and mental health (results will be discussed further in the context of previous research in Chapter Four). Significant findings include:

**High rates of depression and anxiety symptoms, reduced quality of life:** One of the most significant findings of the quantitative study is a high rate of depression symptoms in the sample and, to a lesser extent, a high rate of anxiety (compared to rates in the general population as referenced in Chapter One). Even if we were to exclude those whose depression symptoms were classified as mild by the PHQ-9, that would still leave 34.8% with moderate or severe symptoms, and 47.8% expressing some degree of functional impairment due to low mood. Though unfortunately not entirely inconsistent with other research on ABI and aphasia, these figures are still concerning.

QOLS figures are lower than those of the general population, and similar to studies on chronic conditions such as rheumatoid arthritis and lupus (Burckhardt & Anderson, 2003). Surprisingly, QoL had a slight negative association with language score. Though this effect was not large, it may be related to the increased social support received by those with more severe aphasia in this sample (discussed below).

**‘Change since onset’ a significant predictor of mental health:** In spite of overall severity of aphasia and ‘time since onset’ not correlating with mental health measures, the degree of change since onset proved to be very significant, correlating moderately with the depression scale, and showing highly significant regression interaction with the depression, anxiety and quality of life scales. The possible implications of this will be discussed further in Chapter Four.
Those with more severe aphasia received more social support: Those with more severe aphasia in the sample received a higher amount of socially supportive behaviours. This may reflect a well-supported sample, with those who need more help in day-to-day life generally receiving it.

Social support positively predicts aphasia improvement (or vice-versa): A longitudinal study would be needed to definitively establish the direction of causation in this case, though given the fact that social support generally correlated with more severe aphasia in this sample rather than less (as may be expected if improvement in aphasia was facilitating greater social support), it is tempting to hypothesize that receiving social support and a higher level of interaction may aid in aphasia recovery. Practicing language skills is, after all, a large part of aphasia treatment.

Aphasia severity, subtype and time since onset not associated with mental health in this sample: Based on the limited amount of previous aphasia research, it was expected that aphasia severity may correlate with poorer mental health. However as discussed in Chapter One, research on the degree to which severity of symptoms in ABI and other acquired disabilities correlates with mental health has often been inconsistent, so this finding is not entirely surprising in that context. Time since onset has also been a factor with mixed findings.

Social support had no observable effect on mental health or quality of life: This is perhaps the most surprising failure to reject the null hypothesis. However given the research discussed in section 1.4, it is clear that the relationship between social interaction and mental health is often not a straightforward one. And though partial correlation failed to unmask a relationship between mental health and social support which may have been hidden by aphasia severity, that is not to say that a lack of adequate social support would not be detrimental to mental health in individuals with aphasia. It is possible that this sample was well enough supported that few such problems existed within it.
**No impact from demographic factors:** Age, gender, marital and family status did not impact mental health or quality of life. Though some past research on ABI has found age or gender to be statistically significant, most has not (see section 1.5).
Chapter 3:
Qualitative Study
Introduction & Methods

Aims
The aim of the qualitative study was to gain further insight into the mental health impact of aphasia, and also potential protective or ameliorative factors. The questions were designed to try to elicit responses on the participants’ feelings about their condition, what aspects bothered them most, and what kind of things helped them feel better at times when their mood was low.

Participants:
The sample was five participants from the quantitative study who volunteered to be re-interviewed (two male and three female; mean age 52.8 years). Inclusion and exclusion criteria were the same as those of the quantitative study; see page 31. They were again interviewed on site at an ABI support charity. The participants had a mean language score of 115.2, a mean QOLS score of 84.2, a mean PHQ-9 depression score of 7.6, and a mean BAI anxiety score of 13.2. This indicates that the group had slightly milder aphasia on average than the overall quantitative group, but that their demographics and mental health were very similar (see p.38 for figures from the quantitative sample).

Procedure:
A semi-structured interview was conducted, with four open questions. Interviews were conducted at a follow-up meeting, separate to the original quantitative interview, and participants completed a supplementary consent form. The interview procedure was adapted somewhat to be suitable for individuals with aphasia. The participants dictated their replies to the interviewer, and for those with less fluency, the interviewer asked yes/no follow-up questions to gain more insight. Replies were then read back to the participants before moving on to the next question, to ensure that the interviewer had accurately captured what the participant wished to say, and to check if there was anything the participant wished to add or change. All potentially identifying information (eg names and specific locations) was redacted.
from the transcripts on the spot. The four questions were as follows, and were read out and repeated or rephrased as needed.

1. How would you describe your mental health/emotional wellbeing at the moment?

2. Do you think aphasia affects your mental health?

2b. (Possible prompting questions). If ‘yes’: In what ways? If ‘no’: Is there anything that you think helps to keep your mental health unaffected?

3. Are there any things you find particularly difficult or upsetting due to aphasia symptoms?

4. Are there any things that help you feel better when you’re feeling down?

**Analysis:**

Thematic content analysis was chosen as the analysis method, with data being coded into recurring themes and grouped under categories. In order to reduce selection bias in the coding process, any discrete topic that arose in the responses of two or more participants was included as a theme, assuming the codes did not better fit into an existing theme. Theme generation was primarily guided by the processes set out in chapters 9-11 of Braun and Clarke (2013).
Results

Current Mental Health:

The initial question of the interview was not designed to present any themes, as such, but rather to inform the rest of the responses. Some themes did emerge in response to this question, which are dealt with in the analysis below. Two participants described their current emotional state as very positive ("Great.", "On a scale from one to ten, that’s a nine.") while two participants described more mixed or negative current states: "When I say emotional, I’m not dying, but I find it difficult at the moment.” One participant did not answer directly, but instead explained some current difficulties which will be included in the thematic analysis below.

Categories:

The themes were divided into the broad categories of ‘challenges and difficulties’ and ‘what helps?’. This was partly by design of the interview questions, and partly simply due to the nature of the responses. Further divisions, such as ‘linguistic’ or ‘personal’ or ‘social’, seemed unwarranted, as this would have created a sense of separation of these subjects which did not exist in the responses. In fact, most of the themes were very interconnected and had some degree of crossover. Overall, 14 themes emerged, with seven in each category.

Challenges and Difficulties:

The Perils of Novelty:

The most common theme to emerge under the ‘Challenges and Difficulties’ category was the challenge of dealing with the new or unfamiliar, and this applied to both situations and people. This theme was present in all responses and covered around 15% of response data overall.
When it came to unfamiliar situations, the difficulty was mostly described as being a lack of context: “I’ve realised I don’t need to 100% understand what is being said to me to get the essence of it. You use eye contact, your other senses. In day-to-day conversations, you need to put a context in what you’re talking about.” This was described by participants as being often frustrating or anxiety-provoking. “And I do find it upsetting sometimes, cos it would be nice to be able to just stroll through and not have to know what’s around the corner.” One participant described how they felt they had to work very hard at, “upper processing what’s going on,” in unfamiliar contexts, and that this resulted in fatigue.

When it came to communicating with unfamiliar people, a number of issues were expressed. A lack of context was also a problem when dealing with officials or services, for example one individual described how difficult it was communicating with the ESB on the phone, in comparison to his family. One participant expressed frustration that unfamiliar individuals often didn’t understand her aphasia and tended to interrupt her rather than giving her time to speak. She contrasted this with the behaviour of those who are close to her: “If it was a family member, they know I have aphasia. And I ask them to just listen to me speaking, and don’t interrupt me.” She opined that it felt like proper two-way communication could be difficult to achieve with strangers. “And if they interrupt me then…it’s not a conversation.” Another participant described the difficulty of engaging with potential partners on dating websites due to her aphasia, and a second described his anxiety about engaging with new rehab professionals whenever someone he had built a rapport with changed jobs.

Overall, unfamiliar circumstances and individuals appeared to deprive the participants of many of their compensatory communication strategies, particularly context cues and the need for understanding from the person they’re communicating with. This theme seemed to provoke feelings of stress, frustration and anxiety to varying degrees in the different participants.

Loss:

The next theme was present in four out of five responses, and covered roughly 10% of response data. The participants described feelings of loss in comparison to their abilities and perception of themselves prior to their aphasia.
The two male participants expressed this particularly in regard to their loss of work and their feelings of discomfort or guilt at no longer being a financial and practical support to the family. It is perhaps worth taking a longer quote from one of the participant’s responses, as he sums up his feelings on the loss of his former role: “For forty years, your job is what you do and it’s who you are, and losing that, to put in simple words, it knocked the s*** out of me big time. I would have always been the ‘man with the plan’, and that’s not the person that I am now. My wife and my son saw me as being the person to look after things, and that changed.” The other male participant found this loss even more psychologically difficult, and said he felt that he was, “of no use,” to his family.

The two female participants who expressed this theme didn’t put it in such relational terms, but likewise expressed a sense of loss at comparing their current language abilities to their abilities pre-injury: “It’s different to how I used to be. And it makes me a little bit upset.” One participant said the comparison made her feel ‘depressed’.

This theme seemed to be one of the greatest sources of sadness and self-worth issues for the participants.

*Feeling ‘Inadequate’*

The next theme was the feeling of being ‘less than’, abnormal and overlooked. Or ‘inadequate’ as one participant put it. This theme was present in three out of five responses and covered roughly 9% of response data overall.

The word ‘normal’ was used a number of times to describe people without brain injury. In reference to trying to have a conversation with a ‘normal person’ and the feeling of inadequacy that engendered, or in trying to fit in with other ‘normal people’ of a participant’s age when their injury made them feel very elderly. One participant described how sometimes partaking in rehab activities and being around others whose symptoms are more severe made them feel more abnormal, rather than less as might be expected: “And, I mean no disrespect, but sometimes you feel, ‘Christ, is this my life now?’ In the middle of all this? Maybe sometimes you’re better off being totally mad than half mad. Cos you’re not on either side. Where do you fit in now?”
Another participant described his frustration and sadness at being othered and overlooked by others due to his symptoms, describing how former colleagues no longer valued his opinions. “...but it’s all do with my fitting in as a ‘normal’ person. I feel others find it easier to talk about me, or past me, than to talk to me... I am no longer seen by anyone as a man. I’m seen totally as a patient.” He said that these feelings of not being taken seriously due to his slower speech and other symptoms often led him not to, “...speak on any serious topic.”

This theme seemed to cause slightly different negative emotions in each of the participants who expressed it. Inadequacy was the primary emotion, but also feelings of isolation, sadness or even anger, and feelings about identity emerged.

‘Too fast’

The next theme was the issue of fast speech and finding it difficult to keep up in certain situations. This theme was also present in three out of five responses, but was a less prevalent topic and covered 3% of response data. This may be because it was described in more practical and less emotional terms (which is not to say that there were no emotions attached to it or that it doesn’t have important implications).

For one participant, he described how his trouble with fast-paced communication sometimes made it difficult to keep up in social contexts: “That ‘craic’ can be lost; it’s quick-quick-quick-quick-quick.” Another described how the pace of communication combined with ‘jumping around’ between a lot of numbers and data terms made it very difficult for her to communicate with the telecom company on the phone, and she now got someone else to do it for her.

Though this theme was not one of the most discussed by participants, it is clear that this issue can contribute to difficulty in social situations and problems with accomplishing certain tasks independently, which may then contribute to the feelings expressed in other themes.
Interpersonal Difficulties

This theme was expressed by two of the five participants and covered 7% of response data overall. This theme covers difficulties encountered in pre-existing personal relationships due to aphasia.

One participant opined that it was much more difficult for them to partake in humour amongst family and friends than it had been prior to their ABI. They felt that the ability to tell and understand a joke or funny story often relied on subtleties of language that were difficult for them now, and that maybe this was particularly socially important in Ireland. This participant also said that sometimes these type of ‘trading story’ social gatherings with their family could be very fatiguing, and he felt that this was unfair to his family: “Sometimes you get a pain in your b*****s and just want to be away, and just wish they would finish their stories, and that’s not fair. And that’s part of the relationship with my family. Sometimes you can just play and go through it, and other times you can’t. You’re just not up for playing... It is hard work. Sometimes you know your family just want you to be back to how you were. And that’s sad.”

The other participant who expressed this theme expressed it in terms of his marital relationship with his wife. He felt that his aphasia contributed significantly to ‘relationship problems’: “I say something, and I can’t think of the right word, and I fit in a word to suit. But that can be taken up totally differently by the person you’re talking to.” He said that he often tried not to think of these issues, because it became ‘too much’.

This theme could be categorised emotionally as a source of frustration and sadness for the participants, and as adding to a sense of isolation.

Frustration:

This theme was also present in two of five responses, and covered 3% of response data. This was the participants’ feeling of frustration at their struggle to articulate their thoughts and feelings.

One participant described this feeling as being ‘tormented’ by their difficulties, especially soon after their injury: “I think that the damage to the brain has caused the brain to wander
and get confused. I think because of my aphasia, and without knowing how the brain worked, I was very tormented by my ability to think and that.” The other participant simply described a sense of frustration at being unable to ‘get the words out of [her] mouth’. When further asked if frustration was a big issue for her, she replied that it was, “Very big.”

Again, though this was not a huge theme, it is easy to see how it may contribute to other issues which were expressed.

**Physical Health Challenges:**

This was the final theme identified under the ‘challenges and difficulties’ category. It was present in two out of five responses and also covered around 3% of response data.

Two participants described how physical issues had made maintaining good mental health more difficult. For one participant, this issue was more in the past, during a difficult year he had in his rehab process: “I had pains constantly, I couldn’t sleep, I had a spine issue.” He said these problems added to a feeling of ‘going mad’ during that time. He didn’t describe exactly how he’d overcome these issues, but they seemed to be mostly behind him.

For the other participant, his chronic physical issues posed a much bigger stumbling block, and he described how he had to miss rehab activities he enjoyed in order to attend regular medical appointments. He also described being unable to partake in physical hobbies he enjoyed due to feeling too weak.

Overall, it seemed that physical health issues added another level of difficulty to the rehab process, and reduced quality of life for the two participants.

**What Helps?**

**‘Getting Rid of the Stress’**

The first theme in this category relates to outlets for enjoyment and stress relief through hobbies and activities. It was present in all five responses (in part because the last question
was geared towards collecting data on this type of topic), and covered approximately 11% of response data overall.

Participants described hobbies and activities they enjoyed, most of which helped to take their mind off things or ‘turn off the brain’, as one participant put it. Three participants mentioned exercise as being something that helped them a lot, including walking, dancing, cycling. One participant described his feelings while cycling by saying: “You don’t need to communicate with anyone, and you don’t need to think about anything. You’re in the moment.” Two participants talked about the ‘endorphins’ or ‘free high’ they experienced from exercise.

Creative pursuits were also mentioned, with one participant describing her enjoyment of painting, and another describing his extensive poetry writing over the years of his recovery. Both mentioned the importance of self-expression in these hobbies, and the poetry writer also emphasised the feeling of accomplishment after completing a poem, and that looking back over old poems allowed him to see how far he’d come in his rehab. However he also opined that it was possible to, “…think too much of your sorrow,” an opinion also shared by other participants, so sometimes doing something to take their minds off things was better. Though one participant also felt it was possible to think too little: “If I don’t think, I can get out of a downward spiral, but then I can get into the stage of just being a vegetable as well.”

Finally, two participants mentioned consuming entertainment as being important hobbies for them, with one participant describing her enjoyment of television as a way to relax, and another describing how she’d recently gotten satisfaction from reading books, even if it took her a lot longer than it used to. Singing in a rehab choir and listening to music were also mentioned positively, with one participant describing his increased feelings of confidence from singing in the choir and being given solo parts.

Overall, it was clear that the participants’ hobbies were a great source of enjoyment and stress relief for them.
Companionship:

This theme was present in four out of five responses, however as only two participants expanded significantly on it, it covered only 4% of response data. This theme covered comfort gained from interactions with family, close friends and companion animals.

One participant referred to the value of companionship and having someone to talk to by quoting, “Talking is healing,” while another reflected on having found a family photo earlier that day and it lifting their spirits.

Of the two who expanded on the theme more, one talked about her friends and how she liked to chat. She said that they sometimes ‘got a good laugh’ out of her mixing up words, and while she would be offended if a stranger did that, she doesn’t mind when it’s her friends. The final participant described the value of talking with her friend/housemate, and emphasised that the fact that this friend knew her before her injury made it easier to communicate with her. She also talked about the comfort she derived from spending time with her pets, cuddling and looking after them. When asked if the lack of language necessary to spend quality time with animals made it easier, she agreed that it did.

The degree to which participants spoke about companionship varied, but it was clearly an important source of support and enjoyment.

Resilience and Determination:

The next theme was present in three out of five responses and covered 11% of response data overall. It dealt with participants’ reflections on their own strength and the importance of moving forward.

Participants described the importance of taking things day by day, and the importance of challenging themselves. “A huge part of it is... You have to keep a line for yourself, and you have to push yourself up to it. Cos if you let yourself fall too far, it gets harder to have a conversation.” Pushing themselves was seen as important both for the purposes of recovery, and to gain a sense of accomplishment and motivation by making progress and overcoming
challenges. There was some crossover with discussion of hobbies here in terms of being a source of accomplishment.

It is worth taking a longer quote from a participant who described the need for grit, determination and taking things one step at a time in combating their symptoms of depression: “I have to keep pushing myself to stay on the good side. If I think about the mental health, I can swing very easily into a big dark spiral. So I take each hour as it comes, and I try to figure out what’s the next hour – what I have to do. And if I think about it that way, I can keep control of it. I think. I hope.”

While for others, there was more of a note of pride in their own resilience and how they had handled the challenges they’d been dealt: “I suppose it depends on your personality, how you deal with this... I’m a determined type of woman, and I still am... I will make it work.”

**Feeling Capable:**

This theme was also present in three out of five responses, and covered 8% of response data. The participants described the positive impact of activities that helped them feel capable and useful in practical ways.

One participant talked about how getting involved with volunteering, for ABI and other causes, was very helpful for them. Another spoke about how tidying up his room or his office at home could help lift his mood and give him a sense of satisfaction: “It’s satisfying to get the job done. But it’s more satisfying that I did it.”

The third participant described her process of reading a book on money management: “I go through it and I highlight things that look useful, and then I take them down in my own script and I have them if I need them.” (Note that some people with aphasia find it easier to read their own handwriting.) This knowledge then helped her feel informed when a family member came to her with a money issue: “And I read the book, and it explained what a debit card was, that it’s like an ATM card. And it was plain English, and then I understood all about it, and that was great.”

These activities helped the participants to feel more confident in themselves, and seemed to help combat the psychological burden of feeling ‘disabled’.
**Professional Support**

The next theme occurred in two out of five responses, and covered 6% of response data overall. Two participants praised the professional support they had received in a number of ways.

One participant talked about a period of low mood they had gone through earlier in their rehab, and that seeing a counsellor really helped them. They also expressed their enjoyment of the choir that was offered by the rehab day services. The other participant said that the rehab day service had really helped him understand his symptoms better. He also praised the activities and sense of involvement and fellowship: “There’s always something...going on. And even though you can’t physically do it, you feel like you’re part of it. I mean, I wouldn’t be anywhere near the yoga if it wasn’t going on here. It’s fun... You see with this going on, a large part of the population have difficulties in some way. And while you think everyone is, you know, ‘normal’, in a lot of cases they aren’t.”

It was clear the participants’ derived a lot of good from their participation with the service.

**Adaptation:**

The next theme was also present in two out of five responses and covered 2% of response data. This theme had some commonalities with the Resilience and Determination theme, but it was decided to include it separately because it was expressed in a more passive way.

One participant spoke about how they had gradually gotten over certain issues and put them behind them. Another described how her feelings about aphasia had mellowed over time: “A couple of years ago, I would have gotten upset... I try to live with it now. I wasn’t coping. And I get frustrated. But now I call it... I call it only aphasia.”

Where the Resilience and Determination theme was the participants expressing change through determination and action, Adaptation was more expressing change through the simple passage of time.
**Being Upfront**

The final theme was present in two out of five responses. Though it covered only 1% of data, it certainly seemed worth including as a separate theme, as it comprised a practical adaptation strategy that didn’t fit in any other theme.

This was the idea of being upfront with new people about having a communication problem, and asking them to speak more slowly or write information down: “Now at the start when I talk to the bank or whoever, I say I have a communication difficulty. And then I have the control.” Both participants expressed this theme in the context of dealing with utilities and services. “I ask them to slow down. Particularly with numbers, I say no-no-no stop. I ask them to write them down.”

This strategy seemed to empower the participants in these types of interactions.
Discussion

It’s clear from the results that the participants found aphasia to be extremely challenging at times and overall detrimental to their mental health and quality of life. However, they also showed a large degree of resilience, and most seemed to employ the use of positive coping strategies. There was also significant variation in the mental health of the participants, with one participant in particular struggling with negative thoughts. It is also worth noting that, possibly due to self-selection, four of the participants had aphasia which may be described as mild, while one had symptoms which would be described as moderate.

While it may not be accurate to call them overarching themes, a number of ‘recurring motifs’ did appear in the data. The first occurred in a large number of themes (most prominently in Feeling ‘Inadequate’, Loss, Resilience and Determination and Adaptation) and is the idea of comparison. We see multiple types of comparison being made, some helpful for emotional wellbeing and others harmful. In the data, the participants compare themselves to ‘normal’ people and feel lesser than them, and they compare themselves to the person they were prior to brain injury and feel a deep sense of loss and sadness. On the other side, they compare where they are now to where they were at the start of their rehabilitation journey and feel pride in their accomplishments and determination, and have a note of hopefulness about the future. One individual compared themselves to those around them in rehab and felt dismayed that this was now their place in life, while another compared themselves to the same people and felt comforted to know he wasn’t the only one with challenges. It is true to say that, as highly social animals, no one exists in a bubble, and this remains very much the case in those with aphasia. For these participants, comparison enabled them to judge their own condition, for better and worse.

The other motif to emerge was somewhat related, and was that of progress. This was expressed in many of the themes in the ‘What helps?’ category. Setting goals seemed to be important for the participants, with one even describing how lost he felt at various points in his rehab when he wasn’t sure what the next milestone should be. These were not goals in the sense of formal, SMART goals, but rather certain individual objectives and accomplishments that gave them a sense of satisfaction. Progress is what enabled the
participants to make positive comparisons to the past, and this finding emphasises the importance of continued treatment in aphasia, and continuing active rehab when possible. Without forward progress, it may get more difficult for individuals with aphasia to maintain a sense of accomplishment and motivation, leaving only the negative social comparisons of disability that many other individuals with aphasia may also be prone to.

Results are further discussed in context of previous research in Chapter Four.
Chapter 4: Discussion & Conclusions
4.1 Review of Research Questions:

1. Does aphasia have a significant impact on mood or anxiety levels?
Probably, yes. Rates of both depression and anxiety symptoms were significantly higher than in
the general population, and rates of depression were also higher than in most ABI studies
(discussed further in section 4.2). As there was no control group, it cannot be definitively said
that the high rates of depression and anxiety in this sample were due to aphasia. However given
the fact that aphasia was the primary disability amongst participants, and that those in the
qualitative study all believed aphasia had a negative impact on their mental health, it seems like
that aphasia was a large contributor to the results.

2. Does the type of aphasia (expressive/receptive) have an impact on this potential link?
Not in this sample, no.

3. Does the severity of symptoms mediate the link?
No, not in this sample.

4. Does the degree of symptom improvement since onset have an effect?
Yes, greater symptom improvement is associated with lower depression symptoms, lower
anxiety symptoms, higher quality of life and greater social support. The idea of rehab progress
being important to mental health also arose in the qualitative study.

5. Do gender or age have an effect?
No, not in this sample.

6. Do the factors of social support, quality of life, cognitive reserve or attendance at a support
group have an effect?
The factors of social support and quality of life were found to have multiple interactions, while
no significant effects were found for cognitive reserve or support group attendance.
4.2 Results in Context:

In the context of ABI literature, rates of possible depression found in the sample appear to be higher than rates found in most general ABI studies. The Hackett and Pickles (2014) meta-analysis found rates of 25% in their one to five year post-onset sample and 23% at time points after five years. Meanwhile the Osborn, Mathias and Fairweather-Schmidt (2014) meta-analysis found rates of 32%, while in this sample, 61% had clinically significant depression symptoms according to the PHQ-9, 35% had symptoms which were moderate or higher, and 48% expressed functional impairment due to depression symptoms. These results are more in line with the Shehata et al. (2015) study, which found mean depression scores on the Beck Depression Inventory among a sample of people with aphasia to be over twice as high as those from a no-aphasia stroke group. Though more study is still needed, the results of this study contribute to the evidence which suggests that those with aphasia may be a particularly at-risk subgroup for depression in an already at-risk group.

The anxiety results from this study appear to be quite in-line with findings of general ABI studies, with the figure of 18% being within the range of 13-28% estimated the Mallya et al. (2015) review on anxiety rates in TBI. It was notable in the qualitative study that most of the anxiety expressed by participants related to social interaction, which does make sense in the context of aphasia. The Beck Anxiety Inventory and many other commonly used inventories do not include questions on social anxiety, so this may be a facet that is being overlooked in ABI (and aphasia in particular) and could benefit from more study in future.

In terms of research on factors which may affect mental health in stroke and ABI, most of this study’s findings are not entirely unusual. As discussed thoroughly in section 1.5, findings on the degree to which ABI severity or level of disability impact on mental health have been very mixed, and this is also true of the effect of time elapsed since onset. So in that context, the absence of significance for those associations in this study is not outside the norm. This is also true for research on other types of acquired disabilities such as spinal cord injury, as discussed in section 1.3 (and in fact depression rates tend to be very similar in ABI and SCI studies). Gender and age also seem to have no impact more often than not, and this study mirrors the somewhat unusual finding of many other studies on ABI and other acquired conditions in finding depression and anxiety symptoms to be equally common in men and women. Amongst aphasia studies specifically, Cruice et al. (2003) and Bullier et al. (2019) both
found negative associations between severity of aphasia and QoL, which this study did not (it in fact found a slight positive association). It is of course never clear to what degree publication bias may impact the amount of positive versus null findings which are published, but it is certainly possible that a different or slightly larger sample size may have produced different findings. It is also possible those with more severe aphasia in their samples were not as well socially supported, which would have an impact on most QoL scales.

The most novel findings in this study in the context of the literature remain the importance of ‘change since onset’ as a predictor, and the high level of social support received by those with more severe symptoms. The qualitative results also represent novel findings from an under-studied population.

4.3 Is It All Relative?

Probably the most significant and novel finding of this study was the discovery of ‘change since onset’ as a psychosocial predictor. While of course this finding would need to be replicated in further studies to be certain of its validity as a phenomenon, a theoretical basis for the finding may still be hypothesized.

Research on psychosocial adaptation has been widespread in various forms, but even within the area of adaptation to disability, few unifying theories or frameworks have been proposed. A complete overview of the research on various conditions is beyond the scope of this write-up, however some researchers have attempted to define psychosocial adaptation or develop adaptation theories. A 2005 review provides a well-organised overview of proposed domains and responses of adaptation to chronic illness or disability (often abbreviated as CID). It proposes a number of basic concepts: stress, crisis, loss and grief, body image, self-concept, stigma, uncertainty and unpredictability, and quality of life. And a number of common psychological responses: shock, anxiety, denial, depression, anger/hostility, and adjustment (Livneh & Antonak, 2005). It is easy to see how a large number of these factors would be impacted by the trajectory of symptoms as well as the severity. In progressive conditions like Multiple Sclerosis, it is certainly true that uncertainty and unpredictability have been identified as key factors contributing to poorer mental health (Alschuler & Beier, 2015). Initially, this project had been envisioned to include Primary
Progressive Aphasia as well as aphasia caused by ABI, as it was hypothesized that, though symptoms may often be very similar, the negative course of PPA would make individuals with the condition even more at-risk for poor mental health. However although it did not prove possible to include a PPA sample in the necessary timeframe, the CSO variable was retained, as it was considered that an upwards trajectory or a high degree of recovery may still show psychological benefits over a flatter recovery trajectory.

If we look outside of research on disability, it is known that the idea of ‘relativity’ is important in mental health. We know that poverty, for example, has a much more significant effect on mental health in unequal societies (Das et al., 2007). It is not only the realities of poverty that impact mental health, but also the knowledge that you are struggling more than others in your society. Similarly, research has shown that spending a lot of time on social media engaging in unfavourable social comparison also can have very negative effects for self-esteem and mental health (Hunt et al., 2018). Initial research and writing on this topic was completed most famously by Leon Festinger (1954) in his ‘Theory of Social Comparison’. While the research is of course old from a cultural context and others have expanded on it since, there is little reason to think that his findings of the importance of outward comparison in setting ‘levels of aspiration’ and assessing one’s own performance have changed drastically in the intervening years. This idea of comparison was seen in the qualitative study in the theme of Feeling ‘Inadequate’, but as discussed in the discussion section of Chapter Three, the idea of comparison was also present in the theme of Loss, when participants compared themselves to their ‘past selves’ and past abilities. And in the themes of Resilience and Determination and Adaptation, a more favourable form of ‘self-comparison’ was seen, where participants reflected on how far they’d come in their rehab, often with a sense of pride. Less research has been conducted on this inward form of comparison, but it makes some sense in everyday terms. To use a financial analogy, a person making €60k a year may be gutted to have to take a job paying €30k a year. It would mean a loss in standard of living, social status, and quite possibly a decline in the person’s sense of self-worth, if financial success was something they valued. However, if this person then had to live on €30k for a time, they may be delighted with a raise up to €50k and it may help diminish many of the negative feelings the pay-cut caused, even if initially a €10k pay cut would have been viewed extremely negatively. Similarly, many people would be terrified of the idea of enduring a brain injury
and developing aphasia. Yet when this becomes a person’s reality, a degree of adaptation must necessarily take place. Gains which take place after that then become rewarding, as was shown in the qualitative participants’ sense of pride in their rehab accomplishments, even if those accomplishments are abilities which would be taken for granted by most people. Perhaps objective ability is not always as important as subjective trajectory.

While it is easy to get carried away with this line of thought, it must be mentioned that this theory is just one possibility, and it is of course also possible that better mental health is the factor which led to greater recovery of aphasia symptoms in this sample. If this were the case, it would underline the large impact mental health can have on neuro-rehab, and the importance of early screening and psychotherapeutic intervention in people with mental health issues following ABI. A longitudinal analysis would be needed to follow the interaction between these factors.

4.4 Limitations, and Future Research:

The main limitation of this study was its small sample size. While the quantitative results may represent real trends in the aphasia population, it is also possible that some or many would not replicate in a larger sample size. Future research in this area would therefore benefit from a larger sample, and also from a longitudinal design which would give more insight into some of the associations found. A matched control group of individuals with ABI and no aphasia symptoms would also be a useful addition.

If investigating ‘change since onset’ as a factor in an aphasia population in a non-longitudinal design, it may be beneficial to gain access to initial language assessments and repeat the same assessments again to gain a ‘change’ figure, if this is feasible, as it would eliminate the need for any retrospective ratings. Additionally, investigations of anxiety in the aphasia population may benefit from using a social anxiety scale.

In the qualitative component, as with most qualitative research, it is of course uncertain to what degree the experiences of the five participants reflect the experiences of others with aphasia or other attendees of ABI day services. It is also the case that the sample was self-selecting, and possibly as a result of this, they had less severe aphasia (on average) than the
overall quantitative sample. Future research may consider going to greater lengths to get those with more severe aphasia involved in qualitative research, presuming appropriate methodological adaptations have been put in place.

4.5 Conclusions:

Results suggest that those with aphasia may represent a particularly at-risk subgroup for adverse psychological outcomes within the ABI population. If a greater degree of symptom improvement really does serve as a protective factor, as results may indicate, then it emphasises the importance of continued speech and language treatment for those with chronic aphasia, as evidence suggests individuals can make progress even many years post-onset. Results from the qualitative study also emphasise the psychological importance of progress and moving forward in rehab. Additionally, given the very high prevalence of depression symptoms, those with aphasia may benefit from being offered occasional mental health ‘check-ups’ at rehab services or in primary care, so that any clinical issues can be identified and treated.


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Appendix A: Intro Questions

Please underline or circle your answer, where appropriate.

**Age:**

**Gender:** Male / Female

1. **When** were you first **diagnosed** with aphasia?
   - Month:    Year:

2. What is the **cause** of your aphasia?
   - Stroke    Other

3. Have you attended a **support group** for aphasia or stroke since you were diagnosed?
   - No    an aphasia group    a stroke group

4. Have you attended a **support group** for aphasia or stroke **in the past 6 months**?
   - No    an aphasia group    a stroke group

5. **Before** you had aphasia, were you ever diagnosed with a **mental illness**?
   - No    depression    an anxiety disorder    other
Appendix B: Language Assessment and Scoring Scheme

[Receptive] Can you **understand** speech easily?

1 2 3 4 5
Never Always

[Expressive] Can you **express** yourself and **speak** easily?

1 2 3 4 5
Never Always

[R] Can you **read** easily?

1 2 3 4 5
No Yes

[E] Can you **write** easily?

1 2 3 4 5
No Yes

[R] Are you able to **understand simple sentences** such as, “Do you want some tea?” , “Did you enjoy it?”, “I didn’t like it.” etc.

1 2 3 4 5
Never Always
[R] Are you able to **understand complicated sentences** such as, “I wasn’t sure if you were enjoying it, but then I thought I saw you smile, and it was alright in the end, wasn’t it?” or, “It started raining and I thought, ‘Oh no, that’s the day ruined,’ and sure enough they started to put everything away.”

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[R, reverse scoring (ie 1=5 and 5=1)] Do you ever find that your speech **doesn’t make any sense** to others?

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[E] Are you able to **answer questions by saying ‘yes’ or ‘no’?**

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[E] Are you able to **express yourself in short sentences**? For example, “I like it,” or, “I’m cold.”

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[E] Are you able to **express yourself in long sentences**? For example, “I wasn’t sure if you were coming, since you were sick the other day,” or, “I went for a nice walk earlier, but it was quite hot.”

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[R Change; subtract answer from answer to Q1, and multiply answer by 2] When you were first diagnosed with aphasia, could you understand speech easily?

1 2 3 4 5
Never Always

[E Change; subtract answer from answer to Q2, and multiply answer by 2] When you were first diagnosed with aphasia, could you express yourself and speak easily?

1 2 3 4 5
Never Always

[Change] If your aphasia has gotten better, how much better would you say it has gotten?

0 1 2 3 4 5 6 7 8 9 10
No better Much better

[Change] If your aphasia has gotten worse, how much worse would you say it has gotten?

0 1 2 3 4 5 6 7 8 9 10
No worse Much worse
Could you tell me about the weather today?

[R; double scored] Sense/semantics:

1 2 3 4 5

[E; double scored] Grammar:

1 2 3 4 5

[E; double scored] Fluency:

1 2 3 4 5

Could you tell me about the clothes you're wearing today?

[R; double scored] Sense/semantics:

1 2 3 4 5

[E; double scored] Grammar:

1 2 3 4 5

[E; double scored] Fluency:

1 2 3 4 5

[R; double scored] Can you take your pen and tap it on the table 4 times? OR Can you nod your head 3 times and then shake it once?

Understanding:

1 2 3 4 5
[R; double scored] Could you put three sheets of paper on top of each other, and then do a 'thumbs up' sign?

Understanding:
1 2 3 4 5

Possible expressive score range (with lower indicating more impairment): 13-65
Possible receptive score range (with lower indicating more impairment): 13-65
Total possible overall (expressive + receptive) score: 130
Total possible change score: -26 to 26

If a scale starting at zero is necessary, 13 can be subtracted from final expressive and receptive scores, or 26 from the total score (excluding the change component).
Appendix C: Aphasia-friendly PHQ-9

Over the last 2 weeks, how often have you been bothered by any of the following problems?

1. Little interest or pleasure in doing things

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<td>Sometimes</td>
<td>Often</td>
<td>Nearly every day</td>
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2. Feeling down, depressed, or hopeless

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<td>Not at all</td>
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3. Trouble falling or staying asleep, or sleeping too much

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<td>Not at all</td>
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4. Feeling tired or having little energy

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<td>Not at all</td>
<td>Sometimes</td>
<td>Often</td>
<td>Nearly every day</td>
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5. **Poor appetite** or **overeating**

0  1  2  3  
Not at all  Sometimes  Often  Nearly every day

6. Feeling **bad about yourself** — or that you are a failure or have let yourself or your family down

0  1  2  3  
Not at all  Sometimes  Often  Nearly every day

7. **Trouble concentrating** on things, such as reading the newspaper or watching television

0  1  2  3  
Not at all  Sometimes  Often  Nearly every day

8. **Moving or speaking** so **slowly** that other people could have noticed? Or the opposite — being so **fidgety** or **restless** that you have been moving around a lot more than usual

0  1  2  3  
Not at all  Sometimes  Often  Nearly every day

9. **Thoughts** that you would be **better off dead** or of **hurting yourself** in some way

0  1  2  3  
Not at all  Sometimes  Often  Nearly every day
If you checked off any problems, **how difficult** have these problems made it for you to do your work, take care of things at home, or get along with other people?

0 | 1 | 2 | 3
---|---|---|---
Not difficult at all | | | Extremely difficult
Appendix D: Debriefing Form

Thank you for taking part in this study, ‘The Mental Health Impact of Aphasia’. The information you have given will be used to help identify mental health risk factors and protective factors in people with aphasia, and may be useful in future research and/or clinical guidelines in the area.

If you experience distress or sadness as a result of any of the topics raised in this study, there are a number of ways to seek help.

If you are in extreme distress and feel as though you may harm yourself or others, the best place to go is your local hospital emergency department.

If your distress is less acute, please talk about it with your keyworker, psychologist or Dr Elaine Kelly here at Headway. It would also be a good idea to talk to your GP about your feelings.

Some people with aphasia may also find it helpful to call the Samaritans on 116 123 or email jo@samaritans.org, or call Aware (10am-10pm) on 1800 80 48 48.