Clinical psychologists’ experiences of supporting people with aphasia as part of a multidisciplinary team

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ABSTRACT

Background: Aphasia is a communication disability resulting from acquired brain injury and affects more than 350,000 people in the UK (Stroke Association, n.d.). People with aphasia experience numerous emotional and psychosocial challenges associated with loss of language. Psychological support for people with aphasia in the UK tends to be provided by clinical psychologists or clinical neuropsychologists working in NHS services as part of a multidisciplinary team (MDT). However, there is no research to date exploring how they experience supporting people with aphasia.

Aims: This research aims to explore how clinical psychologists make sense of and address the emotional outcomes associated with aphasia, and how they experience working as part of an MDT when supporting people with aphasia, including what roles they take and what they find useful when doing this work.

Methods: This is a qualitative study employing the use of individual, semi-structured interviews with seven clinical psychologists who have experience of supporting people with aphasia as part of their work in an NHS MDT context. Data was analysed using reflexive Thematic Analysis (TA).

Results: Four main themes and seven subthemes were constructed through the analysis. The main themes were: 1) Working with Distress; 2) The MDT as a Resource; 3) Challenging Assumptions – Defending Capacity and Championing Psychological Support; and 4) Moving Beyond Language – (Re)Connecting with What’s Important.

Conclusions/Implications: Clinical psychologists employ an individualised approach to making sense of and working with emotional responses to aphasia, including working sensitively with frustration. They discussed supporting colleagues to understand and address psychological aspects of aphasia and viewed interdisciplinary working as important, with a particular emphasis on joint working with SLT colleagues. The findings provide unique insights into how clinical psychologists work with people with aphasia and have implications relating to the development of training resources.

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1. INTRODUCTION

In this chapter I provide an overview of aphasia, including the types and causes, before discussing what is known about the associated emotional and psychosocial outcomes. I then summarise what is understood about living well or living successfully with aphasia, as reported by people with aphasia. Literature relating to the availability of psychological support for people with aphasia in existing UK service pathways is explored, as well as how the work of speech and language therapists (SLTs) fits in with this. Finally, several key studies exploring mental health professionals' experiences of working with people with aphasia are reviewed. I then present the rationale for this research and the research questions.

1.1. Literature Search

A narrative review of the literature was undertaken between September 2020 and January 2022 with the purpose developing an awareness of the research relating to aphasia and the emotional and psychosocial outcomes associated with it, and to serve as a backdrop to the research topic. A narrative review was deemed to be appropriate due to the broad nature of the background, which involves several interlinking fields of study with different populations, ideas, and concepts (Ferrari, 2015). My initial search for literature involved using two electronic databases: EBSCO APA PSYCHINFO and EBSCO CINAHL Plus. The following search terms were used:

> *("aphasia" OR "aphasic" OR "people with aphasia" AND "emotion*" OR "mood" OR "feeling*" OR "affect" OR "mental health" AND "therapy" OR "treatment" OR "intervention" OR "counselling" OR "psychotherapy")*

This search yielded 1209 results, which were ordered by relevance. I manually scanned the titles and abstracts of the first 220 hits. At this point I noted that the titles and abstracts of articles no longer appeared to connect to the research topic and, given the results had been ordered by relevance, scanning of the remaining articles was not undertaken. Seemingly relevant articles from the first

220 hits were reviewed in full and downloaded to reference manager, Mendeley, and organised into folders accordingly. During the review process, many additional relevant studies were identified from the reference lists of papers found in the initial search.

1.2. Overview of Aphasia

Aphasia is an acquired communication disability, usually resulting from damage to the left cerebral hemisphere: the area of the brain responsible for controlling language (Brady et al., 2016). Depending on the exact location and severity of injury, aphasia may involve difficulties with language comprehension or expression, “in the verbal, written, and signed modalities” (Worrall et al., 2016, p.848). Aphasia is not caused by cognitive deficits and does not affect a person’s thinking skills or intellect but people with aphasia may struggle to express their thoughts due to difficulties with processing language (Niemi & Johansson, 2013). A person may experience cognitive difficulties resulting from their brain injury in addition to aphasia.

1.2.1. Types of Aphasia

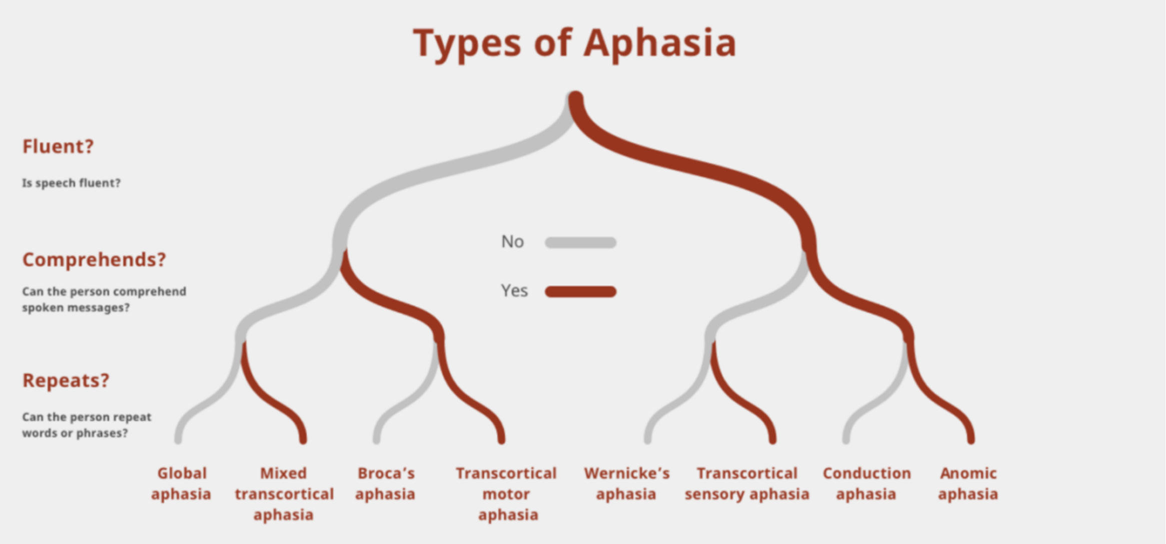
The precise location of the brain injury is associated with many different “types or patterns of aphasia”, which can evolve over time as changes associated with brain recovery occur (National Aphasia Association, n.d.). Whilst no two people with aphasia present the same, these types or patterns generally fall into two main categories of aphasia: fluent and non-fluent. Figure 1 shows some of the different types of aphasia, falling within the fluent and non-fluent categories.

‘Fluent’ Aphasia: People with fluent aphasia have usually experienced damage to the left temporal lobe. The most common type of fluent aphasia is Wernicke’s aphasia. People with this type of aphasia may speak in sentences that do not make sense, are difficult to follow and/or may use words that do not exist. People with fluent aphasia are also more likely to have difficulties with understanding language (receptive difficulties).

Non-fluent Aphasia: People with non-fluent, or ‘expressive’ aphasia typically have more difficulties with speaking than understanding, and speech is likely to be effortful in quality. Difficulties can range from mild word-finding problems or grammatical errors, to being unable to form single words. The most common form of non-fluent aphasia is Broca's aphasia, which results from damage to an area within the left inferior frontal lobe of the brain (Santo Pietro et al., 2019).

Figure 1

Types of Aphasia



Note. Types of Aphasia. From *Aphasia Definitions*, by National Aphasia Association, n.d. (https://www.aphasia.org/aphasia-definitions/). Copyright www.aphasia.org.

People can experience different combinations of these types of aphasia, such as global aphasia and mixed non-fluent or mixed transcortical aphasia (National Institute of Deafness and Other Communication Disorders [NIDCD], 2017).

1.2.2. Causes of Aphasia

1.2.2.1. Stroke

The most common cause of aphasia is stroke. Approximately one third of stroke survivors experience aphasia (Brady et al., 2016; Dickey et al., 2010; Mitchell et al., 2021; Pedersen et al., 1995; Wade et al., 1986). NICE (2019, p.1) states that, "stroke happens when the blood supply to part of the brain is cut off, or when there is bleeding in or around the brain". Two main types of stroke are generally agreed upon (Donkor, 2018; Stroke Association, n.d.; National Institute of Neurological Disorders and Stroke [NINDS] & National Institutes of

Health, 2009). Ischaemic stroke is the most common type of stroke (Virani et al., 2021), and happens when the blood supply to the brain is blocked (often by a blood clot), causing abrupt problems with functioning, often with varied lasting outcomes. A transient ischaemic attack (TIA), often referred to as a ‘mini stroke’, results from a temporary blockage, meaning symptoms usually last just a few minutes. Haemorrhagic stroke occurs when an artery in the brain ruptures, resulting in bleeding and damage to the brain tissue (Department of Health National Audit Office, 2010). Chronic hypertension, cerebral amyloid angiopathy, blood disorders, aneurysms or other structural abnormalities in the blood vessels can all increase the likelihood of a blood vessel rupturing (NINDS & National Institutes of Health, 2009). As with other types of acquired brain injury, people with aphasia caused by stroke often experience additional outcomes, all of which have implications for physical and psychosocial functioning.

Physical Impairments: The most common physical impairments experienced by people who have a stroke are, “numbness, weakness (hemiparesis) or paralysis (hemiplegia) on the side of the body contralateral to the stroke” (Barrows et al., 2021, p.5), which can lead to impaired upper and/or lower limb function and mobility.

Cognitive Impairments: Population-based studies have demonstrated that approximately one third of people who have a stroke experience changes to their cognition (Patel et al., 2002; Tatemichi et al., 1994). These can include problems with attention, memory, executive function, perception, and language (Barrows et al., 2021). Cognitive deficits often have implications for functional recovery (Park et al., 2015). They can cause difficulties with carrying out activities of daily living or vocational tasks and are associated with higher rates of disability (Douiri et al., 2013) and unemployment (Kauranen et al., 2013), as well as reduced well-being (Haslam et al., 2008).

Psychological Outcomes: For most, the life altering nature of stroke necessitates a degree of psychological ‘adjustment’, and national guidelines state psychological care should be available in all stroke services (Intercollegiate Stroke Working Party, 2016). Research shows that around a third of stroke survivors go on to develop a clinical diagnosis such as depression or anxiety (Hackett et al., 2005; Mitchell et al., 2017). Risk factors cited in the literature include: left hemisphere stroke (typically associated with more disability); communication difficulties such as aphasia; family history of mood disorder; or personal history of mood disorder (Hackett et al., 2005; Mitchell et al., 2017).

1.2.2.2. Other Causes of Aphasia

Aphasia can also result from other kinds of brain damage, such as from a brain tumour or infection, head injury, or from neurodegenerative illnesses like dementia (NIDCD, 2017). Primary Progressive Aphasia (PPA) is a rare dementia, usually resulting from, “damage to brain cells in the front and sides of the brain, called the frontal and temporal lobes” (Alzheimer’s Research UK, 2018. p.6). PPA has three ‘variants’ or subtypes: semantic dementia, progressive non-fluent aphasia, and logopenic aphasia (Gorno-Tempini et al., 2011), each with different characteristics in terms of how they impact language expression and comprehension. Unlike aphasias caused by stroke or other types of acquired brain injury, language impairment in PPA is “gradual in onset and insidiously progressive” (Douglas, 2022, p.2).

1.3. Understanding the Emotional Impact of Aphasia

Understanding the emotional aspects of aphasia is complicated and involves teasing out the varying and nuanced ways aphasia impacts the psyche separate to the other effects of the causal injury or condition. Psychological concepts such as trauma, loss, and grief are frequently used to explain emotional responses to changes people can experience following brain injury or illness (Lincoln et al., 2012). As such, terms like ’adjustment’, ‘adaptation’, and ‘coping’ are common when describing the psychological processes involved in overcoming or navigating psychological distress or improving quality of life; also reflecting the chronicity or permanence of outcomes experienced by many (Gracey et al., 2008; Lincoln et al., 2012; Sharpe & Curran, 2006; Simblett et al., 2015). Research suggests that the communication difficulties experienced by people with aphasia present unique challenges to negotiating aspects of their lives including their identity (Shadden, 2005), relationships (Cruice et al., 2006; Northcott & Hilari, 2011), and activities (Sjöqvist Nätterlund, 2010); all of which have implications in terms of psychosocial and emotional wellbeing. Comparing experiences of stroke survivors with and without aphasia can help provide some insights. For example, research shows that stroke survivors with aphasia have worse mental health outcomes than those without (Cruice et al., 2010; Hilari, 2011; Laures-Gore et al., 2020), and aphasia is frequently cited as a risk factor for depression or anxiety in stroke survivors (Hilari et al., 2012; Mitchell et al., 2017). This is clinically relevant given ongoing mood difficulties are associated with higher mortality (Ayerbe et al., 2014) and worse functional and social outcomes for stroke survivors (Li et al., 2019; Paolucci et al., 2019).

Language problems have historically led to people with aphasia being excluded from participating in research exploring quality of life, emotional wellbeing, and mental health (Dalemans et al., 2009). However, significant efforts have been made by researchers in recent years to include the voices of people with aphasia, even those with more severe types, in studies. Efforts have included: adapting research materials and designing measures to ensure they are 'aphasia friendly' (Hilari et al., 2010; Simmons-mackie et al., 2014); undertaking training in supported conversation skills to better enable participation in interviews (Lanyon et al., 2018a); bringing resources, such as an aphasia friendly booklet (Northcott & Hilari, 2011) or photos and pictures (Moss et al., 2021) to support the interviewee; and involving friends and family where appropriate. Consequently, there is now a substantial body of literature speaking to the experiences of people with aphasia.

The following sections explore the literature relating to the psychosocial and emotional impact of aphasia. Whilst there are some common themes, the emotional aspects discussed do not necessarily represent experiences of all people with aphasia. Much of the research has been undertaken within the context of stroke, and by researchers and clinicians who work with stroke patients. In contrast, little is known about how people experience their aphasia when it is caused by other types of injury or illness. For example, there is only a small amount of literature examining the psychosocial and emotional experiences of people with PPA, for whom difficulties with language worsen over time. This is partly due to PPA being rare. It is estimated there are around just 2300 people living with the condition in the UK (Volkmer, Spector, Warren, et al., 2020), representing less than one percent of the 350,000 people with aphasia in the UK (Stroke Association, n.d.). It is important to acknowledge that people with these types of aphasia likely face additional challenges or ‘threats’ to their emotional wellbeing relating to the progressive nature of their condition (Schaffer et al., 2021, p.2053).

1.3.1. Identity

There is a body of work exploring the impact of brain injury on self-construct or identity (Ellis-Hill et al., 2000; Gracey et al., 2008; Guise et al., 2010; Nilsson et al., 1997; Nochi, 1998). This is different to the changes in affect or social functioning, often termed ‘personality changes’, caused by specific neurological and cognitive impairments (Yeates et al., 2008). Although people may experience both and the latter may also contribute to an altered sense of self. People have reported viewing themselves differently, often more negatively, following injury (Ellis-Hill et al., 2000; Kuluski et al., 2014; Lapadatu & Morris, 2019), or feeling as though others view and treat them differently (Anderson & Whitfield, 2013; Pallesen, 2014). Much of the work theorises that comparison of self pre and post injury creates a sense of loss or confusion around identity or a ‘threat to self’ (Gracey et al., 2009), leading to emotional distress; a process Lapadatu & Morris (2019) explain using self-discrepancy theory. Self-discrepancy theory (Higgins, 1987) proposes that incompatible beliefs about different representations of the self give rise to feelings of discomfort or distress. Drawing on ideas from social identity theory (Tajfel & Turner, 1979), brain injury can also impact identity through loss of functional abilities and reduced participation in social groups and activities.

Aphasia has been described as ’identity theft’ in the literature (Shadden, 2005). Identity has been defined as, “a composite of roles, values and beliefs that are acquired and maintained through social interactions” (Shadden & Agan, 2004, p.175). Aphasia simultaneously disrupts identity and takes away one of the most important tools used for renegotiating it (Shadden & Agan, 2004): language. Yet despite this fundamental link between language, communication and identity, Taubner et al. (2020) stressed that much of the research on identity within the stroke literature excludes people with aphasia. For some, aphasia appears to disrupt identity through changes to their roles within their families and friendships. For example, people have shared the way in which aphasia diminished or weakened their sense of identity as a parent due to difficulties communicating with their children (Manning et al., 2017). In one study, people with aphasia frequently described, “identity changes and an altered sense of self post-stroke”, with one person describing themselves as more ‘hot tempered’ due to frustrations around not being able to speak (Moss et al., 2021, p.601). Indeed, whilst some people may experience what is commonly termed ‘emotional lability’ following brain injury, observed changes in affect in a person with aphasia may simply reflect attempts to navigate new challenges in communication within their interactions. Indeed, anger and frustration were noted to be “the most dominant feelings” resulting from communication breakdowns during conversations by Johansson et al. (2012, p.149). People have also discussed the way in which others’ perceptions or prejudices have negatively impacted their sense of self. For example, some have reported feeling as though others do not view them as ‘whole person’ due to their aphasia (Dalemans et al., 2010), and others have discussed concerns that people perceive them as ‘stupid’ or even drunk, and do not take them seriously (Taubner et al., 2020).

1.3.2. Relationship Changes and Loneliness

Social isolation is a frequent consequence of brain injury, contributing to psychological distress and reduced quality of life. Language has been described as the ‘currency’ of relationships (Parr et al., 1997), and it is notable that people with aphasia often report becoming socially withdrawn or feeling lonely (Hilari & Northcott, 2006; Ruggero et al., 2019; Sjöqvist Nätterlund, 2010). Stroke survivors with aphasia tend to have fewer social contacts than those without (Cruice et al., 2006) and find it harder to retain friendships (Hilari & Northcott, 2006; Northcott & Hilari, 2011). Reasons cited in the literature include a lack of awareness about aphasia from others, or difficulties understanding the individual (Brown et al., 2012), which can create feelings of uncertainty and can even lead to friends and family avoiding the person (Cruice et al., 2006; Northcott & Hilari, 2011). People with aphasia have reported loss of confidence due to communication difficulties, leading to avoidance of social interactions, and contributing to isolation (Wray & Clarke, 2017). They have described changes in the nature of the interactions they share with friends, such as finding it more difficult to have a two-way conversation that flows easily, becoming more passive, or finding it harder to share humour (Hilari & Northcott, 2006; Northcott & Hilari, 2011; Taubner et al., 2020), and report less satisfaction with their social contact and engagement overall (Cruice et al., 2006). Some people have reported negative responses from friends, such as impatience, being cut off, or even being mocked (Manning et al., 2021; Northcott et al., 2016; Northcott & Hilari, 2011). Manning et al. (2021) suggested younger people with aphasia are at risk of losing friendships through difficulties participating in online/virtual communication formats, such as WhatsApp or other social media platforms.

Families respond to the effects aphasia in different ways, with some reporting it can be hard adapting to the changes aphasia brings to the family dynamic (Manning et al., 2021). For example, parents with aphasia have described being unable to interact with their children in the same way as before (Taubner et al., 2020), feeling pushed away by their children, or have experienced a sense of role reversal, leading to conflict (Manning et al., 2021). Many people experience changes to relationships with their partners or spouses, such as reduced autonomy and shared decision making (Dietz et al., 2013; Fotiadou et al., 2014). Partners or spouses have described challenges adapting to a new role of ‘caregiver’, or of negotiating the balance between providing support and promoting autonomy within interactions with their loved one (Brown et al., 2011b, 2012; Dietz et al., 2013). However, positive changes to relationships, such as feeling closer, or ‘strengthened bonds’ between one another have also been reported (Moss et al., 2021).

1.3.3. Participation and Vocational Changes

The importance of social participation is reflected in the goals people with aphasia have around communication, which usually relate to their ability to function socially and improve their confidence (Worrall et al., 2011). However, people with aphasia face internal and external barriers to participation related to their communication difficulties. For instance, people with aphasia have reported feeling left out or vulnerable during social gatherings (Dalemans et al., 2010; Northcott & Hilari, 2011), and have described difficulties with following an interaction, particularly in the absence of a good communication partner who is patient, accepting, and willing to support conversation (Dalemans et al., 2010). Lack of public awareness about aphasia can lead to people experiencing negative interactions when they are out in the community and leads to avoidance of unfamiliar places, further reducing opportunities for participation (Sjöqvist Nätterlund, 2010; Wray & Clarke, 2017). It has been shown that, following a stroke, people with aphasia engage in fewer leisure and social activities that typically require communication than those without, including shopping, hobbies, and travel (Hilari, 2011). This is further evidence of the way aphasia can be a barrier to accessing public services and transport (Dalemans et al., 2010).

Return to work is cited as a key issue in the wider rehabilitation literature as it relates to social participation and perceived life satisfaction (Hinckley, 2002). Many people with aphasia experience job loss through redundancy and early retirement. This results in huge changes to daily routine, activity, and social networks, which can lead to reduced confidence and sense of autonomy (Barry & Douglas, 2000; Manning et al., 2021; Sjöqvist Nätterlund, 2010). Worrall et al. (2017) found that people with post-graduate qualifications were less likely to report successfully living with aphasia. The authors suggest that the centrality of language within the lives of people with higher educational qualifications may exacerbate the negative impact of aphasia on quality of life. Another possible explanation is that people with post-graduate qualifications are more likely to have employment in roles necessitating higher levels of language use and may, therefore, be less likely to be able to return to their previous job following acquiring aphasia.

1.4. What do People with Aphasia Say Enables them to ‘Live Well’ or ‘Live Successfully’?

Much of what is understood about what supports the emotional wellbeing and mental health of people with aphasia connects with the social model of disability. The social model of disability distinguishes biological impairment from disability, viewing the latter as the result of *social* barriers rather than something rooted within the individual (Sabatello, 2013). In this vein, the Life Participation

Approach to Aphasia (LPAA) (Chapey et al., 2000) emphasises the importance of supportive environments to communication and participation. The LPAA views communication as a basic need and a human right and aims to maximise wellbeing and quality of life through the process of participation, always centring the person with aphasia in decisions about their life (Chapey et al., 2000).

Similarly, ideas about what it means to 'live well' or 'live successfully' – concepts borrowed from gerontology - with aphasia are based on a model of recovery that acknowledges the empowering aspects of self-management, whilst recognising structural influences and barriers that inhibit participation (Manning et al., 2017). Moving away from biomedical conceptualisations of impairment and treatment, this model focuses on holistic support towards 'living well' or 'living successfully', whatever this looks like for the individual (Manning et al., 2017). Qualitative research investigating what it means to live well or live successfully with aphasia from the perspectives of people with aphasia yields many overlapping and inter-connecting themes (Brown et al., 2010, 2012; Grohn et al., 2012; Hinckley, 2006; Manning et al., 2017, 2021), some of which will be explored below.

1.4.1. Participation

Participation is fundamentally linked with life satisfaction and is an important measure of health; so much so that it is included in the International Classification of Functioning, Disability and Health ([ICF] WHO, 2001). Participation, referred to in one study as 'doing things' (Brown et al., 2010), is a key ingredient to living well/successfully with aphasia (Brown et al., 2012; Grohn et al., 2012; Manning et al., 2017, 2021). Participation in meaningful activities in the different domains of home, leisure and work provides stimulation and pleasure, contributes a sense of purpose and independence, and fosters a sense of achievement and normality (Brown et al., 2012). People with aphasia have discussed the importance continuing to feel like a useful, valued, and respected member of their families, social circles, and wider communities (Brown et al., 2010; Dalemans et al., 2010; Manning et al., 2017, 2021). People with aphasia who are unable to return to previous jobs have spoken about finding fulfilment, meaning, or purpose through different employment or volunteering opportunities, with many becoming involved in peer support or advocacy for others with aphasia (Brown et al., 2011a; Douglas, 2022; Mackenzie et al., 2011; Manning et al., 2021; Worrall et al., 2011).

Manning et al. (2017) discuss structural and attitudinal barriers to effective participation, including limited levels of public (and professional) awareness about aphasia, and lack of access to appropriate and acceptable services, particularly in the longer-term. In contrast, they emphasised factors which facilitate participation for people with aphasia, including, “increased public awareness of aphasia, skilled and supportive conversation partners, and policies and procedures to support autonomous participation in the workplace and in public and commercial services and facilities” (p.10).

1.4.2. Supportive and Meaningful Relationships

Self-construct is informed by our social context and group membership (Tajfel & Turner, 1979). As such, relationships can be viewed as key to retaining or reconstructing a sense of personal and social identity for people with aphasia. Supportive and meaningful relationships also provide valuable sources of practical and emotional support and connection (Brown et al., 2012; Grohn et al., 2012; Manning et al., 2017; Moss et al., 2021). Research suggests that friendships are the most likely type of relationship to be lost following aphasia caused by a stroke (Barry & Douglas, 2000; Hilari & Northcott, 2006), and that people with strong friendships prior to aphasia find it easier to retain them (Northcott & Hilari, 2011). Participants with post-stroke aphasia in Brown et al.'s (2010) study reported losing friends, and described an increased appreciation for their friendships that had withstood their stroke and aphasia.

People with aphasia have discussed the characteristics of supportive and meaningful relationships, including the importance of friends and family members not treating them differently because of their aphasia (Anderson & Whitfield, 2013; Dalemans et al., 2010; Manning et al., 2021; Sjöqvist Nätterlund, 2010). Participants in Moss et al.'s (2021) study described how being with friends where they could share ‘normal’ interactions was important to feeling connected to life. Other qualities people with aphasia have said they value in relationships are respect, patience, tolerance and acceptance of their aphasia (Anderson & Whitfield, 2013; Brown et al., 2010; Dalemans et al., 2010), as well as feeling like an equal contributor within the relationship (Manning et al., 2017, 2021). Findings from a recent systematic review highlighted that meaningful and supportive relationships were facilitated through access to information, support and training for family members and friends (Manning et al., 2017).

1.4.3. Positivity

Positivity, or having a positive outlook, have been described as important factors for living well/successfully with aphasia. For instance, participants in one study discussed how focusing on improvements in their communication, being grateful or appreciative for what they have, ‘trying new things’, and having a sense of humour enabled them to continue ‘striving for a positive way of life’ (Brown et al., 2010). They also acknowledged that developing a positive outlook could take time, and that maintaining positivity continued to be challenging at times. In a similar vein, Grohn et al. (2012) identified “personal attitudes, qualities and feelings” (p.396), including optimism, hope, determination, and gratitude, which enabled participants to maintain a positive outlook. The importance of maintaining a positive outlook to living well/successfully with aphasia extends to those providing services. For instance, people with aphasia and family members reported that a positive and encouraging attitude from their speech and language therapist (SLT) helps to instil hope during the rehabilitation journey (Brown et al., 2012). Adopting a ‘can do’ attitude appears to also be important amongst SLTs who work with people with PPA, who reported focusing on abilities and strengths, rather than on disability (Kindell et al., 2015).

1.4.4. Information and Awareness

Access to information and awareness about aphasia are viewed as important for living well/successfully by people with aphasia (Grohn et al., 2012; Manning et al., 2017; Manning, MacFarlane, et al., 2020), their family members (Brown et al., 2012), and by SLTs (Brown et al., 2011a; Manning, Cuskelly, et al., 2020; Volkmer et al., 2022; Worrall et al., 2011). Whilst improving, limited public awareness of aphasia (Code, 2020) means that most people who acquire aphasia have no prior knowledge about it, contributing to feelings of confusion, fear, and anxiety (Harris, 2017; Johansson et al., 2012; Liechty & Buchholz, 2006; McKillop, 2012; Saner, 2022). People have discussed wanting more information about aphasia in the early stages, with many not recalling being provided any at the point of their discharge from hospital (Manning, MacFarlane, et al., 2020). Having an understanding of aphasia and feeling able to explain it to others appears to be important for building confidence and enhancing social participation (Manning, MacFarlane, et al., 2020; Worrall et al., 2011).

Hilton et al. (2014) highlighted the role of others in shaping the experience of the person with aphasia, emphasising the value in providing information, communication training, or emotional support to relatives and friends. Provision of information about aphasia, or training, as well as involving them in the rehabilitation process, appears to reduce anxiety and positively impacts relationships (Hilton et al., 2014).

As discussed previously, social participation and sense of autonomy can be further improved when members of the public or service providers understand aphasia (Manning et al., 2017). For instance, people with aphasia valued interactions with healthcare professionals where they were, “spoken to directly and treated as equal and intelligent” (Manning et al., 2017, p.12). Professionals can demonstrate awareness and support through providing longer appointments (Manning, MacFarlane, et al., 2020), engaging in active listening (Liechty & Buchholz, 2006), and taking the time to involve people in decisions about their care. In contrast, a lack of knowledge about aphasia amongst healthcare professionals can lead to poor quality care or mistreatment. People have reported being excluded from discussions and decisions about their care (Carragher et al., 2021; Worrall et al., 2011), or their doctors being unwilling to adapt their communication (Burns et al., 2015). Others have had their aphasia misinterpreted as ‘challenging behaviour’ (Manning, MacFarlane, et al., 2020) or have had assumptions made about their cognitive skills (Burns et al., 2015). Lack of awareness about primary progressive aphasia means that many people face challenges with getting a correct diagnosis, delaying access to appropriate support (Douglas, 2022; Volkmer, Spector, Warren, et al., 2020).

1.4.5. Access to Ongoing and Flexible Support

People with aphasia have discussed wanting an “open door policy” when it comes to speech and language therapy (Manning, MacFarlane, et al., 2020, p.3445), and those with post-stroke aphasia have reported value in having a 'life-after-stroke coordinator’, whom they could contact in the longer term for advice, information and emotional support. However, most therapy provision occurs within the context of rehabilitation settings, during the acute and post-acute phases, contributing to ‘front-loading’ of services (Manning et al., 2017; Manning, MacFarlane, et al., 2020). Very few people with aphasia have discussed support from healthcare services being available later in their journey, with longer-term support seemingly accessed mostly via third sector organisations.

1.4.5.1. Speech and Language Therapy

A qualitative meta-analysis identified communication as playing an, “integral role for living successfully with aphasia across all areas of life” (Brown et al., 2012, p.149). People with aphasia value having access to good quality speech and language therapy, tailored to their needs and wishes (Manning, MacFarlane, et al., 2020). For many, speech and language therapy will include conversation therapy, “designed to enhance conversational skill and confidence” (Simmons-Mackie et al., 2014, p.512). Communication partner training, involving up-skilling of non-aphasic people, is the most common way of employing conversation therapy approaches (Simmons-Mackie et al., 2014) and has been shown to be effective at improving conversational participation for people with aphasia caused by stroke, (Simmons-Mackie et al., 2010), as well as those with primary progressive aphasia (Volkmer, Spector, Meitanis, et al., 2020). Training has also been shown to improve relatives’ perceptions of the communication impairment of the person with aphasia (Hilton et al., 2014).

Reviewing relevant literature on the topic, Worrall (2019) described the ‘seven habits of highly effective aphasia therapists’, which were confirmed by people living with aphasia. Prominent themes relate to relationship-centred care, connecting the person with appropriate peer support in the community, keeping longer-term outcomes in mind, collaborative goal setting processes, promoting access to speech and language therapy at all stages, screening and providing support for mental health difficulties, and advocacy. In the conclusion, Worrall (2019) highlighted how the habits, “parallel many of the themes of both the LPAA and the social model approach” (p.445) through their emphasis on the role of participation and social contexts to the experiences of people with aphasia.

People with aphasia have expressed a desire for longer-term access to speech and language therapy (Manning, MacFarlane, et al., 2020). However, large caseloads, limits on numbers of sessions, and issues relating to the organisation and structure of relevant health services make offering this unlikely for many SLTs (Manning, Cuskelly, et al., 2020; Wray et al., 2020). What is more, whilst speech and language therapy is understood to improve quality of life for people with primary progressive aphasia (Ruggero et al., 2019), the commissioning patterns of UK National Health Service (NHS) services mean that many people do not meet referral criteria for services comprising SLTs who are able to provide support for communication; thus many people fall through the gaps (Volkmer, Spector, Warren, et al., 2020).

1.4.5.2. Aphasia Groups

Whilst not explicitly named as a theme within the literature, aphasia groups based in the community often enable participation, foster relationships and provide a space for practising communication skills, whilst allowing people with aphasia to become “active members of support organisations” (Brown et al., 2012, p.147). One review highlighted that, “the growing interest in groups seems [...] to reflect a broader shift away from traditional individual focused medical models of healthcare, towards social and life participation approaches” (Pettigrove et al., 2021, p.9). Worrall (2019) emphasised the importance of people with aphasia being supported to connect with groups that meet their needs. Poorly facilitated groups or dynamics leading to imbalanced interactional patterns can lead to some people with aphasia reporting increased feelings frustration, isolation or exclusion (Lanyon et al., 2018b; Pettigrove et al., 2021). Such experiences are not conducive to effective participation and lead to further disablement (Worrall, 2019). However, the right group can provide a unique type of support that people with aphasia cannot get from statutory services: ongoing access to a peer network and a safe environment for people to “learn new skills, practice communication, chat about mutual experiences and begin to make sense of and to process feelings" (Manning et al., 2021, p.1508).

1.4.5.3. Formal Psychological Support

Interestingly, there was little mention of accessing formal psychological support to address psychosocial and emotional difficulties within the literature on living well/successfully with aphasia. Although some people with aphasia reported positive experiences of accessing counselling (Manning, MacFarlane, et al., 2020; Moss et al., 2021), it did not feature as a theme within the studies. Where this type of support was referenced, it was often within the context of highlighting issues with access (Manning et al., 2017). As discussed in the previous section, many of the emotional challenges experienced by people with aphasia relate to issues with identity, or changes to their relationships and ability to participate that arise from communication difficulties. The literature on living well/successfully suggests such challenges can often be addressed through proactive support aimed at reducing the impact of communication difficulties on these areas of living, and without the need for formal psychological therapy. For example, people with aphasia have discussed the emotional support offered through their relationships with friends and family members, or of the role aphasia groups play in enabling the processing of feelings (Moss et al., 2021).

As will be discussed in more detail later, formal psychological support is typically accessed by people identified as experiencing higher levels distress or specific challenges relating to psychosocial adjustment to aphasia. Therefore, whilst it may be the case that many people do not require psychological support to live well/successfully, for others it may play a crucial role in their ability to process and navigate emotional challenges and adjust to life with aphasia. The issues with access to this type of support discussed seems to suggest that there is an unmet need, but also makes it unsurprising that it did not feature as a factor important to living well/living successfully.

1.5. How Services Currently Support the Emotional and Mental Health of People with Aphasia

1.5.1. Stepped Psychological Care

Given the most common cause of aphasia is stroke, in the UK most people with aphasia are supported within the context of NHS stroke services, where psychological support is provided through a stepped care model (Kneebone, 2016). Within the first step, care and support is provided to all patients by members of the multidisciplinary team (MDT). Physiotherapists, SLTs, occupational therapists (OTs), nurses and rehabilitation assistants are all involved in promoting emotional wellbeing through processes such as active listening and individualised goal setting. In addition, MDT members are expected to screen for mood difficulties such as depression and anxiety (Kneebone, 2016). People identified as requiring support for mood difficulties access this through steps two and three of the model. Within step two, low intensity and brief psychological interventions, such as behavioural activation, motivational interviewing, and problem-solving may be delivered by members of the MDT, with support or training from psychologists where possible (Kneebone, 2016). For people with severe or persistent psychological difficulties, or those with concurrent cognitive impairments, support from a qualified clinical psychologist or clinical neuropsychologist is indicated and may include specialist neuropsychological assessment and interventions such as individual or family therapy.

For the stepped care model to work effectively, all health professionals that encounter the person have a role to play in assessing and monitoring psychological wellbeing. However, research shows that professionals working in stroke services often lack confidence or skills in communicating with people with aphasia (Baker, Rose, et al., 2021; Carragher et al., 2021; van Rijssen et al., 2021), or feel ill-equipped to assess for mood difficulties and provide emotional support (Baker, Rose, et al., 2021; Northcott et al., 2017; Sekhon et al., 2015; van Ewijk et al., 2021). One Australian study found that health professionals in acute stroke settings, “experience negative emotions following an unsuccessful interaction” and limit their conversations with people with aphasia (Carragher et al., 2021, p.3009). Another study found that healthcare professionals in the Netherlands viewed communication difficulties as impeding healthcare activities, and reported feelings of discomfort, insecurity and frustration associated with their work with people with communication difficulties (van

Rijssen et al., 2021). This is echoed in the experiences of people with aphasia, who have reported that health professionals often fail to adapt clinical interventions to meet their communication needs (Burns et al., 2015).

1.5.2. The Role of SLTs

Due to the nature of their role in supporting communication, SLTs are often first to notice when people with aphasia may be experiencing mood difficulties (Baker, Worrall, et al., 2021). They are uniquely placed to offer emotional support to people with aphasia and have been described as “skilled helpers for mood management” (Ryan et al., 2019, p.786). Research using surveys and interviews indicates that SLTs recognise and appreciate the challenges that many people have in coming to terms with the life-changing nature of aphasia, and view addressing emotional wellbeing as part of their role (Hilari et al., 2015; Northcott et al., 2017, 2018a; Sekhon et al., 2015; van Ewijk et al., 2021; Wray et al., 2020). In a UK based survey, the majority of SLTs reported that at least half of their clients experience psychological difficulties (Northcott et al., 2017). Many SLTs have reported providing emotional support within the context of speech and language therapy, often employing counselling techniques like active listening or motivational interviewing (Pompon, 2021; Rose et al., 2014).

However, research suggests some SLTs experience uncertainty or conflict regarding their role in addressing psychological distress in their clients with aphasia (Ryan et al., 2019). Some have reported believing they are best placed to address psychological wellbeing indirectly through language and communication work (Northcott et al., 2018; van Ewijk et al., 2021). Whilst many SLTs have expressed they wish to provide psychological support, they often describe feeling under-skilled or unsupported to do so (Northcott et al., 2017, 2018; Sekhon et al., 2015; van Ewijk et al., 2021). Evidence suggests SLTs value input from mental health colleagues with relevant expertise (Northcott et al., 2017, 2018a). However, they have also reported working jointly could be challenging at times; for example when feeling their own expertise was not valued or when there is a “mismatch between SLT and MHP goals and approaches” (Northcott et al., 2018, p.27).

Research shows SLTs would like training to support them to have conversations about psychological difficulties (Sekhon et al., 2019; Wray et al., 2020) and suggests most who receive training in counselling, or more structured therapeutic approaches, such as Solution Focused Brief Therapy (SFBT) or Acceptance and Commitment Therapy (ACT), find it useful (Sekhon et al., 2019). SLTs in Northcott et al.'s (2018) study described becoming more client-led in their practice as a result of training, as well as feeling more confident working with client emotions. However, despite calls for more training pre-qualification (Sandberg et al., 2021), the amount of training in counselling or therapeutic approaches SLTs receive appears inconsistent, and undertaking specific courses is often dependent on individual interest levels (Sekhon et al., 2019).

SLTs also have a role in raising awareness about aphasia, and providing training to their mental health colleagues on communicating effectively with people with aphasia appears to be actively encouraged (Sandberg et al., 2021). However, in one study less than half of SLTs were involved in providing education and training to the public or other healthcare professionals (Manning, Cuskelly, et al., 2020). What is more, whilst collaborative working and training between disciplines is purported to be mutually beneficial in increasing the skill-sets of both SLTs and mental health professionals (MHPs), Ryan et al. (2019) highlighted a gap in the literature regarding the efficacy of “aphasia-specific communication training approaches for professionals working in specialist mental health roles” (p.790).

1.5.3. Availability of Psychological Support

Despite the numerous emotional outcomes associated with aphasia, evidence suggests that psychological support for people with aphasia remains limited (Baker, Worrall, et al., 2021; Clarke, 2013; Moss et al., 2021). SLTs have cited issues accessing psychological support for their clients, particularly for those with higher levels of communication difficulties (Manning, Cuskelly, et al., 2020; Wray et al., 2020). Research suggests some MHPs lack the necessary communication skills to work with people with aphasia (Ryan et al., 2019; Sekhon et al., 2015) and sometimes overestimate their abilities in this area (Northcott et al., 2017). SLTs across studies have reported experiences of

MHPs rejecting referrals due to viewing people with aphasia as unable to engage in therapy and/or declining SLT input to do so (Northcott et al., 2017, 2018a; Ryan et al., 2019). They also reported working jointly with mental health colleagues could be challenging at times; for example when feeling their own expertise was not valued or when there is a “mismatch between SLT and MHP goals and approaches” (Northcott et al., 2018, p.27).

Findings from Northcott and colleagues’ UK-based research suggest that availability of a stroke specialist psychologist makes access to psychological support for people with post-stroke aphasia more likely. Both their survey respondents and focus group participants reported some positive experiences of working collaboratively in these instances and of welcoming support from colleagues with appropriate skills (Northcott et al., 2017, 2018a). This would suggest that there are specific skills that psychologists employ when working with people with communication difficulties, such as aphasia. However, there is very little evidence available describing what this looks like, either within the research literature, or within clinical psychology handbooks or training programmes. Public awareness of aphasia has historically been extremely limited, with just 15% of people in the US having heard the term in 2016 (National Aphasia Association, n.d.). In 2022 this figure had increased to 67%, with 40% being able to identify it as a language disorder (National Aphasia Association, n.d.). Anecdotally, there is very little teaching about aphasia during clinical psychology training courses. Where aphasia is taught, content tends cover aetiology and presentations, rather than how to support communication or work therapeutically with individuals.

1.5.4. Specialist Interventions: Availability and Effectiveness

There is limited research regarding the efficacy of specific psychological interventions for people with aphasia. However, this may be reflective of the types of challenges faced by people with aphasia, which often relate to ‘adjustment’ to the changes or losses they have experienced (which may extend beyond those associated with aphasia). Such difficulties are arguably not well captured by psychiatric diagnoses. This has implications for interventions, which are likely to be more formulation-driven or bespoke and may involve integrating and adapting therapeutic approaches to meet the needs of the person with aphasia. This certainly seems to be the case when consulting guidance around psychological interventions for neurological conditions more widely (British Psychological Society, 2021). Such interventions may also need to factor in adjustment to other outcomes relating to the causal condition (e.g., those relating to stroke, dementia, brain tumour, etc.) and are often offered in tandem with other therapies, such as occupational therapy, physiotherapy, or speech and language therapy. It can therefore be argued that the ways in which psychological support is provided makes it harder to establish effectiveness through traditional research methods like randomised controlled trials (RCTs), which typically involve measuring the efficacy of protocol-driven interventions targeted for specific diagnoses.

Despite this, efforts have been made to establish the effectiveness of applying condition-specific therapies frequently used within the general population to people with aphasia. In their systematic review of psychological interventions for depression in people with aphasia, Baker et al. (2018) conclude there is a lack of evidence for effective treatments, particularly for people with aphasia with moderate to severe depression. The authors highlight limitations within the existing research, citing lack of inclusion or lack of clarity around inclusion of people with aphasia; inconsistent descriptions of aphasia severity and type; lack of detail about adaptations to interventions; and difficulty identifying the ‘active ingredient’ within the intervention. Results from a recent feasibility trial exploring the use of adapted Solution Focussed Brief Therapy (SFBT) for improving psychological wellbeing in people with aphasia, delivered by SLTs (Northcott, Thomas, et al., 2021) have taken a step toward considering client acceptability. Findings showed that the approach was acceptable to people, even those with severe types of aphasia, and that people felt supported and valued the strengths-based nature of the intervention (Northcott, Simpson, et al., 2021). Clinical effectiveness was not ascertained.

So far, this chapter has reviewed a body of research literature relating to the emotional and psychosocial challenges experienced by people with aphasia, as well as how people with aphasia overcome these. Mainly, the work has been undertaken by speech and language researchers and practitioners with a special interest in the field of aphasiology, many of whom are passionate about improving wellbeing and quality of life for people with aphasia. There are several studies examining how SLTs view their role in supporting the mental health and wellbeing of people with aphasia. These studies provide insight into the realities of accessing psychological support for people with aphasia within stroke services, and multidisciplinary working between SLTs and MHPs.

1.6. Mental Health Professionals' Experiences of Supporting People with Aphasia

I undertook a scoping review to assess the availability and nature of literature specifically relating to MHPs experiences of working with people with aphasia, given the apparent lack of this within the research addressed so far. A scoping review was identified as appropriate because of my intention to include research employing a range of methods/methodologies, to summarise any key findings, and to identify any gaps in understanding how MHPs approach working psychologically with people with aphasia (Arksey & O'Malley, 2005).

1.6.1. Search Strategy

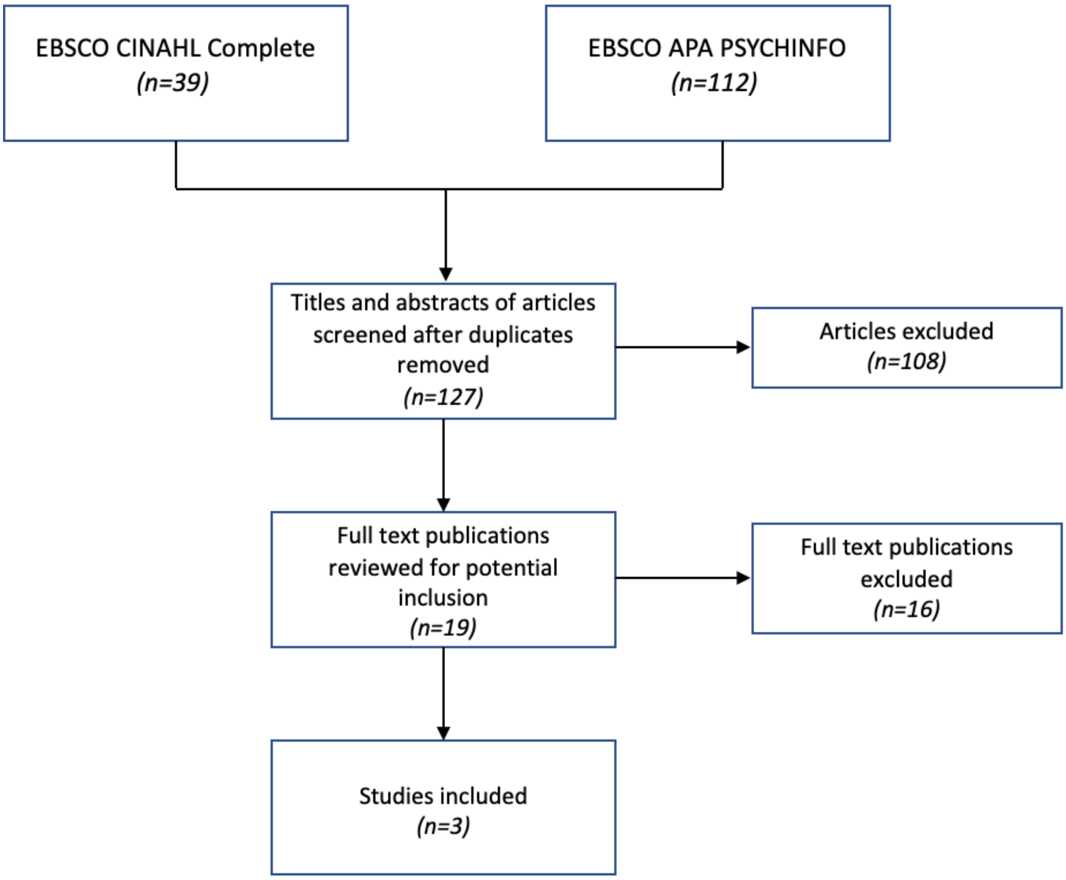
In May 2022, I completed a scoping review of the literature. This involved searching two electronic databases: EBSCO APA PSYCHINFO and EBSCO CINAHL Complete, using the following search terms, derived from the initial narrative review:

> *AB (aphasia OR aphasic OR people with aphasia) AND (emotion OR mood OR mood difficulties OR feeling OR affect OR mental health) AND (therapy OR treatment OR intervention OR talk* therapy OR counselling OR psychotherapy) AND (psychologist OR clinical psychologist OR clinical neuropsychologist OR therapist)*

This search yielded 127 original articles after removal of duplicates, which were ordered by relevance. I manually scanned the titles and abstracts of all articles, and 108 papers were discounted due to not being relevant to working psychologically with people with aphasia (e.g., focusing on speech and language therapy interventions). The remaining 19 papers were subsequently screened for relevance. Only three of these papers focused explicitly on experiences and perspectives of how MHPs work with people with aphasia. Figure 2 is a flow chart representing the literature selection process.

Figure 2

Flowchart of literature selection process for scoping review



1.6.2. Santo Pietro et al. (2019)

The US based authors of this paper have combined expertise in the fields of speech and language pathology and clinical psychology. In their introduction they outline their interest in the overlap between the Life Participation Approach to Aphasia (LPAA) and behavioural approaches to treating depression. As described previously, the LPAA views re-engagement and enhanced participation in life, however this looks for the client, as the primary goal for recovery (Chapey et al., 2000). The authors go on to review literature with the purported (paraphrased) aims of: 1) exploring psychological needs of people with aphasia, 2) determining factors impeding provision of psychological support, 3) instructing MHPs around best practice relating to communicating with people with aphasia, 4) familiarizing MHPs with the LPAA, and 5) recommending approaches to providing psychotherapeutic treatment for depression in individuals with aphasia within community mental health settings.

Within the review the authors consider theoretical approaches to conceptualising depression and their application to people with aphasia, including cognitive and behavioural theories, as well as those underpinning acceptance-based approaches. They highlight the paucity of adequate tools and measures for assessing depression in people with aphasia, speculating that this might contribute to a lack of psychological support for people with aphasia. Finally, they highlight evidence for the effectiveness of behavioural activation in treating depression in people with aphasia, which they feel are compatible with a life participation approach and ‘hold promise’. They provide suggestions for adapting communication when utilising behavioural activation, such as using closed questions, taking more time, and being creative with record keeping of therapy homework tasks.

A strength of the paper is its attention to how cognitive-behavioural therapy (CBT) interventions, like behavioural activation, might be practically applied and adapted to suit the needs of people with aphasia experiencing depression, drawing on the theories and knowledges developed by SLTs. However, the ideas are theoretical in nature, and it is unclear whether such applications are based on real experiences of MHPs delivering interventions. How clinicians have found doing this work, or how people with aphasia experience such interventions remains unaddressed. The authors’ discussion on the compatibility between behavioural activation and life participation approaches provides an interesting and compelling argument for applying this approach when working therapeutically with people with aphasia. However, the focus on behavioural activation as a treatment for depression also arguably encourages a reductive understanding of the ways aphasia impacts psychological wellbeing and might unintentionally direct clinicians towards a (perhaps unnecessarily) limited pool of treatment options when working with people with aphasia who are experiencing mood difficulties.

1.6.3. Morrow-Odom & Barnes (2019)

This study anonymously surveyed 1,758 qualified MHPs, such as counsellors, psychologists, and social workers, practising in the US state of North Carolina. The study aimed to determine MHPs level of awareness about aphasia, experience of training related to aphasia, as well as their experience and confidence levels in working with people with aphasia. Most participants self-identified as counsellors or therapists. Eighty-five percent of participants reported they had heard of aphasia, and 65% correctly identified it as a language disorder. Over half of the sample reported that they had not provided support to a person with aphasia, with psychologists being more likely to have provided services. Most respondents expressed a degree of doubt in their ability to provide services 'in an ethical manner', with just 27% indicating they were very or somewhat confident.

This appears to be the first and only large sample survey exploring MHPs knowledge of aphasia and experience of working with people with aphasia. The authors question the availability of information and training on aphasia for MHPs, as well as accessibility of psychological support for people with aphasia. A main weakness of the study, identified by the authors, relates to the sample, which included respondents whose work setting may have limited their exposure to people with aphasia (e.g., school counsellors). They report the inclusion of this data may have skewed the results. Nonetheless, the results helpfully demonstrate a lack of knowledge and confidence about working with people aphasia amongst MHPs working in generalised settings. It is important not to make assumptions from the findings about the knowledge and confidence of practitioners who work in settings where they would more commonly be expected to provide support to people with aphasia. Indeed, when considering future directions, the authors suggest that it would be useful to understand how MHPs who *do* hold experience of working with people with aphasia or their families approach treatment and any barriers they experience.

1.6.4. Strong & Randolph (2021)

Unlike Morrow-Odom & Barnes' (2019) relatively inexperienced sample, this study involved semi-structure interviews with six MHPs who had experience of working in rehabilitation and of providing services to people with aphasia across the USA. Four participants had completed a licensed master's program in social work (LMSC), allowing them to provide psychotherapy. The two remaining participants held a PhD in rehabilitation psychology and a master's degree in rehabilitation counselling respectively. The authors cite research evidencing a lack of psychological support for people with aphasia in their introduction and summarise literature relating to SLTs experiences in providing counselling or accessing support from MHPs; much of which has been mentioned in this introduction in previous sections. The stated aim of the study was to, "explore the lived experience of mental health providers servicing people living with aphasia" (p.2683).

Interpretive Phenomenological Analysis (IPA) of the interview data led to the authors identifying three themes within and across the interviews: 1) 'Barriers', 2) 'Interprofessional Collaboration', and 3) 'Therapy Looks Different'. Each theme contained at least two sub-themes. Just one of their participants had received formal training on working with people with aphasia, with most reporting their learning had come from on-the-job experience; a finding supported elsewhere (Santo Pietro et al., 2019). All the participants acknowledged a lack of accessible mental health services for people with aphasia. They felt that collaboration with SLT colleagues was essential when providing support and had learned valuable skills relating to communicating with people with aphasia from joint working. Participants discussed ways in which therapy 'looks different' when working with people with aphasia, such as using more direct or closed questions, being upfront about when there are challenges with understanding, and managing dynamics between the person with aphasia and their 'care partner', if present.

This study is the first of its kind to document MHPs' experiences of providing psychological support and therapy to people with aphasia. As commented on by the authors, the reported experiences of the participants are not intended to be generalised to all clinicians and services. Nonetheless, the findings reinforce the idea that there is a lack of availability or access to training about aphasia for MHPs. Whilst previous research has identified that SLTs value collaboration and support from mental health colleagues (Northcott et al., 2017, 2018b), the findings of this study demonstrate MHPs view joint working as equally beneficial. The authors suggest that by incorporating approaches developed by SLTs, such as the LPAA and supported conversation methods, MHPs can enhance their own therapy provision for people with aphasia. They also advocate for, “utilizing existing protocols, such as stepped psychological care” (p.2689) to optimise psychological care for people with aphasia.

1.7. Research Gap and Relevance to Clinical Psychology

The research reviewed so far indicates that availability of psychological support for people with aphasia is limited and suggests that MHPs may lack skills important for working with people with aphasia. In the UK psychological support for people with aphasia is mostly provided in the context of specialist NHS services (e.g., stroke or dementia services), by clinical psychologists or clinical neuropsychologists, whose training involves teaching in cognitive neuroscience, and placements working with adults with neurological conditions, such as stroke, dementia, or other kinds of brain injury (British Psychological Society, 2019a, 2019b). However, there does not appear to be any research exploring clinical psychologists’ experiences of working with people with aphasia. It is therefore unclear how they make sense of the emotional and psychological impact of aphasia or how they view their role in supporting the emotional and mental health of people with aphasia. In addition, there is no literature exploring clinical psychologists’ understandings of how to work therapeutically with this population, including how they support communication needs. Finally, whilst clinical psychologists that support people with aphasia tend to work within MDTs, we do not know how they experience this work or what they find helpful and unhelpful when working in this way.

1.8. Research Aims and Questions

This study aims to begin to address some of the identified gaps in the research. Considering the reported issues with access to psychological support, the potential skill deficits of some psychologists reported by SLTs, and the identified importance of joint working between psychologists and SLTs, it would be helpful to explore how clinical psychologists and clinical neuropsychologists who support people with aphasia experience doing this type of work. Ultimately, it is hoped that dissemination of this information will be useful to individuals, teams, and training bodies interested in strengthening or improving services and support for people with aphasia who are experiencing emotional difficulties. The aims of this research are underpinned by three key questions:

1. How do clinical psychologists understand and address the emotional outcomes of aphasia?
2. What kinds of roles do clinical psychologists take in the MDT when working with people with aphasia?
3. What do clinical psychologists find useful when supporting people with aphasia as part of an MDT?

2. METHODOLOGY

This chapter begins with a description of my philosophical stance and how this has influenced the chosen methodology and analytic method. Following this, an outline of the key ethical considerations for the research and how they were addressed is provided. The chapter concludes with a detailed account of the methods employed for data collection and analysis.

2.1. Philosophical Stance

Pragmatism is the philosophical system underpinning this research. Sitting outside of metaphysical polarities such as realism and relativism, pragmatism can be said to reject what Rorty (1999) refers to as ‘platonic distinctions’, offering an alternative to “...traditional assumptions about the nature of reality, knowledge and inquiry” (Kaushik & Walsh, 2019, p.2). Instead, central to pragmatism are the notions of action and consequence. It is only through action and interaction with the world that we experience ‘reality’ (Kaushik & Walsh, 2019). As such, our conception of reality is based on our unique (albeit often socially shared) experience, is constantly changing, and can be defined and interpreted in different ways depending on what is most useful in a given context (Morgan, 2014). Put simply, pragmatists would argue that “reality is what works” (Kaushik & Walsh, 2019, p.3).

When considering how knowledge is acquired many pragmatists draw on the work of American philosopher and psychologist, John Dewey. Dewey used the term ‘inquiry’ to describe the active and experiential process of “using a belief in practice” (Morgan, 2014, p4), or bringing about change or improvement through the production of what he called, ‘warranted assertions’ (Kaushik & Walsh, 2019). Inquiry is not aimed at achieving truth and pragmatists have argued that ideas themselves have no substance other than their practical consequences; thus they are always open to revision (Rorty, 1999). As such, pragmatism embraces both qualitative and quantitative research methods, allowing the researcher to adopt whichever methods will be most useful for solving a particular problem or answering a particular research question. What is more, pragmatists acknowledge that the methods chosen will be impacted by the researcher's own experiences, beliefs and values, as well as social structures and power. Morgan (2014) emphasises the social and emotional aspects of conducting research from a pragmatist stance, noting that "our feelings color every aspect of the inquiry process" (p.4). Cornish & Gillespie (2009) discuss the merits of adopting a pragmatist philosophy within health psychology research, including the way in which, "it's focus on the interests served by knowledge invite questioning of whose interests are being served" (p.803). They argue that this makes it usefully critical without undermining the validity of different forms of knowledge.

Pragmatism was felt to be a good fit for this research. Operating from a epistemological stance sitting on the realist-relativist continuum would entail working with assumptions about the extent to which constructs such as aphasia and emotions are representative of an external reality, as well as taking a stance about whether hearing clinical psychologist's experiences constitutes 'knowledge'. A pragmatist would likely argue that whilst it is practical to treat aphasia and emotions as 'real' to discuss the impact of one on the other, deciding whether they are real in the sense that they mirror an external reality or not is irrelevant to addressing the problem. Instead, a pragmatist might assert a more useful starting point is to consider the 'problem' which, for the purposes of this research, is recognised as a lack of understanding about how clinical psychologists work in multidisciplinary teams to support people with aphasia, specifically in relation to their emotional needs. From here, continuous reflection and engagement with one's own belief system is employed to arrive at and address the research questions or 'solve the problem' (Kaushik & Walsh, 2019). Based on my specific context of growing up with a parent with aphasia, and my experiences so far of working in mental health settings and of clinical psychology training, I hold a set of beliefs about the importance of the research topic and the potential benefits to be gained from carrying out the research. Using this set of beliefs, or 'warranted assumptions', in active engagement with the surrounding literature is what guided the development of the research questions and chosen methodology. This is a circular process that has involved revisiting and reformulating the ‘problem’ and can be considered an inquiry in and of itself.

2.2. Qualitative Methodology

Whilst its pluralistic nature makes it an obvious choice for many researchers adopting a mixed methods approach (Johnson & Onwuegbuzie, 2004; Kaushik & Walsh, 2019), pragmatism inherently supports any methodology which can be shown to usefully serve the interests of the research. In the absence of previous literature relevant to clinical psychologists and their work with people with aphasia, there are no “preconceived variables” to test or measure using a quantitative approach (Willig, 2021, p.9). As such, a qualitative approach employing the use of individual, semi-structured interviews, was felt to be the best way of addressing the research questions, which are concerned with exploring the meanings and experiences of clinical psychologists in relation to this topic.

2.3. Reflexive Thematic Analysis

Reflexive Thematic Analysis (TA) was chosen as the analytic method for its ability to identify ‘patterns of meaning’ across the interview data (Braun & Clarke, 2006, 2021a). TA is notably, “compatible with both essentialist and constructionist paradigms within psychology” (Braun & Clarke, 2006, p.5), and this could be argued to be inconsistent with a pragmatist stance, which would eschew either of these positions. However, the theoretical flexibility of TA, along with its commitment to the research question(s) and emphasis on the values and reflexivity of the researcher in shaping the analysis echo some of the features of pragmatism. Reflexive TA embraces the subjectivity of the researcher and is unconcerned with providing an ‘unbiased’ account in its efforts to address the research question(s) (Braun & Clarke, 2021a). Rather, it emphasises, “...deep reflection on, and engagement with the data” to produce or generate themes that hold meaning and tell a story (Braun & Clarke, 2019a, p.593).

An inductive or ‘data driven’ approach, in which themes were constructed through coding and interpretation of the content was applied when analysing the data. This is because whilst there were some general assumptions guiding the research questions, such as that it is worthwhile to explore the experiences of clinical psychologists working in MDTs with people with aphasia, or that clinical psychologists have useful ideas about the emotional aspects of aphasia, there were no pre-existing *theoretical* assumptions about the experiences of clinical psychologists guiding it. Patterns in the data were identified at both the semantic and latent level, with interpretations about potential unspoken underlying assumptions or meanings being made through careful analysis of the data (Braun & Clarke, 2006).

2.4. Ethical Considerations

2.4.1. Ethical and Health Research Authority Approval

Ethical considerations for this research project were informed by the British Psychological Society’s Code of Human Research Ethics (BPS, 2014). Approval for this project was sought from the University of East London School of Psychology Ethics Committee. The ethical approval application, risk assessment, ethics review decision, ethical amendments form, and request for title change to an ethics form can be found in Appendices A - E. In addition, Health Research Authority (HRA) approval was necessary to recruit NHS staff as participants. As such, a separate application was made online via the Integrated Research Application System (IRAS). A copy of the approval letter can be found in Appendix F.

2.4.2. Informed Consent

All prospective participants were emailed a participant information sheet (PIS; Appendix G) to read in their own time and aid them in deciding whether they wished to participate. Some people had read this prior to contacting me, however, others were emailed a copy after seeing a shorter recruitment poster (Appendix H) and expressing an interest. Written consent from those wishing to participate was gained through use of a consent form (Appendix I) sent by email. At the beginning of the interview participants were reminded that they could stop the interview at any point. They were also reminded about the 3-

week timeframe for withdrawing their data from the research. This was also stated on the debrief letter (Appendix J).

2.4.3. Confidentiality and Anonymity

I conducted all interviews in a private setting via MS Teams. Participants were encouraged to find a similarly private space where they were unlikely to be interrupted prior to the interview. I confirmed this with participants at the beginning of each interview. Recordings of the interview were made and only I was able to listen back to the interview. At the point of transcription all identifiable information provided, such as names or workplaces, was either omitted or changed to protect the anonymity of participants. For instance, each participant was given a pseudonym. Anonymised extracts of the interviews have been included in the results but were chosen carefully to ensure anonymity is respected. This information was provided to participants in the PIS, as well as verbally at the beginning of each interview. Participants were encouraged to express any concerns they might have relating to confidentiality or anonymity.

2.4.4. Possible Distress

It was not anticipated that the interviews would involve discussion of sensitive topics which could lead to distress for either me or participants. However, to manage the potential risk of this happening, I agreed in advance to seek support from my research supervisor if I felt that the interviews brought up difficulties for me. To minimise any possible distress for participants, I reminded participants at the start of each interview that they could pause or stop the interview at any time. They were also provided contact details for my research supervisor and the chair of the School of Psychology Research Ethics Sub-Committee on the PIS and debrief letter in case they wished to raise any concerns about the conduct of the research, Finally, participants were encouraged to use the support systems in place at their workplaces, such as their occupational health team or HR, to address any work-related issues that came up during the interviews.

2.4.5. Data Storage and Security

In line with UEL's Research Data Management Policy a research data management plan was developed (Appendix K). All data collected and created as part of the research (e.g. interview recordings, transcriptions, consent forms, analysis etc.) was stored electronically in separate folders on a password protected laptop on UEL OneDrive for Business. On submission of this thesis, copies of the anonymised transcriptions will be provided to my supervisor, to be retained by them for a period of up to three years on their password protected OneDrive in case of future publication.

2.5. Data Collection

2.5.1. Inclusion Criteria

The research was interested in recruiting clinical psychologists or clinical neuropsychologists who work with people with aphasia as part of an MDT. As stated in the introduction, in UK NHS settings that treat people with aphasia (e.g., stroke services), psychological support is typically provided by qualified clinical psychologists or clinical neuropsychologists (directly or indirectly through supervision of other health professionals. Therefore, for this research it was important that participants held a relevant qualification. As the research questions specifically refer to the ways in which psychologists work with and support colleagues from other disciplines, such as SLTs, it was also important that they worked as part of an MDT. Finally, to ensure the research remained somewhat representative of present-day clinical experience and practice only those with current or recent experience (less than two years) in such roles were recruited.

2.5.2. Sample Size

The literature and guidance regarding sample size in qualitative research offers conflicting accounts. It is generally acknowledged qualitative research requires smaller samples to allow for a sufficiently in-depth and thorough analysis (Sandelowski, 1995). However, the provision of a-priori numerical guidelines is criticised by some (Vasileiou et al., 2018), as are notions of data or theme ‘saturation’ (Braun & Clarke, 2019b), for being neo-positivist in their attempts to separate the researcher from the process of producing a rich and meaningful analysis from the data. Malterud et al. (2016) suggest using their concept of ‘information power’ to consider - using various interacting variables such as study aim(s), sample specificity, and quality of dialogue - how many participants may be needed. As suggested by Braun & Clarke (2022), I used this concept to actively reflect on the richness of data collected from the interviews and how this fitted with my aims for the research.

2.5.3. Recruitment Process

Recruitment via non-NHS organisations comprised emails (Appendix L) sent to ‘gatekeepers’ (e.g., a manager, communications officer, or administrator) of ten private organisations, requesting for them to forward the email and attached participant information sheet (Appendix G) to relevant members or contacts of the organisation. Recruitment via NHS organisations worked in a similar way: lead clinicians at two NHS trusts for which the research was granted approval were emailed, requesting for them to forward the email, and attached participant information sheet to employees at their discretion. In addition to advertising the research via organisational gatekeepers or lead clinicians, a recruitment poster (Appendix H) was used to publicise the research on the social media platforms, Facebook, Twitter, Instagram, and LinkedIn.

Interested participants contacted me by email. At this stage any questions were responded to, and I ensured that each prospective participant had a copy of the PIS. If they had not already seen or read this (for example, if they had approached the me after viewing the poster on social media), they were sent a copy and were prompted to read it prior to deciding as to whether they wished to take part. I also sought to clarify eligibility if this was unclear; for instance, if the person had not explicitly stated their professional qualification or clinical experience. Interviews were then arranged with eligible people still wishing to participate.

2.5.4. Interviews

An interview guide (Appendix M) was created for submission of the research proposal and subsequently revised and agreed with my research supervisor. The schedule was designed to ensure that discussions remained relevant to the research aims and questions. However, the style of the interviews was semi-structured and informal in nature, allowing for additional exploration of content raised by the participants.

The length of interviews ranged from 20 minutes to 44 minutes. All the interviews were completed over MS Teams and were recorded using the in-app feature. As mentioned in section 2.4.2, informed consent was revisited at the beginning of each interview and the opportunity was given to discuss any concerns relating confidentiality or anonymity. After the interview, participants were thanked for their time and were emailed a debrief letter (Appendix J).

2.5.5. Participants

Interviews were carried out with seven participants between April and July 2022. During the interview participants were asked about their work setting, including how long they had worked there for. Nearly all the participants worked predominantly with people with acquired aphasia, however, one person worked within a dementia assessment service, thus their work involved assessing and supporting with people with Primary Progressive Aphasia (PPA). Each participant was assigned a pseudonym during data transcription. Information about each participant is summarised in Table 1 below.

Table 1

Participant Details

Pseudonym	Setting	Length of time in role	First job working with people with aphasia?
Lisa	Acute and hyper acute stroke unit (HASU)	2 years 9 months	No
Ashley	Inpatient neuro-rehab (level 2)	2 years 2 months	No
Marie	Inpatient neuro-rehab	4 years	No
Leah	Dementia assessment service	10 years	No
Donna	Community neuro-rehab	16 years	No
Aimee	Community neuro-rehab	5-6 years	No

Georgia	Other[1]	< 1 year	No

2.6. Data Analysis

I have described the way in which I engaged with each part of the reflexive TA below. The procedure I followed was informed by the six phases outlined by Braun & Clarke (2022). Transparency in documenting *how* TA is done and the choices that are made at each step is inherently supportive to the reflexivity of the researcher (Braun & Clarke, 2021a). In the spirit of this I kept a reflexive journal, which documents my ideas and reflections about the data, as well thoughts and feelings during each phase of the analysis. Extracts of this can be found in Appendix N.

2.6.1. Familiarisation with the Data

Familiarisation with the data started during transcription of the interviews, which was undertaken by hand. Interviews were transcribed verbatim, capturing any hesitations, utterances, emphasis in tone, and repetitions made by participants. As the interviews were recorded through MS Teams video was available. Therefore, I also recorded non-verbal data felt to be pertinent, such as nodding or smiling. Following transcription, I listened back to each interview without taking any notes, before listening again and writing down early ideas, opinions, or questions (e.g., any key differences or similarities that I started to notice between interviews). Examples of the notes I made during this stage can be found in Appendix O.

2.6.2. Coding

Coding involved going through each interview using the comments function in MS Word to systematically highlight data felt to be relevant and interesting to the research questions. Codes were identified at both the semantic and latent levels. After coding each interview once, I went back and repeated the process. The second round of coding provided the opportunity to reflect on and make changes to existing codes, as well as identifying and coding bits of data that I may have ‘missed’ during the first round. Example coded interview extracts can

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[1] Detail about this participant’s work setting has been omitted to protect their anonymity

be found in Appendix P. Following the second round of coding I started inputting the coded data extracts into an Excel spreadsheet. A total of 304 coded extracts were inputted on the spreadsheet. Doing this allowed me to notice codes that appeared to capture the same meaning, which were subsequently merged. An extract of the excel spreadsheet with the data extracts and corresponding code iterations can be found in Appendix Q.

2.6.3. Generating Initial Themes

This phase involved beginning to identify patterns of meaning across the coded data and starting to group or 'cluster' them together based on these patterns. I printed out each code with its corresponding data items to help me with clustering the codes (see Appendix R for example maps created). Over time, these clusters formed the basis of candidate themes. Some of the codes were later collapsed together and formed the basis of subthemes. Codes which were not felt to have a place within these clusters were not disregarded altogether but were put aside. A later version of the codes clustered into themes with their corresponding data extracts can be found in Appendix S.

2.6.4. Developing and Reviewing Themes

During this phase I referred to notes made during the familiarisation and coding phases to help guide me, as well as considering how the candidate themes I had developed helped to answer my research questions. I asked myself whether the coded extracts I had grouped together really did represent the meanings captured by candidate themes. At this phase I was wary of falling into the pitfall of creating what Braun & Clarke (2022) refer to as 'topic summaries', as opposed to themes representing a central concept developed through a process of reflexive interpretation and analysis. Presenting a thematic map on MS PowerPoint and discussing this with my research supervisor alongside coded extracts and their relevance to my research questions was a helpful part of this process, leading to further theme and subtheme development.

2.6.5. Refining, Defining and Naming Themes

Using questions posed by Braun & Clarke (2022), I began to develop concise definitions for each theme and further refine where I noticed that some of my themes felt too broad or vague in the meaning they were conveying. Such questions included, “what is the central organising concept of this theme?” and “What does this theme contribute to the overall analysis?” This phase also involved reviewing the names of each of the themes to ensure they captured the overall messages. A map of the final named themes and subthemes can be found in Appendix R.

2.6.6. Writing Up

Writing up the ‘results’ of my analysis provided further opportunities for theme refinement. I expanded on my theme descriptions and used the data extracts ‘in action’ to help evidence my analysis. Once again, I referred to my early notes and my reflexive journal to help crystalise my analysis and the story I wished to tell with the data.

3. RESULTS

Four main themes were constructed through thematic analysis of the interview data: 1) *Working with Distress;* 2) *The MDT as a Resource*; 3) *Challenging Assumptions – Defending Capacity and Championing Psychological Support*; and 4) *Moving Beyond Language – (Re)Connecting with What's Important*. Themes 1, 2 and 4 have corresponding subthemes, as outlined in Table 2. The following sections explore each of these themes and subthemes in more detail, using example extracts from the interviews. Some of the extracts have been condensed for brevity and clarity. Removed sections are indicated using [...]. A table of all data extracts relevant to each theme can be found in Appendix T.

Table 2

Themes and Subthemes

Theme	Subtheme
Theme 1: Working with Distress	*Context is Important* *Frustration is Inevitable* *Supporting Families* *Supporting Colleagues - 'When people start crying, they find it really hard'*
Theme 2: The MDT as a Resource	*MDT Cohesion and Connectivity* *Learning from SLT Colleagues*
Theme 3: Challenging Assumptions – Defending Capacity and Championing Psychological Support	
Theme 4: Moving Beyond Language – (Re)Connecting with What's Important	*Confidence Comes with Experience*

3.1. Theme 1: Working with Distress

This theme explores a central idea articulated in several ways throughout the dataset: that being able to make sense of, contain and respond to distress is an important set of skills clinical psychologists bring to their teams and their work with people with aphasia. The first subtheme represents a pattern in the clinical psychologists' approach to understanding the emotional experiences of their clients with aphasia. The second subtheme highlights the pervasiveness of frustration within participants' experiences of working with people with aphasia. The third subtheme captures how the clinical psychologists view and address the impact of aphasia on the families they work with. Finally, the fourth subtheme explores how the participants viewed their colleagues' ability to engage with emotional aspects of aphasia and the support they felt they could offer to this end.

3.1.1. Subtheme: Context is Important

The clinical psychologists made sense of emotional responses in terms of the varied ways aphasia had disrupted 'normal' life for the individuals they worked with, considering their unique experience and context, as opposed to presenting generalised understandings of how aphasia impacts people psychologically.

> *Yeah, hugely, I don't have any one understanding, I think it'- it, you know, different clients present in such different ways [...] there's that- that fear and anxiety um... and depression and adjustment, um... So there's no- no there's definitely no one understanding. (Marie)*

> *So I think yeah, it's definitely varied, isn't it? Dependent on the extent of it and... how they perceive it and how it's affecting their life... (Georgia)*

> *Um... I think it's so individualised as to what the person values or needs and how that impact on them moving forward in their kind of rehab and recovery. So, I think I've definitely met people who have aphasia but also now are wheelchair dependent and are much more upset about the wheelchair than they are about the aphasia... and vice versa. Erm, it's so individualised (Ashley)*

Whilst acknowledging that experiences such as loss, adjustment and frustration commonly feature in the lives of people with aphasia, the examples participants provided contextualised emotional outcomes, and they endorsed individualised and formulation-driven understandings. Several participants used work as an example of how aphasia might impact people differentially.

> *You know, someone who... I dunno... for want of a better example, works in a call centre, is going to be much more affected by aphasia than like a [inaudible] left sided weakness perhaps... (Ashley)*

> *...there are just some jobs where it just wouldn't be safe (...) 'cause you could potentially put other people at risk (...) I think, you know, again, workplaces are very dependent on language. Erm... they don't really... have ways to compensate for that, many places and so... I think it can make returning to work very difficult depending on what the roles do- the role that the person is doing but I would say that nearly all jobs involve some form of language at some point (Donna)*

Most spoke about the way in which aphasia can result in people being unable to return to work, however some explicitly discussed the loss of role or disruption to sense of self or identity this can create for people they had worked with, whose job roles were particularly dependent on language.

> *I see- I see people I've worked with er- a couple of patients recently where... where their job role is so closely linked to being able to being able to communicate and actually, processing that loss and getting their head around, you know, who they are as a person if they're not, you know, if they're not, a lecturer [...] you know, that's their job so it's just a huge shift... to think about, you know, what's life gonna be like, you know who am I without this particular type of role in my life. (Lisa)*

> *I was just um... thinking about the impact of language on people's identity, really, and how much... how much of our...language skills identify, kind of, who we are and get across who we are as a person. So*

> *certainly for- for the teacher that I worked with her whole life was around... language. Um... being able to speak in front of a class and that was her role in identity and I think when people were really struggling to be able to speak and communicate what they are, what they- you know what they want to say... there comes a massive loss with that (Leah)*

3.1.2. Subtheme: Frustration is Inevitable

Whilst the clinical psychologists discussed that emotional responses to aphasia vary from person to person, all emphasised the role frustration plays in the experiences of people with aphasia.

> *I think for everyone language is such a key part to how we communicate with one another, that when you suddenly lose the ability to do that, it's devastating and, um, it can cause huge amounts of frustration and anger, [...] and a lot of sadness as well. Erm, and then to not be able to communicate that - easily with other people, just you know, it's kind of layer upon layer of frustration (Donna)*

> *...the frustration is huge, that's- that's really common (Marie)*

> *...but also real frustration because... we see a lot of frustration and people just can't get their point across. (Leah)*

> *And just not- maybe not – being able to communicate about that and the- and the frustration as a result of that. That’s [...] mainly what I see in my work and mainly what I see with people at that sort of acute stage after their stroke (Lisa)*

> *I guess the other, um, challenge is maybe how frustrated some people get. (Georgia)*

Frustration was framed by participants almost as an inevitable or unavoidable aspect of living with aphasia, and thus an equally inevitable aspect of working psychologically with people with aphasia. They discussed how frustration could manifest in therapy sessions. Therapy was described by one participant as a “live example" for how frustration may play out in people’s everyday lives.

> *...so actually you- your attempt to have a session sort of brings up... this- this is kind of a live example of what- you know of the frustration and erm... this change that I’m gonna have to get used to. This is it here in action and I think, you kind of have to sit with that difficulty (Lisa)*

A couple of participants spoke about navigating a ‘delicate balance’ within the therapeutic space of being persistent in trying to reach understanding, whilst being aware that doing so may lead to more frustration.

> *I have worked with people with aphasia who’re really not tolerant at all and they find it really hard when you don't get what they're trying to communicate quickly, and that's a lot harder to work with because then it's that sort of delicate balance of wanting to properly understand but not... agitating them even more that you're repeatedly misunderstanding (Donna)*

> *And myself and my trainee were like, ‘we don't know what this means’, and you know, you're trying to be really empathic with people and not- not say, ‘I'm sorry I don't know what you mean’ too much... But equally, not just saying yes when you don't understand (Leah)*

However, being able to embrace and navigate the challenges that come with working with frustration was presented as an important aspect of the work. Participants described ways of doing this, such as the importance of remaining patient, empathic, offering reassurance and time, whilst also being upfront when they are unable to understand.

> *I mean for me, it's just kind of being really honest about it and saying, “look, I can see this is really annoying you and winding you up that I'm not getting this and I'm really sorry, but it's really important that I understand properly 'cause I don't want us to go on with the misunderstanding (Donna)*

> *So it's thinking about, um... Just reassuring, you know, "take your time"... "We can have a break whenever you want", um... and a lot of, "can I just check I've understood what you said" [...] So, I do that a lot with people with aphasia. (Georgia)*

The following extract from Donna illustrates the importance of reflexivity within therapeutic work more broadly.

> *Erm, but I guess from the therapist point of view it's about not reacting to that frustration and not taking it personally and not thinking right, I'm a useless therapist, but it's just being able to sit with it and thinking, look, this is a normal reaction to a very frustrating situation (Donna)*

Being aware of thoughts and feelings arising in response to someone's frustration in a session provides an opportunity to reflect on and challenge them in the moment, often allowing for a more helpful and empathic response. For Donna, this involved the internal process of normalising the frustration, which prevented her from taking it personally or 'reacting' unhelpfully.

3.1.3. Subtheme: Supporting Families

Participants recognised that the sense of loss and frustration associated with aphasia often extended beyond the individual, affecting family members, and impacting their relationships with one another.

> *I think on the flip side to that, it's the loss that, um, the caregivers or family members experience as well, and saying that they feel so... frustrated for them that they can't express themselves in the same way. And sometimes they say they feel like, obviously, there's- there's- sort of a- a different person, and then that they've lost that sort of... the person that they were before (Georgia)*

> *And I think also for loved ones and for relatives and, um, people involved in the person's life, it's also really frustrating because they desperately*

> *want to understand... erm, but then all- it- experience that frustration at not being able to understand (Donna)*

As such, most of the clinical psychologists described that part of their work was supporting families to adjust to changes aphasia brings to their lives. For example, Lisa described working with a family, where she helped prepare children who would be seeing their parent with aphasia in hospital for the first time.

> *...we did a piece of work where the kids came in at different times and, you know, sat with their mum and dad and saw their dad for the first time and, you know, we did sort of work with talking to them in advance of this meeting and talking about some of their expectations and their hopes and their fears... (Lisa)*

Others described working with couples, where difficulties with communication were causing problems within the relationship. This type of work was often in collaboration with their SLT colleagues.

> *So, speech therapy do a large part of this but may- like I've done sessions before with a partner there where we might role model kind of alternative communication styles erm for them to be able to kind of use that when the person's discharged or in their time with them. (Ashley)*
>
> *So [...] we got them into a room and then where we just got them to communicate one another [...] almost like doing a systemic therapy, but at the same time the SLT will... um... interrupt by going, "OK, so I think what he's trying to say is XYZ and how do you think you can say in such a way that will mean that you don't have to be so frustrated [...] And then how can the partner try and be a bit more patient? You know, things like that. So trying to improve the communication [...] sometimes we do a bit of facilitation with that. (Aimee)*
>
> *...we did some work with them around, you know, different communication styles and turn-taking and... um... and we videoed um, a*

> *conversation - all of us having a conversation – and then we all looked back and reflected on our own communication... (Donna)*

Several participants also discussed providing information and education to family members, separately from the person with aphasia. However, this was usually in the context of working with individuals who were also cognitively impaired.

> *Um, so I think a lot about education and just - people have valued the opportunity to just talk and ask questions [...] "when- when they're struggling for a word, what do I do?" "Is it helpful for me to fill it in or should I leave them to try and find it?" This- this being able to navigate some of those queries that carers can often have about how best to help their loved one when they're struggling. Erm... yeah (Leah)*

> *But, erm... I think uh – I have- I have a couple of cases just where I've worked where there's been a lot of involvement in... kind of... supporting and educating family members about people's aphasia. (Lisa)*

> *Um... he's got, you know, severe communication difficulties. Um, really severe emotional lability - so with him it was working with his wife, who's an incredible communication partner. Um, and we were thinking about education around the emotional lability, thinking about whether there's a role for medication. (Georgia)*

3.1.4. Subtheme: Supporting Colleagues – 'When people start crying they find it really hard'

Some of the clinical psychologists noted how other members of the multidisciplinary team could neglect to ask about, overlook, or 'shy away from' the emotional aspects of aphasia, including mood or mental health difficulties.

> *I think sometimes, and understandably, the MD- the other members of the MDT can sometimes shy away from, sort of being involved in those sort of moments* (emotive family interactions) *(Lisa)*

> *Erm, I think people probably rely a bit more on like, are they crying in every session rather than thinking too much about the impact on mood and things. I think that also because there's psychologists within the team that might be kind of, just, left to us to consider and less their... role. (Ashley)*

> *...and then there's the mood, mental health, adjustment side as well, which often I find has been overlooked in, um, neuro-rehab (Marie)*

> *So, I think there's a bit of like, upskilling that's needed to then appreciate what that might mean for someone [...] So in answer your question, no, I don't- I don't think they always appreciate that sort of loss and that adjustment and frustration (Georgia)*

As members of the team most frequently working with people with aphasia, SLTs were often positioned by participants as being most likely to pick up on emotional difficulties or refer people for psychological support.

> *I think a lot of it does come back on the speech therapists though because they spend the most time with them so they're more likely to pick up on anything. (Ashley)*

> *...we do get quite a few referrals from my SLT colleagues uh, about people whom they- they, you know, um... they want psychological input. They- they- they do refer people to us. (Aimee)*

> *I think speech therapists are- are very skilled with this and actually I'd say a lot of my speech therapy colleagues, they might've even had very similar conversations or talked about very similar topics w-with, with people that they've met on the wards. Erm, and probably have a level of confidence about- about attempting that communication (Lisa)*

Lisa emphasised that her SLT colleagues have 'similar' conversations to those she might have as a clinical psychologist and went on to express the view that her SLT colleagues are skilled at 'holding' or containing emotions expressed by clients. However, others shared that sometimes their SLT colleagues fail to realise the emotional impact of aphasia, feel ill-equipped, or lack confidence when working in emotive contexts.

> *... sometimes the speech and language therapists, I think [...] they're so focused on their like specific goals and like their specific sort of tasks that they're doing... I- I feel like that they sometimes don't appreciate the psychological element and like the loss and what it actually means, 'cause they're so focused on their specific um... intervention, if that makes sense (Georgia)*

> *I- I think some of them are very... they're not sure what to do. Uh, because... Yeah, because their [...] role is to actually, uh, well try to enhance, or give- provide strategies to, you know, to alleviate the symptoms of aphasia, but [...] when people start crying I think- I think they find it really hard... Not everybody, though, that's- so- so- it's a mixed bag (Aimee)*

Participants discussed how they supported colleagues to notice and engage with the emotional aspects of aphasia; for example, through sharing formulations or providing training.

> *...we in our MDT meetings with, as you'd expect, kind of sharing formulations... Um... sharing different perspectives, particularly where we've got, um, you know, difficulties with families understanding or if it's high expressed emotion, things like that going on, we've got that sort of aspect, as well as supporting the team in their understanding of a client's presentation um... But particularly with aphasia (Marie)*

> *So, it's- I'm not doing it at the moment, but I think we did like six months of monthly training and, um, those were around different topics. So, one was sort of managing distressing conversations, so anything like that around, um, communication difficulties would have come up (Georgia)*

The clinical psychologists also described supporting SLTs, as well as other members of the MDT, to work with high levels of expressed emotion through joint working, offering consultation, or providing informal supervision.

> *...the speech language therapist was kind of finding that really tricky to navigate and... on her own trying to manage it and, so, I joined her [...] But... certainly I know from the speech and language therapist she felt much better supported not having to do those sessions on her own because it was a challenging piece of work (Donna)*

> *...we got a guy who's got quite a moderate- err- severe aphasia and he was very emotionally labile. Erm... but the therapist- like the OTs and physios weren't really sure how to manage that in sessions or couldn't... couldn't really discuss it with him um... very easily so, maybe giving some tips and ideas oh kind of how to manage that, um... that might be an example of kind of something that we come up with (Ashley)*

> *But when I see a SLT colleague I- I can still remember a case where, um... she really felt- I could feel she felt uncomfortable, so I had to check in with the person just to make sure that there wasn't anything, perhaps too close too personal- the- the personal life that might have impacted or... is it just you know something where... It's just so overwhelming, upsetting information that the person is finding it hard (Aimee)*

Such descriptions imply the clinical psychologists feel they have a role in supporting other members of the team to manage more emotive or distressing conversations, which might otherwise feel overwhelming.

3.2. Theme 2: The MDT as a Resource

All the clinical psychologists worked within a multidisciplinary team comprising different health professionals (e.g., speech and language therapists, occupational therapists, physiotherapists, nurses etc.). It was clear from their accounts that most participants enjoyed working in this way and they framed the MDT as an important resource. The first subtheme captures what clinical psychologists felt makes an MDT useful or helpful, and the second subtheme explores what participants valued in terms of support from SLTs when working psychologically with people with aphasia.

3.2.1. Subtheme: MDT Cohesion and Connectivity

The participants' narratives of helpful or 'well-functioning' MDTs suggested they embodied qualities such as cohesion and enabled connection. This was demonstrated through their positive attitudes towards joint working, opportunities for cross-discipline case discussion, working in proximity to one another, and absence of hierarchy.

> *...we tend to have quite a lot of MDT discussions. Um... because [...] it's quite complex, we do tend to need this... Um... SLT... to guide us not just psychology, but other disciplines as well. And likewise, um, we psychology then share information. (Aimee)*

> *Yeah, I think very much especially in our MDT at the moment, it's a really lovely MDT and very sort of, a healthy and well-functioning, but all in one office, which is quite good, because then there's lots of sort of cross talking and [...] we've got three speech language therapists and so speech, psych and OT... I think very much we're all on the same page and we're all kind of constantly checking in with one another. (Marie)*

> *Um... and I think being in a multidisciplinary team is part of that, because I know that I can access resources if I need to via speech and language therapy. Um... So... no, I don't... Yeah, I don't really have any concerns with that (Donna)*

In the below extracts, both Marie and Ashley describe their position within their respective teams. Both accounts evoke issues relating to pay grade, power, and hierarchy, and how these factors have the potential to influence team dynamics.

> *...I know my colleagues have said I'm quite- I'm not an arrogant psychologist, 'cause I think in the past, even in this job, before I was there, there was [...] You know how it is with psychology, I think sometimes the psychologist can position themselves- they're usually the highest banded in the team. There's a kind of - an unspoken hierarchy, um... and I'm very, very keen - very keen for that not to be the case and it isn't the case in our team at all. (Marie)*

> *Well I guess, I feel like I'm in a slightly weird position in that erm... I work in very much in the same way as the other therapists do, like the physios, OTs, speech, so we all kind of timetable our sessions together and we all kind of sit in the same place but because I'm a band 8 and they tend to- well they are more junior, I also go to like the senior meetings and... meetings with like the consultant medical staff, things like that, so I sort of sit in the middle it feels. Kind of a weird limbo position [...] But it's nice, because we kind of get to work with- with everyone as well. So it's a bit easier maybe for me to have a chat with our consultant about something but also know how kind of the OTs are getting on with someone because we have those day-to-day ad hoc chats so I think a large part of my role is consultation so I purposefully sit on the ward with the team rather than up in the psychology department so you can have sort of ad hoc chats so... (Ashley)*

Both participants referred to their position within their teams, as well as how their behaviour contributes towards maintaining a sense of cohesion and camaraderie. Marie's narrative suggests it is important to her that she is not viewed as an "arrogant psychologist", and she frames hierarchy as negative or unhelpful, and as something to be avoided in the context of MDT working. Ashley's account implies a more neutral attitude in relation to hierarchy, and although she described her position of being more senior than other therapists in the MDT as "weird", she also discussed the opportunities this affords her to connect with more senior colleagues. However, her decision to sit on the ward as opposed to separately suggests she feels it is important to be available to more junior colleagues.

In terms of barriers to working in a connected or cohesive way, obstacles to joint working such as lack of time or resource were cited by some participants. This appeared to be more of a challenge to those who worked in acute settings, where the fast pace was perceived as the main barrier to arranging joint sessions.

> *Because it's a medical ward and things move quite quickly, you sort of, you take a bit of time where you can. Erm... so it can be hard to coordinate working jointly ... So, I think it's the setting more than anything that makes it- can make it challenging to do the joint working (Lisa)*

> *Yeah, and on a more sort of practical level erm, everyone's so busy, sometimes having the time to- to maybe sit down together or see someone together [...] just some of those practical things that come with working in hospital (Ashley)*

3.2.2. Subtheme: Learning from SLT Colleagues

All the participants' accounts indicated that they appreciated having the opportunity to work with or consult with an SLT when supporting someone with aphasia.

> *Um... it's been quite interesting actually for me because this is the job where I've had the most um – please forgive my lack of coherence here – the most inter- joined up working with SLT and so they've taught me... a lot – way more than I've learnt on training or other neuro jobs – about aphasia and working with it (Marie)*

SLTs were valued for the advice they could offer around particular communication strategies (i.e., those developed within speech and language therapy sessions) to use with individuals, as well as teaching and support to use communication aids or technology.

> *Or if I speak to the speech language therapist before and I say, you know, what techniques do you usually do? What should I be thinking*

> *about? Cos obviously they're, you know, often working with the patients before I am (Georgia)*

> *... checking with them to see what kind of technology or strategies they use... to facilitate the, um, conversations, um, so I do rely on them (Aimee)*

Leah, who worked within a service without speech and language therapy, discussed how she accessed advice and support from an SLT in a different organisation to support her work with clients with aphasia.

> *So I- so we have something called [name of support service], which is a national organization for rare dementia, and they have, um, a speech therapist within that, and she specializes in primary progressive aphasia. So, I've had conversations with her. (Leah)*

The clinical psychologists also commented on the value of joint sessions with their SLT colleagues when working with people with aphasia. Joint working was viewed as beneficial for all parties: the SLT, the clinical psychologist, and the patient. For the clinical psychologists, it offered opportunities for them to observe and learn more about the kinds of strategies SLTs use to support communication in a session.

> *um... and from my point of view, you know, observing her and how she supported the, um, man with the language difficulties to communicate with his wife was- it was really interesting to kind of be there and observe that and see what her strategies were. (Donna)*

> *I guess the difference will be I will- I- One of the challenges sometimes is that because they can be so severe... that I do need um... a SLT to be in the therapy... of course, with patient's consent. Um, certainly to begin with because I need to understand and observe how the interaction is. (Aimee)*

Aside from learning from their SLT colleagues about how to support communication, some participants also described experiences of joint working, where the SLT's skills and attention to communication freed up thinking space for them to focus on the emotional content.

> *...and she was having individual sessions with the patient - so speech specific - and then I would have sessions, with her, focused on the sort of emotional element... And she would just be absolutely fantastic in [...] sort of breaking down the information, thinking about key- keywords. [...] it's just- it was just really, really helpful. (Georgia)*

> *And it was [...] really helpful, because I was able to sit with her and sort of ask questions and bring up the topics I wanted to bring up that I thought were relevant, erm... while she was sort of, thinking – she was exclusively thinking about their communication needs. And she was helping by writing particular things down or... sort of asking us to pause so she could check the persons understanding (Lisa)*

Joint sessions were viewed as beneficial to the person with aphasia as they enabled a smoother session and minimised the need for them to repeat themselves to multiple health professionals.

> *I feel like I was able to get somewhere quicker and the patient felt, sort of, better supported when there was like another brain thinking- thinking exclusively, you know, about communication and what might help a little bit more. (Lisa)*

> *...I think, you know, rather than the patient having to explain to every new therapist how to communicate [...] it's helpful if we do those joint sessions so that that information about how that person would like to communicate is quickly communicated between all of us and they don't have to keep repeating themselves or going through the really painful process of every time they start with a new therapist not being understood... (Donna)*

3.3. Theme 3: Challenging Assumptions – Defending Capacity and Championing Psychological Support

This theme captures how particular types of assumptions about people with aphasia sometimes manifested in the teams that the clinical psychologists worked in, and their responses to these assumptions. For example, several participants described how when people with aphasia are unable to communicate, colleagues could make assumptions about their cognitive abilities or intelligence. Such assumptions were felt to contribute to unhelpful or harmful ways of interacting with patients/clients with aphasia; including patronising or infantilising responses, as well as dismissing or overlooking their emotional needs, as touched on in the previous theme.

> *...you might have someone who is... just really struggling to communicate. But actually cognitively they're doing really, really well and I think it- it's... that's- that can be very challenging [...] for all staff really but I think more so nursing staff where, you know, you see someone who just- who just can't get their message across and then there's this assumption that well they can't remember things or you know... that they- they just can't talk so they don't sort of maybe stop and try, and try other things and this I think is something that erm [...] they will often tell me that- how frustrating it is that people think they're stupid. [...] So I think this- you know, people can sometimes infantilise erm... people with aphasia (Lisa)*

> *Erm, I'm not sure that the physios or the OTs really think about it that much. Um... yeah. Maybe though. I think sometimes people might just get written off a bit because they can't say what it is that's bothering them. Um... maybe there's just an assumption that they're fine, or not fine. (Ashley)*

> *Sometimes what you find, is people speak in a patronizing way and it is literally the worst. It's that patronizing way or feeling like or sounding like... Almost the person is a bit 'stupid' because of their communication*

> *and like, obviously that is completely awful in the worst, and that's when you have to sort of feed back (Georgia)*

In addition to ‘feeding back’ when they witnessed unhelpful interactions, a couple of the participants described how involvement in capacity assessments provided opportunities to challenge assumptions about cognition and advocate for people with aphasia.

> *And I think also – it comes up a bit in capacity assessments – you know, not assuming someone doesn’t have capacity because they’re aphasic. Like, taking the time to really like try and help them communicate their kind of thoughts and wishes if they can and if another way... um, just some of those things not to yeah, just writing someone off because they can’t say anything, yeah... (Ashley)*

> *And I think often times, and quite appropriately, it’s a speech therapist who might do a capacity assessment or one of the other- you know, one of the other medics or one of the other therapists erm... But I- I’d be keen to not not get involved just because someone has a communication difficulty and I think- I- I’ve often done joint capacity assessments with myself and a speech and language therapist around a- around a particular issue. (Lisa)*

Lisa’s statement that she’d be, “keen to not not get involved” in a capacity assessment for a person with aphasia implies she (perhaps as a clinical psychologist) believes she can bring something useful to the process. This is echoed Ashley’s response to a follow-up question about whether clinical psychologists have a specific role in advocacy and capacity assessments:

> *I think there’s definitely a specific role for psychology and speech in that - within our team I think we’re the ones who tend to be the- who think of that sort of stuff (Ashley)*

Another type of assumption participants spoke about navigating in their work relates to the belief that people with aphasia cannot engage in psychological interventions like talking therapy, that these are not appropriate, or will be of limited use for this population. Accounts from the clinical psychologists demonstrate their experiences of encountering this belief in their teams, and their views about it.

> *Erm, and I often... I might not get a referral sometimes cos people might make the assumption, well this person isn't going to be able to engage in... in psychology (Lisa)*

> *...whilst people might not think that psychological therapy is appropriate for people, um, with aphasia, that isn't true because there are ways that you can adapt your approach to working [...] to make sure that they're able to access it as well (Donna)*

> *Um... I think an overall sort of systemic challenge to start [inaudible] when someone has aphasia there's a belief that they can't engage in, um, talking therapy or psychology (Marie)*

Interestingly, there was some divergence in views on the suitability of psychological therapy for people with receptive aphasia, which was apparent through participants' reported stances towards therapy with this group.

> *...I think the reality is often... is if someone has a receptive aphasia I'm probably not doing a longer piece of sort of clinical work with them (Lisa)*

> *"even if their receptive language is impaired and you're creative and you use different modalities, there's [...] tons you can do" (Marie)*

As with assumptions relating to cognition, taking on an advocacy role appeared to be an important way of responding to the assumption that people with aphasia cannot engage in therapy. For example, two of the participants' accounts evoked a sense of responsibility or duty in relation to 'fighting against' this type of assumption or promoting psychological interventions for people with aphasia.

> *...that's a kind of quite a uniform issue I've seen and something that I have to fight quite strongly against - often I'm not anti-prescription where I think it's appropriate and there is a lot of times where it is...um but I do find sometimes... particularly with this population they are maybe a little bit quicker to prescribe and write off... the possibility of talking therapy... (Marie)*

> *Erm... erm... so I think my role is in a way, it's sort of advocating a little bit for- for how psychology might be able to support in a particular situation... erm... (Lisa)*

3.4. Theme 4: Moving Beyond Language – (Re)Connecting with What's Important

The theme, *Moving Beyond Language– (Re)Connecting with What's Important,* captures an overall pattern relating to how clinical psychologists talked about overcoming language barriers so that meaningful therapeutic work can be undertaken with individuals with aphasia. When reflecting on their work participants identified various strategies for navigating communication challenges. However, some of the most powerful 'interventions' involved stepping away from traditional talking therapy in favour of other, creative ways of communicating and meeting the person's psychological needs.

> *And I think that's one of the most powerful pieces of the work... it's really the- the richness comes with that re-connection to something outside of language. (Marie)*

Connecting to and working with the person's interests, values and strengths within their interventions was described as a way of promoting recovery with less focus on language.

> *...one of the interventions if someone is struggling with the talking therapy, um, would be to liaise very heavily with OT and go for more values driven approach in terms, of you know, connecting values connected with hobbies, connecting with things like that (Marie)*

> *...he loves to talk about his garden – it’s really important to him. But he can't... get across what he needs to say. So we've just talked about having a few words in a notebook for him to help him socially communicate a few keywords. So we're- we're just thinking about practical things around - for him - what he could have to take out to aid communication with him about things that are important to him. (Leah)*

Whilst one of the aims of Leah’s intervention (described above) appears to be around supporting her client to have conversations, it is ultimately about enabling him to connect with and convey what is important to him.

It was clear across the clinical psychologists’ accounts that working psychologically with people with aphasia requires getting to know or getting ‘a sense’ of the person.

> *And when you – when you get a picture and you get a sense of someone, who they are, what their personality, you know what they like and what they don’t like, you know you sort of- you get pulled in quicker and you- you get a sense of you know, what direction you want to go with in terms of setting goals... jointly with them. (Lisa)*

Some participants spoke about how, with time, they were able to gain a deeper understanding of their client’s non-verbal communication.

> *...and because I've worked with her such a long time now, I kind of understand what she's saying without her having to say it sometimes – laughs- (Donna)*

> *So once you get to know a client well with aphasia... um... that bit about body language, intonation, connection, understanding, and being able to involve the family and get to know someone is so key, because actually I found myself having what feel like full blown conversations with someone and what- what they're saying is making no sense at all, but through knowing them so well and underst- if they've got quite good intonation,*

> *even if it's jargon aphasia and they're coming out with the same word over and over and over... you really can... You- you really can understand... (Marie)*

As mentioned by Marie in the above extract, involving family members or loved ones was another way participants were able to get to know and understand their clients with aphasia.

> *Erm... when that's absent and you can't do that in the kind of quick way you would normally do, you know, I think we often rely on family members to give us that sort of information and then you can build on that then when you work with people (Lisa)*

One participant described how working with family members can help her understand cultural differences in communication style, which in turn supports her communication with the person.

> *...the person tends to have their- their own inner language, if you like, some slangs or [...] I'm just thinking now the cultural elements as well, not just racial culture, but family culture - the way of communication may be different. Certain things may mean different things. So I find that family members, or whoever are close to them help... to kind of think about actually [...] what other ways will help to facilitate communication? (Aimee)*

However, Lisa also described how over-reliance on family members can sometimes cause "unwarranted distress" for them and suggested that working directly with the person with aphasia to understand what is important to them remains an important aspect of the work.

> *I think sometimes that can put a lot of pressure on the family member and cause distress- sort of unwarranted distress in them as well. (Lisa)*

Another intervention that several of the clinical psychologists recognised as important involved connecting people with aphasia to wider systems of support to facilitate recovery. Systems of support included friends, the wider community, and peer support groups. Participants viewed this as a valuable intervention because of the ways aphasia was understood to impact confidence and lead to social withdrawal.

> *...my therapy, I'm not just doing therapy, I'm also thinking about wider system - is that if we know that a person has communication problems, we know that this person will have difficulties communicating with the wider system. (Aimee)*

> *...so I'm looking to see whether we can set-up a [name of place] PPA support [...] Particularly important, I think because they don't- they are limiting social contact because of their condition, so being able to go to a group where other people go, "don't worry, you can't find the word I get it", um.. would- would be great, I think, if we can get that up and running (Leah)*

> *...because sometimes I think... Just being in a group helps, and that you're not alone... And usually sometimes people in a group - stroke survivors with aphasia, comes with, you know, diverse backgrounds and different diverse um... impairment, but they also have different strategies as well. So that usually is quite a good support network (Aimee)*

> *...um, just helping her to... see that it's really important to put herself back out there, and that friends are actually very understanding, and she started carrying a card, so she's in the supermarket, she could show people saying that I have difficulty with my speech and then having really positive experiences where people were helping her to get a taxi, and you know, just... really building up her confidence and reducing that... sense of social isolation... (Donna)*

Within these accounts, the aim of promoting connections is not necessarily to use or practice language but is about enabling people with aphasia to have positive social experiences that make them feel understood, supported, and accepted, thereby enhancing their psychosocial and emotional wellbeing.

3.4.1. Subtheme: Confidence Comes with Experience

Some of the clinical psychologists discussed that their confidence and ability to work in these ways with people with aphasia has grown with experience and ‘on-the-job’ learning.

> *Yeah, it's been a really steep learning curve. (Leah)*

> *...very much just sort of on the job, learn as you go sort of thing (Ashley)*

> *Like, I would love some training actually. Yeah, it's all just come from experience um... I remember the uh... speech and language therapist in [name of borough], she used to run a session for the rehab assistants on aphasia and things but I could never make that (Georgia)*

This was also evident from reflections that they previously found working with people with aphasia de-skilling or anxiety-provoking. For example, two of the participants discussed previously viewing language or talking as the main ‘tool’ or mechanism for their work as clinical psychologists.

> *...I mean I think when I first started in my career I found it incredibly challenging. Erm... and if I’m honest I probably felt a sense of... felt myself avoiding work with people with aphasia if I’m being completely honest and I think that comes off the back of... because as psychologists, you know, we’re in the business of talking to people and we’re in the business of trying to make sense of people’s emotions that- that’s primarily what we do... Erm... and when someone doesn’t have the ability to, you know, to share via means of communication erm that, I think that can feel quite de-skilling. (Lisa)*

> *...and I've- I almost learned that too late, I think. I think in my early post qualification - sort of 10 years ago - I was like really... Quite um... anxious about working with clients even when I newly qualified, um, who didn't have language 'cause it was- I saw it as the tool to psychology, and it's only sort of in the last five years or so that I’ve really, really become*

> *confident in realising it’s so- there's so much that can be done... helpful, that's not just medication...to support someone with aphasia. (Marie)*

Their narratives imply that over time they have come to recognise the value of ways of working that are less reliant on talking and have developed the necessary skills to do so.

4. DISCUSSSION

This research is the third study to date to explore MHPs experiences of providing psychological support to people with aphasia (Morrow-Odom & Barnes, 2019; Strong & Randolph, 2021), but is the first one looking specifically at clinical psychologists' experiences of doing this work. In this chapter I discuss how the themes and subthemes constructed through the analysis help to answer the research questions, making connections with existing literature where relevant. I provide a critical evaluation of the research, including reflection on issues relating to quality, highlighting key strengths and limitations. Ideas for future research, as well as implications of the study for services and clinical psychology are considered.

4.1. Summary of the Findings in Relation to the Research Questions

4.1.1. How do clinical psychologists understand and address the emotional outcomes of aphasia?

Participants shared contextualised understandings of the emotional impact of aphasia. This was captured within theme one's first subtheme, *Context is Important*, where most highlighted the individualised nature of aphasia. They considered how loss of work had affected the lives of people they worked with, with particular attention to the impact on role and identity. Previous research suggests loss of work due to aphasia is associated with various emotional challenges, including navigating changes to role/identity, participation, and reduced social networks (Barry & Douglas, 2000; Manning et al., 2017; Sjöqvist Nätterlund, 2010). Interestingly, when sharing examples of their work, participants separately referred to people who had worked as a teacher and as a lecturer, specifically commenting on the significance of language and communication for these people in terms of their job role and professional identity. This would seem to support the suggestion made by Worrall et al. (2017): that the centrality of these skills within the lives of people with higher educational qualifications may make living 'successfully' with aphasia more challenging due to the impact on sense of self or identity loss of language brings. There are several published personal accounts from people with aphasia who were previously working within fields such as publishing, journalism, and academia (Douglas, 2022; Harris, 2017; Liechty & Buchholz, 2006; McKillop, 2012; Saner, 2022). In one of these, the author discusses how their career as a publishing director had come to define them and how they grappled with this loss (McKillop, 2012), echoing the descriptions given by this study's participants of supporting their clients in coming to terms with losing language as a teacher or a lecturer.

The emotion participants consistently discussed encountering when supporting people was frustration, indicating this was something they felt distinguished their work with individuals with aphasia from those without. They described how frustration relating to difficulties with communication plays a significant role in their clients' experiences, both generally, and within therapy. In the research frustration is typically associated with experiences of communication breakdown or unsuccessful interactions (Burns et al., 2015; Johansson et al., 2012; Strong & Randolph, 2021). Participants in the current study explained that frustration from the person with aphasia could make therapy more challenging. However, frustration was also described as something to be 'sat with', normalised, and approached with empathy and understanding. Their accounts suggest they viewed themselves as having a responsibility to be open and honest in communicating difficulties in understanding; something also reported by the mental health providers in Strong & Randolph's study (2021).

Strong & Randolph's (2021) participants reported experiencing frustration, both from the person with aphasia, and within themselves, due to challenges with understanding during counseling or therapy (2021). As described in the literature, people with aphasia appreciate active listening, patience, and encouragement from conversation partners, whether they are friends, family members or healthcare professionals (Liechty & Buchholz, 2006).
Given most therapy approaches are conversational in nature, it is important that psychologists and other MHPs working with people with aphasia are aware of the potential for frustration, and that they feel confident responding to expressions of frustration or anger in a supportive, proactive way.

Within the fourth subtheme, *Moving Beyond Language – (Re)Connecting with What's Important*, participants discussed how taking the time to develop an understanding of their clients' interests and values contributed to their understanding of how aphasia may have created challenges for them. The therapeutic relationship or alliance is generally regarded as a fundamental ingredient or 'common factor' within counselling and psychotherapy approaches (Laska et al., 2014; Wampold, 2016). Therapeutic alliance and adopting a relationship-centred approach to care are also recognised as key components of speech and language therapy, and rehabilitation more generally (Bright et al., 2018; Lawton et al., 2018, 2020; Northcott, Simpson, et al., 2021; Worrall, 2019). People with aphasia have discussed valuing support from health professionals who take the time to understand them (Burns et al., 2015). In the present study many participants stressed the importance building a relationship with their clients with aphasia and getting to know their unique communication style to understand and address the emotional impact aphasia has had.

They discussed how his knowledge helps to shape the focus or direction of their interventions. Participants did not name specific models or therapies they used in their work, perhaps indicating they draw on several approaches to suit the needs of the individual. However, some described the therapeutic power of helping people to connect back with valued interests and hobbies, such as gardening to support reconnection with identity. They also emphasised the importance of promoting social participation to combat social isolation or loneliness and rebuild confidence, recognising these to be areas in which many people with aphasia struggle. They discussed holding awareness of who is in their client's wider system, as well as encouraging reconnection with friends and acquaintances, and attending aphasia support or communication groups. Promoting connection in this way is supported within the research, where people with aphasia have described the importance of meaningful relationships to living well/successfully (Brown et al., 2012; Manning et al., 2021; Moss et al., 2021). This way of working is also reminiscent of both the LPAA approach (an SLT intervention), as well as behavioural activation (a CBT intervention); described as similar and compatible approaches for supporting the mental health and quality of life of people with aphasia in the literature (Morrow-Odom & Barnes, 2019; Santo Pietro et al., 2019).

Participants' descriptions of their work demonstrated they understood the importance of different kinds of support that might be needed for families to adjust to life with aphasia. The disruption that communication difficulties associated with aphasia can cause to families and family relationships is well documented (Brown et al., 2011b; Dietz et al., 2013; Fotiadou et al., 2014; Johansson et al., 2012; Manning et al., 2021; Taubner et al., 2020). Families have previously described the importance of couples working as a "united front" when discussing living successfully with aphasia, and spouses of people with aphasia have spoken about wanting to achieve better communication within their relationship (Brown et al., 2012). However, the previous literature exploring MHPs experiences of supporting people with aphasia has very little to say about working with family members. It is mentioned within one study, where participants describe challenges associated with managing dynamics between people with aphasia and their 'care partners', and advocate for providing separate support (Strong & Randolph, 2021). In contrast, working with couples who were experiencing difficulties in their relationship due to communication issues was a type of support that several participants in this study described offering in collaboration with their SLT colleagues.

Participants also described providing education around aphasia and working exclusively with partners of people with aphasia to develop their knowledge. Research shows that aphasia is poorly understood at a population level in comparison to other neurological conditions (Code, 2020), therefore most people will likely not have heard of it prior to experiencing it directly. People with aphasia notice and appreciate when their conversation partners have some knowledge and understanding of aphasia and adapt their communication accordingly (Johansson et al., 2012). Speech and language therapy approaches, such as communication partner training, recognise the value in providing interventions to partners to improve communication, and are understood to have a positive influence on psychosocial wellbeing and quality of life (Simmons-Mackie et al., 2010, 2016). In addition, clinical guidelines emphasise the importance of stroke services providing "information, advice and support" for families and carers, as well as involving them in treatment where appropriate (Intercollegiate Stroke Working Party, 2016, p.xiv).

4.1.2. What kinds of roles do clinical psychologists take in the MDT when working with people with aphasia?

The clinical psychologists in this study discussed supporting their MDT colleagues to understand and respond to the emotional aspects of aphasia; forming the basis of theme one’s third subtheme: *Supporting Colleagues – ‘When people start crying, they find it really hard’.* Their reports that colleagues from other disciplines did not always appreciate or recognise the psychological impact of aphasia correspond with previous findings that professionals working in stroke services feel under-skilled to assess mood and provide emotional support to individuals with aphasia (Baker, Rose, et al., 2021; Northcott et al., 2017; Sekhon et al., 2015). The literature exploring SLTs views and experiences shows they have varying levels of confidence and competence in recognising and navigating the more emotional aspects of aphasia, as well as finding this type of work mentally stressful (Northcott et al., 2017; Ryan et al., 2019; Sekhon et al., 2015). Whilst participants in this study described their SLT colleagues as skilled at picking up on emotional difficulties, some observed they were sometimes uncomfortable or unsure of what to do when confronted with high levels of distress, echoing what SLTs have reported about themselves in the research (Northcott et al., 2018; Simmons-Mackie & Damico, 2011).

UK national clinical guidelines for stroke services (within which many people with aphasia are treated) emphasise the importance of stepped psychological care involving the whole MDT, with clinical psychologists providing integral support and guidance to other members of the team (Gillham & Clark, 2011; Intercollegiate Stroke Working Party, 2016). The ‘dissemination of psychological skills’ is felt to be an important contribution psychologists make in stroke rehabilitation (British Psychological Society, 2010). SLTs that work with people with aphasia have previously reported feeling less anxious about addressing psychological well-being or working with distress when supported to do so by clinical psychologists (Northcott et al., 2018). In this study participants discussed supporting their SLT colleagues to better understand and respond to the emotional needs of their clients through a variety of methods, including consultation, training, supervision, joint working and sharing psychological formulations.

Another role participants described taking within their teams was that of an advocate. This tended to be in response to what they viewed to be unhelpful assumptions held by their colleagues about people with aphasia, which are explored within the third theme, *Challenging Assumptions – Defending Capacity and Championing Psychological Support*. Participants used phrases such as, ‘fighting against’, or ‘advocating for’ when describing their responses to the belief that people with aphasia would not be able to engage in talking therapy. Interestingly, SLTs have previously discussed experiencing MHPs who do not consider individuals with aphasia to be ‘appropriate candidates’ for therapy (Northcott et al., 2018), or encountering resistance from psychologists when referring clients with aphasia (Ryan et al., 2019). This contrasts with the current findings, where participants described encountering the same ideas and resistance from other professionals and reported actively promoting psychological approaches for people with aphasia. As evidenced by their decision to participate, the clinical psychologists in this study are likely to be especially interested or practised in providing psychological interventions to people with aphasia. Therefore, their views and experiences may not be reflective of all clinical psychologists who work in services supporting people with aphasia.

People with aphasia have spoken about importance of being treated with dignity and respect, as well as wanting others to recognise their intelligence, and view them as, ‘the same person as before’ (Burns et al., 2015; Worrall et al., 2011). Some have reported experiences of doctors making inaccurate assumptions about their cognitive abilities (Burns et al., 2015). In this study, some participants demonstrated they were aware other members of their MDTs could make assumptions about cognition and overlook emotional needs due to communication challenges, often framing this as having negative or harmful consequences. However, just one person described directly challenging a colleague they had witnessed behaving in a patronising way. Others discussed their involvement in capacity assessments, suggesting they perhaps viewed this as an indirect way of challenging assumptions about cognitive abilities, and describing the process as an opportunity to ensure people do not get ‘written off’ due to their aphasia.

4.1.3. What do clinical psychologists find useful when supporting people with aphasia as part of an MDT?

In the theme, *Moving Beyond Language – (Re)Connecting with What's Important*, participants framed family members or loved ones as a resource, which enabled them to better understand their clients with aphasia. This is in line with some previous research, which has positioned the rich knowledge that family members can offer about their loved ones with aphasia as, “a valuable resource within the rehabilitation process” (Brown et al., 2012, p.149). Specifically, participants in the current research spoke about how working with family members could provide a shortcut to understanding their clients' more unique communication style, as well as their interests and values, which in turn benefited the therapeutic relationship and process.

Interestingly, one participant cautioned against over-relying on family members, suggesting that the pressure it places on them can cause distress. This raises an important question around how families of people with aphasia can or should be utilised within the therapy process, as well as who the ‘client' is. As has been discussed, family members are usually navigating their own emotional challenges, and often require support alongside the person with aphasia. Previous research exploring MHPs perspectives does not address this question and there is no set guidance on how and when families should be involved in mental health interventions for people with aphasia. From their accounts, it seemed participants in the current research both provided support *to* and accessed support *from* family members in different circumstances, using their clinical judgment to determine what might be required in each situation.

As captured in the second theme, the MDT was generally viewed as a resource by the clinical psychologists, and they made frequent references to learning from SLTs in the context of working with clients with aphasia. They appreciated the expertise their SLT colleagues could offer around communication and discussed valuing opportunities for joint working. Whilst the participants in this study described positive experiences of joint working, as outlined previously, research exploring SLT's experiences of collaborative working has provided a mixed picture. Some have reported negative experiences, such as MHPs being reluctant to accept help and support from SLTs, or overestimating their abilities (Northcott et al., 2017, 2018a). Factors SLTs have reported contribute to effective support from MHPs include, "...joint working with SLTs; team ethos where interdisciplinary working was the norm; and experience, where the MHP was able to build up specialist skills in aphasia" (Northcott et al., 2018, p.24). Collaborative delivery of interventions from SLTs and MHPs, or skill-sharing to ensure effective delivery, is advocated by MHPs in the literature (Santo Pietro et al., 2019; Strong & Randolph, 2021).

Many of the ways of working discussed by participants in the fourth theme, *Moving Beyond Language – (Re)Connecting with What's Important*, are not unique to working with people with aphasia. For example, taking the time to get to know a patient or client, involving loved ones, and encouraging connection with values, as well as wider systems of support to promote recovery, will be familiar and important elements of many interventions used by clinical psychologists working across a range of settings. However, the participants' emphasis on these processes suggests they understand them to be key ingredients to providing effective psychological support to people with aphasia, for whom language - fundamentally human in nature and a powerful source of connection - is compromised. Importantly, several of the clinical psychologists discussed how developing the skills to work psychologically with people with aphasia had taken time, with some reflecting back on the anxiety they had felt when they were less experienced. Like the MHPs in Strong & Randolph's (2021) research, some participants commented that all their learning about how to work with people with aphasia had been 'on-the-job', and felt that more teaching or training would be useful.

4.2. Critical Evaluation

Defining 'quality' within qualitative research is widely debated (Yadav, 2021). Historically there has been a tendency to apply the same kinds of criteria used to appraise the quality of quantitative studies to qualitative research. However, it is argued that the positivist assumptions underpinning quality indicators, such as researcher objectivity or statistical generalisability make them unsuitable for evaluating qualitative studies (Braun & Clarke, 2022). As such, researchers have been warned against the uncritical application of quality appraisal tools or checklists, in favour of reflexive use of quality ‘markers’ or ‘principles’ with careful consideration of how these fit with the philosophical underpinnings and the methods used for the research in question (Yadav, 2021). I used questions provided by Spencer & Ritchie (2012) to help appraise and reflect on the quality of my research with respect to the following ‘guiding principles’: contribution, credibility, and rigour.

4.2.1. Contribution

This study offers unique insight into the experiences of clinical psychologists that support people with aphasia as part of an MDT, in the context of UK NHS services. The pragmatist stance of this research meant that I was concerned with creating ‘actionable knowledge’ from the outset (Kelly & Cordeiro, 2020). Whilst the aim of this study was not to assess good practice amongst participants, it was hoped that information gleaned from the findings could be useful to others working within services that support for people with aphasia experiencing emotional difficulties. This hope assumes a level of generalisability or ‘transferability’ of the findings from the study participants to clinical psychologists practising in the same or similar contexts.

Comparing the findings with existing literature helped to demonstrate where participants’ accounts correspond with previous research exploring topics such as: a) the emotional impact of aphasia as described by people with aphasia; b) what people with aphasia have said helps them live well/successfully; c) what people with aphasia value from services and health professionals; d) psychological interventions and therapies used with people with aphasia and their families, and; e) what other health professionals (namely SLTs) working with people with aphasia find helpful from clinical psychologists or other MHPs. As such, many of the findings can be argued to represent examples of ‘what works’ in practice, which may be helpful for professionals and services supporting people with aphasia to be aware of. The potential implications of this research are further explored in section 4.3.

4.2.2. Credibility

Credibility is characterised as the ‘believability’ or ‘plausibility’ of the findings, or through asking questions like, ‘how does the evidence support the findings?’ (Spencer & Ritchie, 2012). Discussion of the findings and their relationship with previous research and knowledge is one way of achieving a level of plausibility or believability. I have also attempted to provide a thorough account of my interpretative process and analysis, and have included relevant data extracts in the results section, which are appropriate ways to support the interpretive claims made by the researcher when employing reflexive TA. Whilst other forms of validation, such as theme frequency, triangulation, or ‘member checking’ could be used, these would be viewed as incoherent with a reflexive TA approach, as they undermine the subjectivity of the researcher, which is viewed as a valuable tool within qualitative research, as opposed to a “threat to credibility” (Braun & Clarke, 2021b, p.334).

However, I still hope that the findings ‘hold true’ for participants and feel relevant for other clinical psychologists who work with people with aphasia. Whilst not a ‘quality indicator’ for reflexive TA, sharing the preliminary findings with participants and getting their feedback would have been a way of checking the extent to which my interpretations captured the meanings they were trying to convey. A summary of the findings has since been shared with participants who provided their email address on the consent form, and it is hoped that they will feel able to share their thoughts and opinions with me, and perhaps share the summary on with colleagues. From a pragmatist standpoint, engagement with the findings in this way would provide a useful indication of the study’s credibility and contribution.

4.2.3. Rigour

Assessing rigour within qualitative research, including reflexive TA, involves considering how transparent and reflexive the researcher has been throughout the research process. This can be demonstrated through careful documentation of the research process, including how personal and epistemological ideas influenced decisions relating to the methodology and procedures.

Evidence of reflexivity, often discussed in terms of ‘epistemological’ and ‘personal’, is embedded throughout the sections. For instance, I discuss pragmatism and it’s fit with the research, including its relevance to my choice of analysis. Braun & Clarke critique the notion that, “...there is -always- one perfect analytic method/ology for across-case qualitative analysis...” (Braun & Clarke, 2021a, p.44) and suggest that choices around analytic method will be influenced by subjective ideas around which can be applied most usefully and effectively to address the research question. There are epistemological and procedural reasons for choosing reflexive TA over other qualitative approaches to analysis, previously outlined. However, this choice also reflects my interest in the method, the availability of thought-provoking literature relating to its theoretical development, and a subsequent motivation to apply it to my own analysis thoughtfully. This fits with a pragmatist framework and ideas around method and knowledge as influential to one another (Morgan, 2014).

My commitment to reflexivity is also evident through my discussion of how my own life experiences have shaped my interest in this topic and engagement with this research. I grew up with a parent who, when I was aged 9, had a brain haemorrhage and acquired aphasia. This has had known (and likely unknown) influences on my life, including on my choice of career. As I have gone through my doctoral training, I can recall aphasia being mentioned just a handful of times, namely in the context of neuropsychology teaching sessions. In one lecture we were shown videos of people with Broca’s and Wernicke’s aphasia, and these were discussed in relation to the locations of causal lesions in the brain. What felt missing in our adult neuropsychology teaching sessions were invitations or encouragement to consider the emotional or psychological consequences of brain injury. Nor were we provided any teaching on adapting our communication when working with individuals with communication difficulties resulting from brain injury. This lack of formal teaching, coupled with my personally rooted understanding of the complex psychological aspects of aphasia, left me wondering how clinical psychologists approach working with this population.

Keeping a reflexive journal has supported transparency, as well as my attempt to actively reflect on how my own assumptions or ‘biases’ may have (helpfully or unhelpfully) shaped decisions and interpretations throughout data collection and analysis (see Appendix N for an extract). Discussing developing themes with my research supervisor also aided reflexivity and helped me to notice when my own preconceived ideas were preventing me from staying ‘close’ to the data, leading to interpretations that felt less plausible.

4.2.4. Limitations

Despite applying for HRA approval to be able to approach potential participants via approved NHS organisations, as well as contacting a wide range of non-NHS organisations, issues with recruitment meant that I was not able to interview as many participants as I had initially hoped to. As has been discussed already, it is not philosophically coherent to assert that the relatively small ‘sample’ limits the contribution of the findings in terms of generalisability (Braun & Clarke, 2022). However, whilst the resultant dataset was felt to be ‘rich’ enough to meet the aims of the research, a larger group of participants may have enabled more nuanced understandings of similarities and differences in experiences and practice across the sample, allowing for broader inferences to be made. For example, there was just one participant who worked with people with progressive aphasia. This meant that although certain aspects of their narrative felt incredibly pertinent, they did not fit with the wider patterns of meaning I was constructing through the analysis, and I chose not to include these in the overall story.

One of the overall aims of the research is that the findings will be informative for services hoping to improve the support they offer to people with aphasia. It could be argued that seeking to hear from clinical psychologists first to support this aim positions them as experts or ‘knowers’ on the topic, and perhaps relegates the views and experiences of people with aphasia. Asking people with aphasia about their experiences of accessing support for emotional or psychological difficulties from specialist teams/clinical psychologists would undoubtedly yield useful information for services and professionals to be aware of and is discussed as a potential area for future research in the next section. However, people with aphasia are unlikely to be able to comment on how clinical psychologists operate within MDTs that support them, or how clinical psychologists make sense of and address emotional difficulties associated with aphasia, which were identified as gaps in the research and deemed to be important areas to explore.

4.3. Professional Implications and Future Research

The clinical psychologists in this study were experienced and worked in specialist settings, where they saw people with aphasia as part of their usual practice. This may help to explain why the findings depict psychological support available for people with aphasia more positively than some of the previous literature (Baker et al., 2018; Wray et al., 2020). Indeed, SLTs have cited lack of experience or awareness of aphasia amongst MHPs as a barrier for people with aphasia accessing appropriate psychological support (Northcott et al., 2017, 2018a). Whilst it is unsurprising that experience and confidence leads to better support, it is worth highlighting here because of the lack of formal teaching about aphasia clinical psychologists and other MHPs receive during training noted in the introduction. There is therefore an argument for introducing more teaching around adapting approaches for people with communication disabilities resulting from acquired brain injury or teaching around how to deliver interventions jointly (i.e., with SLTs) and when this may be indicated.

Previous research has suggested it would be helpful to understand more about, “how treatment is carried out” by MHPs working with people with aphasia, including what communication strategies and therapeutic approaches are used (Morrow-Odom & Barnes, 2019, p.19). Whilst participants in the current study discussed some general ways of working within their accounts of supporting people with aphasia as part of an MDT, they were not asked to specify psychological theories, models, or therapeutic approaches they use when doing this work. Clinical psychologists are trained to use different theories and models within different contexts and participants in this study emphasised individualised understandings of their clients’ responses to aphasia. However, given some of the research promoting approaches like behavioural activation or solution focused brief therapy (Northcott et al., 2021; Santo Pietro et al., 2019), it could still be useful to explore which particular tools they tend to draw on to help formulate and address psychological distress when working with people with aphasia.

Research focusing on what people with aphasia find helpful when receiving support from clinical psychologists or other MHPs would be informative for practitioners and organisations hoping to improve psychological services for people with aphasia. Whilst not an aim of the current research, participants' accounts suggested they held views and opinions about what constitutes 'good practice' when working as a clinical psychologist in an MDT with people with aphasia (e.g., when discussing joint working, working with families, working with frustration, taking time etc.). However, there is no official guidance on this topic to date. To this end, future research employing surveys or focus groups (perhaps sampling both professionals and service users with aphasia) could attempt to further explore or substantiate some of the ways of working outlined by clinical psychologists in this study. Data from such research could then be used to develop guidance or training materials for trainee and qualified clinical psychologists.

Evidence suggests there is still an issue with access to psychological support for people with neurological conditions more generally, who are not being seen by specialist services or need support later down the recovery journey (British Psychological Society, 2021). As such, equipping more clinical psychologists working in general mental health settings with basic skills to work with people with aphasia may help to improve access to psychological support for people with aphasia who would not have access to specialist services.

5. CONCLUSION

This study was the first to directly explore clinical psychologists' experiences of supporting people with aphasia as part of an MDT. The findings suggest that clinical psychologists employ an individualised approach to understanding psychological responses to aphasia, work with the person's interests and values, involve family members and colleagues, and view working with frustration as an important and necessary part of this work. They appear to view themselves as having an important role in supporting their MDT colleagues to understand and address emotional outcomes, doing so mainly through joint working, consultation, and promoting or encouraging psychological approaches and referrals. Finally, the clinical psychologists' descriptions of interdisciplinary working (in particular, joint work with SLTs), suggests they view it as key to providing effective support to people with aphasia.

The findings build on existing knowledge gleaned from people with aphasia, as well as other health professionals (namely SLTs), about what helps to support psychosocial and emotional wellbeing, as well as the limited literature regarding MHPs' experiences of supporting people with aphasia. The findings have important implications relating to the potential development of training and resources for clinical psychologists, as well as other MHPs, who support or may support with people with aphasia.

6. REFERENCES

Alzheimer's Research UK. (2018). *What is Primary Progressive Aphasia?* https://www.alzheimersresearchuk.org/wp-content/plugins/mof_bl_0.2.9/downloads/PPA-0421-0423_WEB.pdf

Anderson, S., & Whitfield, K. (2013). Social identity and stroke: "They don't make me feel like, there's something wrong with me." *Scandinavian Journal of Caring Sciences*, *27*(4), 820–830. https://doi.org/10.1111/j.1471-6712.2012.01086.x

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology: Theory and Practice*, *8*(1), 19–32. https://doi.org/10.1080/1364557032000119616

Ayerbe, L., Ayis, S., Crichton, S. L., Rudd, A. G., & Wolfe, C. D. A. (2014). Explanatory factors for the increased mortality of stroke patients with depression. *Neurology*, *83*(22), 2007–2012. https://doi.org/10.1212/WNL.0000000000001029

Baker, C., Rose, M. L., Ryan, B., & Worrall, L. (2021). Barriers and facilitators to implementing stepped psychological care for people with aphasia: Perspectives of stroke health professionals. *Topics in Stroke Rehabilitation*, *28*(8), 581–593. https://doi.org/10.1080/10749357.2020.1849952

Baker, C., Worrall, L., Rose, M., Hudson, K., Ryan, B., & O'Byrne, L. (2018). A systematic review of rehabilitation interventions to prevent and treat depression in post-stroke aphasia. *Disability and Rehabilitation*, *40*(16), 1870–1892. https://doi.org/10.1080/09638288.2017.1315181

Baker, C., Worrall, L., Rose, M., & Ryan, B. (2021). Stroke health professionals' management of depression after post-stroke aphasia: a qualitative study. *Disability and Rehabilitation*, *43*(2), 217–228.

https://doi.org/10.1080/09638288.2019.1621394

Barrows, P. D., Thomas, S. A., & Van Gordon, W. (2021). Assessing Self-Reported Mood in Aphasia Following Stroke: Challenges, Innovations and Future Directions. *Journal of Stroke and Cerebrovascular Diseases*, *30*(1), 105425. https://doi.org/10.1016/j.jstrokecerebrovasdis.2020.105425

Barry, S. S., & Douglas, J. M. (2000). The social integration of individuals with aphasia. *International Journal of Speech-Language Pathology*, *2*(2), 77–91. https://doi.org/10.3109/14417040008996793

BPS. (2014). *BPS Code of Human Research Ethics (2nd edition, 2014)*. https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy - Files/BPS Code of Human Research Ethics.pdf%0Ahttps://www.bps.org.uk/news-and-policy/bps-code-human-research-ethics-2nd-edition-2014

Brady, M. C., Kelly, H., Godwin, J., Enderby, P., & Campbell, P. (2016). Speech and language therapy for aphasia following stroke. *Cochrane Database of Systematic Reviews*, *6*. https://doi.org/10.1002/14651858.CD000425.pub4.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2019a). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Braun, V., & Clarke, V. (2019b). To Saturate or Not to Saturate? Questioning Data Saturation as a Useful Concept for Thematic Analysis and Sample-Size Rationales Useful Concept for Thematic Analysis and Sample-Size Rationales. *Qualitative Research in Sport, Exercise and Health 13*(2), 201-216. https://doi.org/10.1080/2159676X.2019.1704846.

Braun, V., & Clarke, V. (2021a). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, *21*(1), 37–47. https://doi.org/10.1002/capr.12360

Braun, V., & Clarke, V. (2021b). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, *18*(3), 328–352. https://doi.org/10.1080/14780887.2020.1769238

Braun, V., & Clarke, V. (2022). *Thematic Analysis: A Practical Guide*. Sage.

Bright, F. A. S., Kayes, N. M., McPherson, K. M., & Worrall, L. E. (2018). Engaging people experiencing communication disability in stroke rehabilitation: a qualitative study. *International Journal of Language and Communication Disorders*, *53*(5), 981–994. https://doi.org/10.1111/1460-6984.12409

British Psychological Society (2021). *Psychological interventions for people with Huntingdon's disease, Parkinson's disease, motor neurone disease, and multiple sclerosis*. 225–250.

Brown, K., Worrall, L., Davidson, B., & Howe, T. (2010). Snapshots of success: An insider perspective on living successfully with aphasia. *Aphasiology*, *24*(10), 1267–1295. https://doi.org/10.1080/02687031003755429

Brown, K., Worrall, L., Davidson, B., & Howe, T. (2011a). Exploring speech-language pathologists' perspectives about living successfully with aphasia. *International Journal of Language and Communication Disorders*, *46*(3), 300–311. https://doi.org/10.3109/13682822.2010.496762

Brown, K., Worrall, L., Davidson, B., & Howe, T. (2011b). Living successfully with aphasia: Family members share their views. *Topics in Stroke Rehabilitation*, *18*(5), 536–548. https://doi.org/10.1310/tsr1805-536

Brown, K., Worrall, L. E., Davidson, B., & Howe, T. (2012). Living successfully with aphasia: A qualitative meta-analysis of the perspectives of individuals with aphasia, family members, and speech-language pathologists. *International Journal of Speech-Language Pathology*, *14*(2), 141–155. https://doi.org/10.3109/17549507.2011.632026

Burns, M., Baylor, C., Dudgeon, B. J., Starks, H., & Yorkston, K. (2015). Asking the Stakeholders: Perspectives of Individuals With Aphasia, Their Family Members, and Physicians Regarding Communication in Medical Interactions. *American Journal of Speech-Language Pathology*, *24*(2), 341–357. https://doi.org/10.1044/2015

Carragher, M., Steel, G., O'Halloran, R., Torabi, T., Johnson, H., Taylor, N. F., & Rose, M. (2021). Aphasia disrupts usual care: the stroke team's perceptions of delivering healthcare to patients with aphasia. *Disability and Rehabilitation*, *43*(21), 3003–3014. https://doi.org/10.1080/09638288.2020.1722264

Chapey, R., Duchan, J. F., Elman, R. J., Garcia, L. J., Kagan, A., Lyon, J. G., & Simmons-Mackie, N. S. (2000). Life Participation Approach to Aphasia: A Statement of Values for the Future. *The ASHA Leader*, *5*, 4–6. https://doi.org/10.1044/leader.ftr.05032000.4

Clarke, D. J. (2013). The role of multidisciplinary team care in stroke rehabilitation. *Progress in Neurology and Psychiatry*, *17*(4), 5–8. https://doi.org/10.1002/pnp.288

Code, C. (2020). The implications of public awareness and knowledge of aphasia around the world. *Annals of Indian Academy of Neurology*, *23*(8), S95–S101. https://doi.org/10.4103/aian.AIAN_460_20

Cornish, F., & Gillespie, A. (2009). A pragmatist approach to the problem of knowledge in health psychology. *Journal of Health Psychology*, *14*(6), 800–809. https://doi.org/10.1177/1359105309338974

Cruice, M., Worrall, L., & Hickson, L. (2006). Quantifying aphasic people's social lives in the context of non-aphasic peers. *Aphasiology*, *20*(12), 1210–1225. https://doi.org/10.1080/02687030600790136

Cruice, M., Worrall, L., & Hickson, L. (2010). Health-related quality of life in people with aphasia: Implications for fluency disorders quality of life research. *Journal of Fluency Disorders*, *35*(3), 173–189. https://doi.org/10.1016/j.jfludis.2010.05.008

Dalemans, R. J. P., De Witte, L., Wade, D., & Van Den Heuvel, W. (2010). Social participation through the eyes of people with aphasia. *International Journal of Language and Communication Disorders*, *45*(5), 537–550. https://doi.org/10.3109/13682820903223633

Dalemans, R., Wade, D. T., van den Heuvel, W. J. A., & de Witte, P. L. (2009). Facilitating the participation of people with aphasia in research: A description of strategies. *Clinical Rehabilitation*, *23*(10), 948–959. https://doi.org/10.1177/0269215509337197

Department of Health National Audit Office. (2010). Progress in improving stroke care. *London: The Stationary Office*, *February*, 13. http://www.nao.org.uk/wp-content/uploads/2010/02/0910291.pdf

Dickey, L., Kagan, A., Lindsay, M. P., Fang, J., Rowland, A., & Black, S. (2010). Incidence and Profile of Inpatient Stroke-Induced Aphasia in Ontario, Canada. *Archives of Physical Medicine and Rehabilitation*, *91*(2), 196–202. https://doi.org/10.1016/j.apmr.2009.09.020

Dietz, A., Thiessen, A., Griffith, J., Peterson, A., Sawyer, E., & McKelvey, M. (2013). The renegotiation of social roles in chronic aphasia: Finding a voice through AAC. *Aphasiology*, *27*(3), 309–325. https://doi.org/10.1080/02687038.2012.725241

Donkor, E. S. (2018). Stroke in the 21 st Century: A Snapshot of the Burden, Epidemiology, and Quality of Life. *Stroke Research and Treatment*, *2018*. https://doi.org/10.1155/2018/3238165

Douglas, J. T. (2022). My experience of living with nonfluent/agrammatic variant primary progressive aphasia: Challenges, compensatory strategies and adaptations. *International Journal of Language and Communication Disorders*, *Oct 14*, 1–13. https://doi.org/10.1111/1460-6984.12798

Douiri, A., Rudd, A. G., & Wolfe, C. D. A. (2013). Prevalence of poststroke cognitive impairment: South London stroke register 1995-2010. *Stroke*, *44*(1), 138–145. https://doi.org/10.1161/STROKEAHA.112.670844

Ellis-Hill, C. S., Payne, S., & Ward, C. (2000). Self-body split: Issues of identity in physical recovery following a stroke. *Disability and Rehabilitation*, *22*(16), 725–733. https://doi.org/10.1080/09638280050191990

Ferrari, R. (2015). Writing narrative style literature reviews. *Medical Writing*, *24*(4), 230–235. https://doi.org/10.1179/2047480615z.000000000329

Fotiadou, D., Northcott, S., Chatzidaki, A., & Hilari, K. (2014). Aphasia blog talk: How does stroke and aphasia affect a person’s social relationships? *Aphasiology*, *28*(11), 1281–1300. https://doi.org/10.1080/02687038.2014.928664

Gillham, S., & Clark, L. (2011). Psychological care after stroke: Improving stroke services for people with cognitive and mood disorders. *NHS Improvement 0 Stroke*. https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Psychological-Care-after-Stroke.pdf

Gorno-Tempini, M. L., Hillis, A. E., Weintraub, S., Kertesz, A., Mendez, M., Cappa, S. F., Ogar, J. M., Rohrer, J. D., Black, S., Boeve, B. F., Manes, F., Dronkers, N. F., Vandenberghe, R., Rascovsky, K., Patterson, K., Miller, B. L., Knopman, D. S., Hodges, J. R., Mesulam, M. M., & Grossman, M. (2011). Classification of primary progressive aphasia and its variants. *Neurology*, *76*(11), 1006–1014. https://doi.org/10.1212/WNL.0b013e31821103e6

Gracey, F., Evans, J. J., & Malley, D. (2009). Capturing process and outcome in complex rehabilitation interventions: A “Y-shaped” model. *Neuropsychological Rehabilitation*, *19*(6), 867–890. https://doi.org/10.1080/09602010903027763

Gracey, F., Palmer, S., Rous, B., Psaila, K., Shaw, K., O’Dell, J., Cope, J., & Mohamed, S. (2008). “Feeling part of things”: Personal construction of self after brain injury. *Neuropsychological Rehabilitation*, *18*(5–6), 627–650. https://doi.org/10.1080/09602010802041238

Grohn, B., Worrall, L. E., Simmons-Mackie, N., & Brown, K. (2012). The first 3-months post-stroke: What facilitates successfully living with aphasia? *International Journal of Speech-Language Pathology*, *14*(4), 390–400. https://doi.org/10.3109/17549507.2012.692813

Guise, J., McKinlay, A., & Widdicombe, S. (2010). The impact of early stroke on identity: A discourse analytic study. In *Health* (Vol. 14, Issue 1). https://doi.org/10.1177/1363459309347483

Hackett, M. L., Yapa, C., Parag, V., & Anderson, C. S. (2005). Frequency of depression after stroke: A systematic review of observational studies. *Stroke*, *36*(6), 1330–1340. https://doi.org/10.1161/01.STR.0000165928.19135.35

Harris, H. (2017, July 3). My crash course in aphasia, the debilitating loss of the ability to talk. *The Guardian. https://www.theguardian.com/lifeandstyle/2017/jul/03/my-crash-course-in-aphasia-the-debilitating-loss-of-the-ability-to-talk*

Haslam, C., Holme, A., Haslam, S. A., Iyer, A., Jetten, J., & Williams, W. H. (2008). Maintaining group memberships: Social identity continuity predicts well-being after stroke. *Neuropsychological Rehabilitation*, *18*(5–6), 671–691. https://doi.org/10.1080/09602010701643449

Higgins, E. T. (1987). Self-Discrepancy: A Theory Relating Self and Affect.

Psychological Review, *94*(3), 319–340. https://doi.org/10.1037/0033-295X.94.3.319

Hilari, K. (2011). The impact of stroke: Are people with aphasia different to those without? *Disability and Rehabilitation*, *33*(3), 211–218. https://doi.org/10.3109/09638288.2010.508829

Hilari, K., Klippi, A., Constantinidou, F., Horton, S., Penn, C., Raymer, A., Wallace, S., Zemva, N., & Worrall, L. (2015). An International Perspective on Quality of Life in Aphasia: A Survey of Clinician Views and Practices from Sixteen Countries. *Folia Phoniatrica et Logopaedica*, *67*(3), 119–130. https://doi.org/10.1159/000434748

Hilari, K., Needle, J. J., & Harrison, K. L. (2012). What are the important factors in health-related quality of life for people with aphasia? A systematic review. *Archives of Physical Medicine and Rehabilitation*, *93*(1 SUPPL.), S86-S95.e4. https://doi.org/10.1016/j.apmr.2011.05.028

Hilari, K., & Northcott, S. (2006). Social support in people with chronic aphasia. *Aphasiology*, *20*(1), 17–36. https://doi.org/10.1080/02687030500279982

Hilari, K., Northcott, S., Roy, P., Marshall, J., Wiggins, R. D., Chataway, J., & Ames, D. (2010). Psychological distress after stroke and aphasia: The first six months. *Clinical Rehabilitation*, *24*(2), 181–190. https://doi.org/10.1177/0269215509346090

Hilton, R., Leenhouts, S., Webster, J., & Morris, J. (2014). Information, support and training needs of relatives of people with aphasia: Evidence from the literature. *Aphasiology*, *28*(7), 797–822. https://doi.org/10.1080/02687038.2014.906562

Hinckley, J. J. (2002). Vocational and social outcomes of adults with chronic aphasia. *Journal of Communication Disorders*, *35*(6), 543–560. https://doi.org/10.1016/S0021-9924(02)00119-3

Intercollegiate Stroke Working Party. (2016). National clinical guideline for stroke. In *Royal College of Physicians* (Issue 5). https://doi.org/10.7861/clinmedicine.17-5-478

Johansson, M. B., Carlsson, M., & Sonnander, K. (2012). Communication difficulties and the use of communication strategies: From the perspective of individuals with aphasia. *International Journal of Language and Communication Disorders*, *47*(2), 144–155. https://doi.org/10.1111/j.1460-6984.2011.00089.x

Johnson, R., & Onwuegbuzie, A. (2004). Mixed Methods Research: A Research Paradigm Whose Time Has Come. *Educational Researcher*, *33*(7), 14–26. http://edr.sagepub.com/content/33/7/14.short

Kauranen, T., Turunen, K., Laari, S., Mustanoja, S., Baumann, P., & Poutiainen, E. (2013). The severity of cognitive deficits predicts return to work after a first-ever ischaemic stroke. *Journal of Neurology, Neurosurgery and Psychiatry*, *84*(3), 316–321. https://doi.org/10.1136/jnnp-2012-302629

Kaushik, V., & Walsh, C. A. (2019). Pragmatism as a research paradigm and its implications for Social Work research. *Social Sciences*, *8*(9). https://doi.org/10.3390/socsci8090255

Kelly, L. M., & Cordeiro, M. (2020). Three principles of pragmatism for research on organizational processes. *Methodological Innovations*, *13*(2). https://doi.org/10.1177/2059799120937242

Kindell, J., Sage, K., & Cruice, M. (2015). Supporting communication in semantic dementia: clinical consensus from expert practitioners. *Quality in Ageing and Older Adults*, *16*(3), 153–164. https://doi.org/10.1108/QAOA-08-2014-0016

Kneebone, I. I. (2016). Stepped psychological care after stroke. *Disability and Rehabilitation*, *38*(18), 1836–1843. https://doi.org/10.3109/09638288.2015.1107764

Kuluski, K., Dow, C., Locock, L., Lyons, R. F., & Lasserson, D. (2014). Life interrupted and life regained? Coping with stroke at a young age. *International Journal of Qualitative Studies on Health and Well-Being*, *9*(1), 1–13. https://doi.org/10.3402/qhw.v9.22252

Lanyon, L., Worrall, L., & Rose, M. (2018a). Combating social isolation for people with severe chronic aphasia through community aphasia groups: consumer views on getting it right and wrong. *Aphasiology*, *32*(5), 493–517. https://doi.org/10.1080/02687038.2018.1431830

Lanyon, L., Worrall, L., & Rose, M. (2018b). What really matters to people with aphasia when it comes to group work? A qualitative investigation of factors impacting participation and integration. *International Journal of Language and Communication Disorders*, *53*(3), 526–541. https://doi.org/10.1111/1460-6984.12366

Lapadatu, I., & Morris, R. (2019). The relationship between stroke survivors' perceived identity and mood, self-esteem and quality of life. *Neuropsychological Rehabilitation*, *29*(2), 199–213. https://doi.org/10.1080/09602011.2016.1272468

Laska, K. M., Gurman, A. S., & Wampold, B. E. (2014). Expanding the lens of evidence-based practice in psychotherapy: A common factors perspective. *Psychotherapy*, *51*(4), 467–481. https://doi.org/10.1037/a0034332

Laures-Gore, J. S., Dotson, V. M., & Belagaje, S. (2020). Depression in poststroke aphasia. *American Journal of Speech-Language Pathology*, *29*(4), 1798–1810. https://doi.org/10.1044/2020_AJSLP-20-00040

Lawton, M., Haddock, G., Conroy, P., Serrant, L., & Sage, K. (2020). People with aphasia's perspectives of the therapeutic alliance during speech-language intervention: A Q methodological approach. *International Journal of Speech-Language Pathology*, *22*(1), 59–69. https://doi.org/10.1080/17549507.2019.1585949

Lawton, M., Sage, K., Haddock, G., Conroy, P., & Serrant, L. (2018). Speech and language therapists' perspectives of therapeutic alliance construction and maintenance in aphasia rehabilitation post-stroke. *International Journal of Language and Communication Disorders*, *53*(3), 550–563. https://doi.org/10.1111/1460-6984.12368

Li, L. J., Yao, X. M., Guan, B. Y., Chen, Q., Zhang, N., & Wang, C. X. (2019). Persistent depression is a predictor of quality of life in stroke survivors: Results from a 5-year follow-up study of a Chinese cohort. *Chinese Medical Journal*, *132*(18), 2206–2212. https://doi.org/10.1097/CM9.0000000000000400

Liechty, J. A., & Buchholz, J. (2006). The Sounds of Silence: Relating to People with Aphasia. *Journal of Psychosocial Nursing*, *44*(8), 53–55.

Mackenzie, C., Bennett, A., & Cairney, M. (2011). Active citizenship and acquired neurological communication difficulty. *Disability and Rehabilitation*, *33*(3), 187–194.

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qualitative Health Research*, *26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

Manning, M., Cuskelly, C., Russ, E., & Franklin, S. (2020). Supporting people with post-stroke aphasia to live well: A cross-sectional survey of Speech & Language Therapists in Ireland. *Health and Social Care in the Community*, *28*(6), 2105–2116. https://doi.org/10.1111/hsc.13021

Manning, M., Hickey, A., MacFarlane, A., & Franklin, S. (2017). Perspectives of people with aphasia post-stroke towards recovery & living successfully. A systematic review and qualitative evidence synthesis. *International Journal of Integrated Care*, *17*(5), 586. https://doi.org/10.5334/ijic.3906

Manning, M., MacFarlane, A., Hickey, A., Galvin, R., & Franklin, S. (2020). The relevance of stroke care for living well with post-stroke aphasia: a qualitative interview study with working-aged adults. *Disability and Rehabilitation*. https://doi.org/10.1080/09638288.2020.1863483

Manning, M., MacFarlane, A., Hickey, A., Galvin, R., & Franklin, S. (2021). 'I hated being ghosted' – The relevance of social participation for living well with post-stroke aphasia: Qualitative interviews with working aged adults. *Health Expectations*, *24*(4), 1504–1515. https://doi.org/10.1111/hex.13291

McKillop, A. (2012, September 21). Experience: I lost the power of language. *The Guardian*. https://www.theguardian.com/lifeandstyle/2012/sep/21/lost-power-language-aphasia-experience

Mitchell, A. J., Sheth, B., Gill, J., Yadegarfar, M., Stubbs, B., Yadegarfar, M., & Meader, N. (2017). Prevalence and predictors of post-stroke mood disorders: A meta-analysis and meta-regression of depression, anxiety and adjustment disorder. *General Hospital Psychiatry*, *47*, 48–60. https://doi.org/10.1016/j.genhosppsych.2017.04.001

Mitchell, C., Gittins, M., Tyson, S., Vail, A., Conroy, P., Paley, L., & Bowen, A. (2021). Prevalence of aphasia and dysarthria among inpatient stroke survivors: describing the population, therapy provision and outcomes on discharge. *Aphasiology*, *35*(7), 950–960. https://doi.org/10.1080/02687038.2020.1759772

Morgan, D. L. (2014). Pragmatism as a Paradigm for Social Research. *Qualitative Inquiry*, *20*(8), 1045–1053. https://doi.org/10.1177/1077800413513733

Morrow-Odom, K. L., & Barnes, C. K. (2019). Mental health professionals' experiences with Aphasia. *Journal of Rehabilitation*, *85*(1), 15–21.

Moss, B., Northcott, S., Behn, N., Monnelly, K., Marshall, J., Thomas, S., Simpson, A., Goldsmith, K., McVicker, S., Flood, C., & Hilari, K. (2021).

‘Emotion is of the essence. … Number one priority’: A nested qualitative study exploring psychosocial adjustment to stroke and aphasia. *International Journal of Language and Communication Disorders*, *56*(3), 594–608. https://doi.org/10.1111/1460-6984.12616

National Institute of Deafness and Other Communication Disorders (2017). *Aphasia*. https://www.nidcd.nih.gov/health/aphasia

National Institute of Neurological Disorders and Stroke (NINDS), & National Institutes of Health. (2009). *Stroke: Challenges, Progress, and Promise* (Issues 09–6451).

NICE. (2019). Recommendations | Stroke and transient ischaemic attack in over 16s: diagnosis and initial management | Guidance | NICE. *National Institute of Clinical Excellence*, *NG128*(May), 1–3.

Niemi, T., & Johansson, U. (2013). The lived experience of engaging in everyday occupations in persons with mild to moderate aphasia. *Disability and Rehabilitation*, *35*(21), 1828–1834. https://doi.org/10.3109/09638288.2012.759628

Nilsson, I., Jansson, L., & Norberg, A. (1997). To meet with a stroke: Patients’ experiences and aspects seen through a screen of crises. *Journal of Advanced Nursing*, *25*(5), 953–963. https://doi.org/10.1046/j.1365-2648.1997.1997025953.x

Nochi, M. (1998). “Loss of self” in the narratives of people with traumatic brain injuries: A qualitative analysis. *Social Science and Medicine*, *46*(7), 869–878. https://doi.org/10.1016/S0277-9536(97)00211-6

Northcott, S., & Hilari, K. (2011). Why do people lose their friends after a stroke? *International Journal of Language and Communication Disorders*, *46*(5), 524–534. https://doi.org/10.1111/j.1460-6984.2011.00079.x

Northcott, S., Moss, B., Harrison, K., & Hilari, K. (2016). A systematic review of the impact of stroke on social support and social networks: Associated factors and patterns of change. *Clinical Rehabilitation*, *30*(8), 811–831. https://doi.org/10.1177/0269215515602136

Northcott, S., Simpson, A., Moss, B., Ahmed, N., & Hilari, K. (2017). How do speech-and-language therapists address the psychosocial well-being of people with aphasia? Results of a UK online survey. *International Journal of Language and Communication Disorders*, *52*(3), 356–373. https://doi.org/10.1111/1460-6984.12278

Northcott, S., Simpson, A., Moss, B., Ahmed, N., & Hilari, K. (2018). Supporting people with aphasia to ‘settle into a new way to be’: speech and language therapists’ views on providing psychosocial support. *International Journal of Language and Communication Disorders*, *53*(1), 16–29. https://doi.org/10.1111/1460-6984.12323

Northcott, S., Simpson, A., Thomas, S., Barnard, R., Burns, K., Hirani, S. P., & Hilari, K. (2021). “Now I Am Myself”: Exploring How People With Poststroke Aphasia Experienced Solution-Focused Brief Therapy Within the SOFIA Trial. *Qualitative Health Research*, *31*(11), 2041–2055. https://doi.org/10.1177/10497323211020290

Northcott, S., Thomas, S., James, K., Simpson, A., Hirani, S., Barnard, R., & Hilari, K. (2021). Solution Focused Brief Therapy in Post-Stroke Aphasia (SOFIA): feasibility and acceptability results of a feasibility randomised wait-list controlled trial. *BMJ Open*, *11*(8), e050308. https://doi.org/10.1136/bmjopen-2021-050308

Pallesen, H. (2014). Body, coping and self-identity. A qualitative 5-year follow-up study of stroke. *Disability and Rehabilitation*, *36*(3), 232–241. https://doi.org/10.3109/09638288.2013.788217

Paolucci, S., Iosa, M., Coiro, P., Venturiero, V., Savo, A., De Angelis, D., & Morone, G. (2019). Post-stroke depression increases disability more than 15% in ischemic stroke survivors: A case-control study. *Frontiers in*

Neurology, *10*(AUG), 1–9. https://doi.org/10.3389/fneur.2019.00926

Park, Y. H., Jang, J. W., Park, S. Y., Wang, M. J., Lim, J. S., Baek, M. J., Kim, B. J., Han, M. K., Bae, H. J., Ahn, S., & Kim, S. (2015). Executive function as a strong predictor of recovery from disability in patients with acute stroke: A preliminary study. *Journal of Stroke and Cerebrovascular Diseases*, *24*(3), 554–561. https://doi.org/10.1016/j.jstrokecerebrovasdis.2014.09.033

Parr, S., Byng, S., & Gilpin, S. (1997). *Talking about aphasia*. Open University Press.

Patel, M. D., Coshall, C., Rudd, A. G., & Wolfe, C. D. A. (2002). Cognitive impairment after stroke: Clinical determinants and its associations with long-term stroke outcomes. *Journal of the American Geriatrics Society*, *50*(4), 700–706. https://doi.org/10.1046/j.1532-5415.2002.50165.x

Pedersen, P. M., Jørgensen, H. S., Nakayama, H., Raaschou, H. O., & Olsen, T. S. (1995). Aphasia in acute stroke: Incidence, determinants, and recovery. *Annals of Neurology*, *38*(4), 659–666. https://doi.org/10.1002/ana.410380416

Pettigrove, K., Lanyon, L. E., Attard, M. C., Vuong, G., & Rose, M. L. (2021). Characteristics and impacts of community aphasia group facilitation: a systematic scoping review. *Disability and Rehabilitation*, *0*(0), 1–15. https://doi.org/10.1080/09638288.2021.1971307

Pompon, R. H. (2021). Basic Counseling Skills: Working With People With Aphasia and Their Families. *Perspectives of the ASHA Special Interest Groups*, *6*(5), 1003–1014. https://doi.org/10.1044/2021_persp-20-00298

Rorty, R. (1999). Philosophy and Social Hope. In *Penguin*. https://doi.org/10.5860/choice.37-5043

Rose, M., Ferguson, A., Power, E., Togher, L., & Worrall, L. (2014). Aphasia rehabilitation in Australia: Current practices, challenges and future directions. I*nternational journal of speech-language pathology*, 16(2), 169–180. https://doi.org/10.3109/17549507.2013.794474

Ruggero, L., Nickels, L., & Croot, K. (2019). Quality of life in primary progressive aphasia : What do we know and what can we do next ? *Aphasiology*, *33*(5), 498–519. https://doi.org/https://doi.org/10.1080/02687038.2019.1568135

Ryan, B., Bohan, J., & Kneebone, I. (2019). Help-seeking and people with aphasia who have mood problems after stroke: perspectives of speech–language pathologists. *International Journal of Language and Communication Disorders*, *54*(5), 779–793. https://doi.org/10.1111/1460-6984.12476

Sabatello, M. (2013). A Short History of the International Disability Rights Movement. *Human Rights and Disability Advocacy*, *January 2013*, 13–24.

Sandberg, C. W., Nadermann, K., Parker, L., Kubat, A. M., & Conyers, L. M. (2021). Counseling in aphasia: Information and strategies for speech-language pathologists. *American Journal of Speech-Language Pathology*, *30*(6), 2337–2349. https://doi.org/10.1044/2021_AJSLP-20-00312

Sandelowski, M. (1995). *Sample size in qualitative research*. Research in Nursing & Health, 18(2), 179–183. https://doi.org/10.1002/nur.4770180211

Saner, E. (2022, July 4). A new start after 60: 'I lost my ability to speak - and became a film-maker'. *The Guardian. https://www.theguardian.com/lifeandstyle/2022/jul/04/a-new-start-after-60-i-lost-my-ability-to-speak-and-became-a-film-maker*

Santo Pietro, M. J., Marks, D. R., & Mullen, A. (2019). When Words Fail: Providing Effective Psychological Treatment for Depression in Persons with Aphasia. *Journal of Clinical Psychology in Medical Settings*, *26*(4), 483–494. https://doi.org/10.1007/s10880-019-09608-4

Schaffer, K. M., Evans, W. S., Dutcher, C. D., Philburn, C., & Henry, M. L. (2021). Embedding Aphasia-Modified Cognitive Behavioral Therapy in Scrip Training for Primary Progressive Aphasia: A Single-Case Pilot Study. *American Journal of Speech-Language Pathology*, *30*(September).

Sekhon, J. K., Douglas, J., & Rose, M. L. (2015). Current Australian speech-language pathology practice in addressing psychological well-being in people with aphasia after stroke. *International Journal of Speech-Language Pathology*, *17*(3), 252–262. https://doi.org/10.3109/17549507.2015.1024170

Sekhon, J. K., Oates, J., Kneebone, I., & Rose, M. (2019). Counselling training for speech–language therapists working with people affected by post-stroke aphasia: a systematic review. *International Journal of Language and Communication Disorders*, *54*(3), 321–346. https://doi.org/10.1111/1460-6984.12455

Shadden, B. (2005). Aphasia as identity theft: Theory and practice. *Aphasiology, 19*(3-5): 211-223. https://doi.org/10.1080/02687930444000697

Shadden, B. B., & Agan, J. P. (2004). Renegotiation of identity: The social context of aphasia support groups. *Topics in Language Disorders*, *24*(3), 174–186. https://doi.org/10.1097/00011363-200407000-00005

Sharpe, L., & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Science and Medicine*, *62*(5), 1153–1166. https://doi.org/10.1016/j.socscimed.2005.07.010

Simblett, S. K., Gracey, F., Ring, H., & Bateman, A. (2015). Measuring coping style following acquired brain injury: A modification of the Coping Inventory for Stressful Situations Using Rasch analysis. *British Journal of Clinical Psychology*, *54*(3), 249–265. https://doi.org/10.1111/bjc.12070

Simmons-Mackie, N., & Damico, J. S. (2011). Counseling and aphasia treatment: Missed opportunities. *Topics in Language Disorders*, *31*(4), 336–351. https://doi.org/10.1097/TLD.0b013e318234ea9f

Simmons-mackie, N., Kagan, A., Victor, J. C., Carling-rowland, A., Mok, A., Hoch, J. S., Huijbregts, M., & Streiner, D. L. (2014). *The assessment for living with aphasia: Reliability and construct validity*. *16*(1). https://doi.org/10.3109/17549507.2013.831484

Simmons-Mackie, N., Raymer, A., Armstrong, E., Holland, A., & Cherney, L. R. (2010). Communication partner training in Aphasia: A systematic review. *Archives of Physical Medicine and Rehabilitation*, *91*(12), 1814–1837. https://doi.org/10.1016/j.apmr.2010.08.026

Simmons-Mackie, N., Raymer, A., & Cherney, L. R. (2016). Communication Partner Training in Aphasia: An Updated Systematic Review. *Archives of Physical Medicine and Rehabilitation*, *97*(12), 2202-2221.e8. https://doi.org/10.1016/j.apmr.2016.03.023

Simmons-Mackie, N., Savage, M. C., & Worrall, L. (2014). Conversation therapy for aphasia: A qualitative review of the literature. *International Journal of Language and Communication Disorders*, *49*(5), 511–526. https://doi.org/10.1111/1460-6984.12097

Sjöqvist Nätterlund, B. (2010). A new life with aphasia: Everyday activities and social support. *Scandinavian Journal of Occupational Therapy*, *17*(2), 117–129. https://doi.org/10.3109/11038120902814416

Spencer, L., & Ritchie, J. (2012). In Pursuit of Quality. In D. Harper, & A. R. Thompson (Eds.), Q*ualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners* (pp. 227-242). Wiley-Blackwell.

Strong, K. A., & Randolph, J. (2021). How Do You Do Talk Therapy With Someone Who Can’t Talk? Perspectives From Mental Health Providers on

Delivering Services to Individuals With Aphasia. *American Journal of Speech-Language Pathology*, *30*, 2681–2693. https://doi.org/10.52015/numljci.v19i1.102

Tajfel, H., & Turner, J. (1979). An integrative theory of inter-group conflict. In W. Austin & S. Worchel (Eds.), *The Social Psychology of Inter-group Relations* (pp. 33–37). Brooks/Cole.

Tatemichi, T. K., Desmond, D. W., Stern, Y., Paik, M., Sano, M., & Bagiella, E. (1994). Cognitive impairment after stroke: Frequency, patterns, and relationship to functional abilities. *Journal of Neurology Neurosurgery and Psychiatry*, *57*(2), 202–207. https://doi.org/10.1136/jnnp.57.2.202

Taubner, H., Hallén, M., & Wengelin, Å. (2020). Still the same?–Self-identity dilemmas when living with post-stroke aphasia in a digitalised society. *Aphasiology*, *34*(3), 300–318. https://doi.org/10.1080/02687038.2019.1594151

The British Psychological Society. (2010). *Psychological Services for Stroke Survivors and their Families – Briefing Paper 19*. Division of Neuropsychology. https://doi.org/10.53841/bpsrep.2010.rep87

The British Psychological Society. (2019a). *Standards for the accreditation of Doctoral programmes in clinical psychology*. *January*. www.bps.org.uk/partnershipwww.bps.org.uk/partnership

The British Psychological Society. (2019b). *Standards for the accreditation of programmes in adult clinical neuropsychology*. *January*, 1–44. www.bps.org.uk/partnershipwww.bps.org.uk/partnership

van Ewijk, L., Bootsma, T. M. C., van Rijssen, M., & ter Wal, N. (2021). Speech language therapists' experiences with subjective well-being in people with aphasia. *International Journal of Language and Communication Disorders*, *56*(3), 473–484. https://doi.org/10.1111/1460-6984.12596 van Rijssen, M. N., Veldkamp, M., Bryon, E., Remijn, L., Visser-Meily, J. M. A., Gerrits, E., & van Ewijk, L. (2021). How do healthcare professionals experience communication with people with aphasia and what content should communication partner training entail? *Disability and Rehabilitation*, *44*(14), 3671–3678. https://doi.org/10.1080/09638288.2021.1878561

Vasileiou, K., Barnett, J., Thorpe, S., & Young, T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology*, *18*(1), 1–18.

Virani, S. S., Alonso, A., Aparicio, H. J., Benjamin, E. J., Bittencourt, M., Callaway, C. W., Carson, A. P., Chamberlain, A., Cheng, S., Delling, F. N., Elkind, M. S. V, Evenson, K. R., Ferguson, J. F., Gupta, D. K., Khan, S. S., Kissela, B. M., Knutson, K. L., Lee, C. D., Lewis, T. T., … Tsao, C. W. (2021). Heart Disease and Stroke Statistics - 2021 Update. A Report from the American Heart Association. *Circulation*, *143*, E254–E743. https://doi.org/10.1161/CIR.0000000000000950

Volkmer, A., Cartwright, J., Ruggero, L., Beales, A., Gallée, J., Grasso, S., Henry, M., Jokel, R., Kindell, J., Khayum, R., Pozzebon, M., Rochon, E., Taylor-Rubin, C., Townsend, R., Walker, F., Beeke, S., & Hersh, D. (2022). Principles and philosophies for speech and language therapists working with people with primary progressive aphasia: an international expert consensus. *Disability and Rehabilitation*, *0*(0), 1–16. https://doi.org/10.1080/09638288.2022.2051080

Volkmer, A., Spector, A., Meitanis, V., Warren, J. D., & Beeke, S. (2020). Effects of functional communication interventions for people with primary progressive aphasia and their caregivers: a systematic review. *Aging and Mental Health*, *24*(9), 1381–1393. https://doi.org/10.1080/13607863.2019.1617246

Volkmer, A., Spector, A., Warren, J. D., & Beeke, S. (2020). Speech and language therapy for primary progressive aphasia: Referral patterns and barriers to service provision across the UK. *Dementia*, *19*(5), 1349–1363. https://doi.org/10.1177/1471301218797240

Wade, D. T., Hewer, R. L., David, R. M., & Enderby, P. (1986). Aphasia after stroke: Natural history and associated deficits. *Journal of Neurology Neurosurgery and Psychiatry*, *49*(1), 11–16. https://doi.org/10.1136/jnnp.49.1.11

Wampold, B. E. (2016). How important are the common factors in psychotherapy? An update. *World Psychiatry*, *14*(3), 270–277. https://www.div12.org/psychological-treatments/treatments/

WHO. (2001). International Classification of Functioning, Disability and Health: ICF. *World Health Organisation*. https://apps.who.int/iris/bitstream/handle/10665/42407/9241545429.pdf

Willig, C. (2021). *Introducing Qualitative Research in Psychology* (4th ed). McGraw-Hill Education.

Worrall, L. (2019). The seven habits of highly effective aphasia therapists: The perspective of people living with aphasia. *International Journal of Speech-Language Pathology*, *21*(5), 438–447. https://doi.org/10.1080/17549507.2019.1660804

Worrall, L., Hudson, K., Khan, A., Ryan, B., & Simmons-Mackie, N. (2017). Determinants of Living Well With Aphasia in the First Year Poststroke: A Prospective Cohort Study. *Archives of Physical Medicine and Rehabilitation*, *98*(2), 235–240. https://doi.org/10.1016/j.apmr.2016.06.020

Worrall, L., Sherratt, S., Rogers, P., Howe, T., Hersh, D., Ferguson, A., & Davidson, B. (2011). What people with aphasia want: Their goals according to the ICF. *Aphasiology*, *25*(3), 309–322. https://doi.org/10.1080/02687038.2010.508530

Worrall, L., Simmons-Mackie, N., Wallace, S. J., Rose, T., Brady, M. C., Kong,

A. P. H., Murray, L., & Hallowell, B. (2016). Let’s call it “aphasia”: Rationales for eliminating the term “dysphasia.” *International Journal of Stroke*, *11*(8), 848–851. https://doi.org/10.1177/1747493016654487

Wray, F., & Clarke, D. (2017). Longer-term needs of stroke survivors with communication difficulties living in the community: A systematic review and thematic synthesis of qualitative studies. *BMJ Open*, *7*(10), 1–18. https://doi.org/10.1136/bmjopen-2017-017944

Wray, F., Clarke, D., & Forster, A. (2020). “Guiding them to take responsibility”: exploring UK speech and language therapists’ views of supporting self-management of aphasia. In *Aphasiology* (Vol. 34, Issue 4). https://doi.org/10.1080/02687038.2019.1697865

Yadav, D. (2021). Criteria for Good Qualitative Research: A Comprehensive Review. *Asia-Pacific Education Researcher*, *31*(6), 679–689. https://doi.org/10.1007/s40299-021-00619-0

Yeates, G. N., Gracey, F., & McGrath, J. C. (2008). A biopsychosocial deconstruction of “personality change” following acquired brain injury. *Neuropsychological Rehabilitation*, *18*(5–6), 566–589. https://doi.org/10.1080/09602010802151532

7. APPENDICES

APPENDIX A – ETHICS APPROVAL

UNIVERSITY OF EAST LONDON
School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL FOR RESEARCH INVOLVING HUMAN PARTICIPANTS
(Updated October 2019)

FOR BSc RESEARCH
FOR MSc/MA RESEARCH
FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

1. Completing the application

1.1 Before completing this application please familiarise yourself with the British Psychological Society's Code of Ethics and Conduct (2018) and the UEL Code of Practice for Research Ethics (2015-16). Please tick to confirm that you have read and understood thes ☒ es:

1.2 Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will then look over your application.

1.3 When your application demonstrates sound ethical protocol, your supervisor will submit it for review. By submitting the application, the supervisor is confirming that they have reviewed all parts of this application, and consider it of sufficient quality for submission to the SREC committee for review. It is the responsibility of students to check that the supervisor has checked the application and sent it for review.

1.4 Your supervisor will let you know the outcome of your application. Recruitment and data collection must NOT commence until your ethics application has been approved, along with other research ethics approvals that may be necessary (see section 8).

1.5 Please tick to confirm that the following appendices have been completed. Note: templates for these are included at the end of the form.

- The participant invitation letter ☒
- The participant consent form ☒

- The participant debrief letter ☒

1.6 The following attachments should be included if appropriate. In each case, please tick to either confirm that you have included the relevant attachment, or confirm that it is not required for this application.

- A participant advert, i.e., any text (e.g., email) or document (e.g., poster) designed to recruit potential participants.

  Included ☒ or (email to service gatekeeper and participants)

  Not required (because no participation adverts will be used) ☐

- A general risk assessment form for research conducted off campus (see section 6).

  Included ☐ or

  Not required (because the research takes place solely on campus or online) ☒

- A country-specific risk assessment form for research conducted abroad (see section 6).

  Included ☐ or

  Not required (because the researcher will be based solely in the UK) ☒

- A Disclosure and Barring Service (DBS) certificate (see section 7).

  Included ☐ or

  Not required (because the research does not involve children aged 16 or under or vulnerabl ☒ ults)

- Ethical clearance or permission from an external organisation (see section 8).

  Included ☐ or

  Not required (because no external organisations are involved in the research) ☒

- Original and/or pre-existing questionnaire(s) and test(s) you intend to use.

  Included ☐ or

  Not required (because you are not using pre-existing questionnaires or tests) ☒

- Interview questions for qualitative studies.

Included ☒ or

Not required (because you are not conducting qualitative interviews) ☐

- Visual material(s) you intend showing participants.

Included ☐ or

Not required (because you are not using any visual materials) ☒

2. Your details

2.1 Your name: Julia Keleher

2.2 Your supervisor's name: Amy Bartlett

2.3 Title of your programme: Professional Doctorate in Clinical Psychology

2.4 UEL assignment submission date (stating both the initial date and the resit date): May 2022

3. Your research

Please give as much detail as necessary for a reviewer to be able to fully understand the nature and details of your proposed research.

3.1 The title of your study:

"How can clinical psychologists best support their MDT colleagues in addressing the emotional outcomes associated with working with people with aphasia?"

3.2 Your research question:

1. What are clinical psychologists' understandings of the emotional outcomes of aphasia?
2. What do clinical psychologists find useful in supporting their MDT colleagues in their work with people with aphasia?
3. What kinds of roles do clinical psychologists take in the MDT when working with people with aphasia?

3.3 Design of the research: Qualitative research design using individual semi-structured interviews.

3.4 Participants:

In line with the research questions and epistemological stance, the proposed research will comprise of individual semi-structured interviews with 8-12 qualified clinical psychologists and/or clinical neuropsychologists who have current or recent experience of working with people with aphasia as part of an MDT in NHS settings, such as stroke units or community teams.

Inclusion/eligibility criteria:

- Working age adults (18 and over)
- Must have current or recent (within 2 years) experience of working in an NHS team that supports people with aphasia (e.g. stroke rehabilitation)
- Must be a qualified clinical psychologist or clinical neuropsychologist

Exclusion criteria:

- Not qualified (e.g. trainee clinical psychologist)
- Not currently employed by the NHS
- No experience of working in an NHS team supporting people with aphasia

3.5 Recruitment:

Participants will be recruited using convenience sampling on the basis of their eligibility and availability. The researchers will approach gatekeepers (e.g. service leads or managers) at relevant services, including any NHS organisations for which approval has been granted, by email in the first instance, asking them to support with recruitment for the research. Gatekeepers can then choose to circulate an email with staff members at their discretion, which will contain brief information about the proposed research, with the participant information sheet (Appendix A) as an attachment. Draft emails to service gatekeepers and prospective participants can be found in Appendix B and Appendix C respectively.

The research does not explicitly involve other organisations, however, organisations such as the ones below may be approached via email (Appendix B) as part of the recruitment process and can choose whether to forward on the participant information sheet to those on their mailing list.

- The British Psychological Society (BPS): Division of Clinical Psychology and BPS Division of Neuropsychology special interest groups
- UK Clinical Neuropsychology training courses accredited by the BPS Division of Neuropsychology
- Research forums
- The charity sector

The researchers will also publicise the research via the social media platforms, Twitter, Instagram and Linkedin using a recruitment poster (Appendix E), which contains the same information as the recruitment emails.

People who are interested in participating will be able to contact the researcher via the email address provided on the participant information sheet and recruitment poster. At this stage, the researcher will be able to answer any additional questions the person may have, send them a copy of the participant information sheet if they do not already have this, and check their eligibility. Following this, a convenient time for the online interview will be arranged.

3.6 Measures, materials or equipment:

- Laptop with the following software installed:
    - MS Office
    - MS Teams
- Guide interview schedule (Appendix E)

3.7 Data collection:

Semi-structured interviews lasting approximately one hour will be used to gather data relevant to the proposed research questions. The interview questions will focus on exploring clinical psychologists' understandings and experiences of their work with people with aphasia and of their role within an MDT. A proposed interview schedule can be found in Appendix E.

Due to the COVID-19 pandemic it is very likely that interviews will be held over video or audio depending on participant preference. For interviews Microsoft Teams will be used and will be recorded using the in-app recording feature.

3.8 Data analysis:

Reflexive thematic analysis will be used to analyse the interview data. It is felt an inductive or 'data driven' approach, in which themes are constructed through coding and interpretation of the content, would lend itself to the analysis, given there are no pre-existing theoretical assumptions about the experiences of clinical psychologists guiding it.

4. Confidentiality and security

It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the UEL guidance on data protection, and also the UK government guide to data protection regulations.

4.1 Will participants data be gathered anonymously?

No

4.2 If not (e.g., in qualitative interviews), what steps will you take to ensure their anonymity in the subsequent steps (e.g., data analysis and dissemination)?

Interviews will take place online and in a private setting and will be recorded on Microsoft Teams. Any identifiable information provided (names, workplaces etc.) will be changed when transcribing the interview to protect participants' anonymity. Information from the interview may be included in the write up of the research in the form of quotes. However, any quotes used will be chosen carefully to ensure the anonymity of participants is respected. It is hoped that this research will be useful to professionals and so it may be published and appear in academic journals.

4.3 How will you ensure participants details will be kept confidential?

Interviews will take place online and in private and will be recorded on MS Teams. Any direct or indirect identifiable information provided (names, workplaces etc.) will be changed when transcribing the interview to protect the participants' anonymity. Any MS Teams interview recordings will be stored securely on the UEL networked H: Drive and backed up on OneDrive for Business. Anonymised transcriptions of interviews will be stored in a separate folder on the researcher's password protected computer. Transcriptions will be backed up in a separate folder on OneDrive for Business. Only the researcher will be able to listen back to the interview and only they and the research supervisor (Director of Studies – DoS) will have access to the anonymised transcriptions. Electronic consent forms will be downloaded and stored securely on the UEL networked H: Drive and backed up on OneDrive for Business. Local copies (e.g. downloaded from email) will be deleted. Any hard copies of consent forms will be scanned in and stored in the same way before being destroyed.

Anonymised extracts from the interview may be included in the write up of the research to be used in presentations, reports, publications and any other ways in which the finding will be disseminated. However, any extracts used will be chosen carefully to ensure the anonymity of participants is respected.

4.4 How will the data be securely stored?

Any MS Teams interview recordings will be stored securely on the UEL networked H: Drive and backed up on OneDrive for Business. Anonymised transcriptions of interviews will be stored in a separate folder on the researcher's password protected computer. Transcriptions will be backed up in a separate folder on OneDrive for Business. Only the researcher will be able to listen back to the interview and only they and the research supervisor (Director of Studies – DoS) will have access to the anonymised transcriptions. Electronic consent forms will be downloaded and stored securely on the UEL networked H: Drive and backed up on OneDrive for Business. Local copies (e.g. downloaded from email) will be deleted. Any hard copies of consent forms will be scanned in and stored in the same way before being destroyed.

4.5 Who will have access to the data?

Only the researcher will be able to listen back to the interview and only the researcher and the research supervisor will have access to the anonymised transcriptions. A copy of the anonymised transcription may be made available to markers on request.

4.6 How long will data be retained for?

Original interview recordings will be stored securely up until the research has been examined and has been awarded a pass mark; at which point they will be destroyed. Anonymised interview transcriptions and consent forms will be retained by the researcher's director of studies (DoS) (supervisor) for 3 years on their password protected OneDrive in case of future publication.

5. Informing participants

Please confirm that your information letter includes the following details:

5.1 Your research title: ☒

5.2 Your research question: ☒

5.3 The purpose of the research: ☒

5.4 The exact nature of their participation. This includes location, duration, and the tasks etc. invo ☒

5.5 That participation is strictly voluntary: ☒

5.6 What are the potential risks to taking part: ☒

☒

5.7 What are the potential advantages to taking part:

5.8 Their right to withdraw participation (i.e., to withdraw involvement at any point, no questions asked ☒

5.9 Their right to withdraw data (usually within a three-week window from the time of their participation ☒

5.10 How long their data will be retained for: ☒

5.11 How their information will be kept confidential: ☒

5.12 How their data will be securely stored: ☒

5.13 What will happen to the results/analysis: ☒

5.14 Your UEL contact details: ☒

5.15 The UEL contact details of your supervisor: ☒

Please also confirm whether:

5.16 Are you engaging in deception? If so, what will participants be told about the nature of the research, and how will you inform them about its real nature?

No deception will be used.

5.17 Will the data be gathered anonymously? If NO what steps will be taken to ensure confidentiality and protect the identity of participants?

Data will not be gathered anonymously as the method for data collection is individual interviews and by virtue of responding to the recruitment email they will be making themselves known to the researcher. However, participants' data will be stored securely and no identifiable information will be reported in the results so participants' identity will remain anonymous beyond the data collection stage. Prospective participants will be made aware of this through the information sheet. Further information about steps being taken to ensure confidentiality is maintained can be found in sections 4.2 and 4.3.

5.18 Will participants be paid or reimbursed? If so, this must be in the form of redeemable vouchers, not cash. If yes, why is it necessary and how much will it be worth?

Participants will not be paid or reimbursed for their time. This information is contained in the participant information sheet.

6. Risk Assessment

Please note: If you have serious concerns about the safety of a participant, or others, during the course of your research please see your supervisor as soon as possible. If there is any unexpected occurrence while you are collecting your data (e.g. a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.

6.1 Are there any potential physical or psychological risks to participants related to taking part? If so, what are these, and how can they be minimised?

Although unlikely given the nature of the interview there is a small chance that some sensitive topics may be raised by participants that could cause psychological distress for either the research participant or researcher. To manage the risk to participants the following precautions will be taken:

- Researcher to remind participant that they can pause or stop the interview at any time.
- Participants will also have a copy of the participant information sheet with details for the research supervisor and chair of School of Psychology Research Ethics Sub-Committee if they have concerns about the research

  Though unlikely, participants will be encouraged to use the support systems in place at their workplaces to address any work-related issues that may arise in the course of the interviews.

6.2 Are there any potential physical or psychological risks to you as a researcher? If so, what are these, and how can they be minimised?

Although unlikely given the nature of the interview there is a small chance that some sensitive topics may be raised by participants that could cause psychological distress for either the research participant or researcher. To manage the risk to the researcher the following precautions will be taken:

- Researcher to ensure they take appropriate steps to manage their own wellbeing, such as seeking support from their director of studies (DoS) if they feel the interview has brought up difficulties for them

6.3 Have appropriate support services been identified in the debrief letter? If so, what are these, and why are they relevant?

No; N/A.

6.4 Does the research take place outside the UEL campus? If so, where?

No. The research will take place online.

If so, a 'general risk assessment form' must be completed. Note: if the research is on campus, or is online only (e.g., a Qualtrix survey), then a risk assessment form is not needed, and this appendix can be deleted. If a general risk assessment form is re ☒ d for this research, please tick to confirm that this has been completed:

6.5 Does the research take place outside the UK? If so, where?

No

If so, in addition to the 'general risk assessment form', a 'country-specific risk assessment form' must be also completed (available in the Ethics folder in the Psychology Noticeboard), and included as an appendix. [Please note: a country-specific risk assessment form is not needed if the research is online only (e.g., a Qualtrix survey), regardless of the location of the researcher or the participants.] If a 'country-specific risk assessment form' *is* needed, please tick to confirm that this has been included:

However, please also note:

- For assistance in completing the risk assessment, please use the AIG Travel Guard website to ascertain risk levels. Click on 'sign in' and then 'register here' using policy # 0015865161. Please also consult the Foreign Office travel advice website for further guidance.
- For *on campus* students, once the ethics application has been approved by a reviewer, all risk assessments for research abroad must then be signed by the Head of School (who may escalate it up to the Vice Chancellor).
- For *distance learning* students conducting research abroad in the country where they currently reside, a risk assessment must be also carried out. To minimise risk, it is recommended that such students only conduct data collection on-line. If the project is deemed low risk, then it is not necessary for the risk assessments to be signed by the Head of School. However, if not deemed low risk, it must be signed by the Head of School (or potentially the Vice Chancellor).
- Undergraduate and M-level students are not explicitly prohibited from conducting research abroad. However, it is discouraged because of the inexperience of the students and the time constraints they have to complete their degree.

7. Disclosure and Barring Service (DBS) certificates

7.1 Does your research involve working with children (aged 16 or under) or vulnerable adults (*see below for definition)?

No.

7.2 If so, you will need a current DBS certificate (i.e., not older than six months), and to include this as an appendix. Please tick to confirm that you have included this: ☐

Alternatively, if necessary for reasons of confidentiality, you may email a copy directly to the Chair of the School Research Ethics Committee. Please tick if you have done this instead: ☐

Also alternatively, if you have an Enhanced DBS clearance (one you pay a monthly fee to maintain) then the number of your Enhanced DBS clearance will suffice. Please tick if you have included this instead: ☐

7.3 If participants are under 16, you need 2 separate information letters, consent form, and debrief form (one for the participant, and one for their parent/guardian). Please tick to confirm that you have included these: ☐

7.4 If participants are under 16, their information letters consent form, and debrief form need to be written in age-appropriate language. Please tick to confirm that you have done this ☐

* You are required to have DBS clearance if your participant group involves (1) children and young people who are 16 years of age or under, and (2) 'vulnerable' people aged 16 and over with psychiatric illnesses, people who receive domestic care, elderly people (particularly those in nursing homes), people in palliative care, and people living in institutions and sheltered accommodation, and people who have been involved in the criminal justice system, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak to your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible. For more information about ethical research involving children click here.

8. Other permissions

9. Is HRA approval (through IRAS) for research involving the NHS required? Note: HRA/IRAS approval is required for research that involves patients or Service Users of the NHS, their relatives or carers as well as those in receipt of services provided under contract to the NHS.

Yes. HRA and R&D only. NHS employees who will be recruited through their NHS workplace.

If yes, please note:

- You DO NOT need to apply to the School of Psychology for ethical clearance if ethical approval is sought via HRA/IRAS (please see further details here).
- However, the school *strongly discourages* BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.

- If you work for an NHS Trust and plan to recruit colleagues from the Trust, permission from an appropriate manager at the Trust must be sought, and HRA approval will probably be needed (and hence is likewise strongly discouraged). If the manager happens to not require HRA approval, their written letter of approval must be included as an appendix.
- IRAS approval is not required for NHS staff even if they are recruited via the NHS (UEL ethical approval is acceptable). However, an application will still need to be submitted to the HRA in order to obtain R&D approval. This is in addition to a separate approval via the R&D department of the NHS Trust involved in the research.
- IRAS approval is not required for research involving NHS employees when data collection will take place off NHS premises, and when NHS employees are not recruited directly through NHS lines of communication. This means that NHS staff can participate in research without HRA approval when a student recruits via their own social or professional networks or through a professional body like the BPS, for example.

9.1 Will the research involve NHS employees who will not be directly recruited through the NHS, and where data from NHS employees will not be collected on NHS premises?

Yes

9.2 If you work for an NHS Trust and plan to recruit colleagues from the Trust, will permission from an appropriate member of staff at the Trust be sought, and will HRA be sought, and a copy of this permission (e.g., an email from the Trust) attached to this application?

N/A.

9.3 Does the research involve other organisations (e.g. a school, charity, workplace, local authority, care home etc.)? If so, please give their details here.

The research does not explicitly involve other organisations, however, organisations such as the ones below may be approached via email (see Appendix B for email) as part of the recruitment process and can choose whether to forward on the participant information sheet to those on their mailing list.

- The British Psychological Society (BPS): Division of Clinical Psychology and BPS Division of Neuropsychology special interest groups
- UK Clinical Neuropsychology training courses accredited by the BPS Division of Neuropsychology

- Research forums (e.g. Organisation for Psychological Research into Stroke (OPSYRIS))
- The charity sector (e.g. UK Stroke Association Professionals' Network; Aphasia Alliance)

Furthermore, written permission is needed from such organisations if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material owned by the institution/organisation. If that is the case, please tick here to confirm that you have included this written per☐ion as an appendix:

In addition, before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as 'my' or 'I' with 'our organisation,' or with the title of the organisation. This organisational consent form must be signed before the research can commence.

Finally, please note that even if the organisation has their own ethics committee and review process, a School of Psychology SREC application and approval is still required. Ethics approval from SREC can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s as may be necessary.

9. Declarations

Declaration by student: I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor.

Student's name (typed name acts as a signature): Julia Keleher

Student's number: u1945472 Date: 12.04.2021

As a supervisor, by submitting this application, I confirm that I have reviewed all parts of this application, and I consider it of sufficient quality for submission to the SREC committee.

APPENDIX B – RISK ASSESSMENT FORM

UEL Risk Assessment Form

Name of Assessor:	Julia Keleher	**Date of Assessment**	14.06.2021
Event title:	"How can clinical psychologists best support their MDT colleagues in addressing the emotional outcomes associated with working with people with aphasia?"	**Date, time and location of activity:**	Research will take place between July 2021 and May 2022. An individual interview will be scheduled with each participant as required during this timeframe.
Signed off by Manager (Print Name)			

Please describe the activity in as much detail as possible (include nature of activity, estimated number of participants, etc) **If the activity to be assessed is part of a fieldtrip or event please add an overview of this below:**
Semi-structured interviews taking place online via Microsoft (MS) Teams with between 8 and 12 qualified clinical psychologists and clinical neuropsychologists.
Overview of FIELD TRIP or EVENT:

Guide to risk ratings:

a) Likelihood of Risk	**b) Hazard Severity**	**c) Risk Rating (a x b = c)**
1 = Low (Unlikely)	1 = Slight (Minor / less than 3 days off work)	1-2 = Minor (No further action required)
2 = Moderate (Quite likely)	2= Serious (Over 3 days off work)	3-5 = Medium (May require further control measures)
3 = High (Very likely or certain)	3 = Major (Over 7 days off work, specified injury or death)	6-9 = High (Further control measures essential)

Which Activities Carry Risk?

Activity / Task Involved	**Describe the potential hazard?**	**Who is at risk?**	**Likelihood of risk**	**Severity of risk**	**Risk Rating (Likelihood x Severity)**	**What precautions have been taken to reduce the risk?**	**State what further action is needed to reduce risk (if any) and state final risk level**	**Review Date**
Online interview	Discussion of sensitive topics which may give rise to psychological distress	Participant and/or researcher	1	1	1	Researcher to remind participant that they can pause or stop the interview at any time Researcher to ensure they take appropriate steps to manage their own mental wellbeing, such as seeking support from their director of studies (DoS) if they feel the	Participants will have a copy of the participant information sheet with details for the research supervisor and chair of School of Psychology Research Ethics Sub-Committee if they have concerns. Though unlikely, participants will be	14.08.2021

						interview has brought up difficulties for them	encouraged to use the support systems in place at their workplaces to address any work-related issues that may arise in the course of the interviews.	

A comprehensive guide to risk assessments and health and safety in general can be found in UEL's Health & Safety handbook at http://www.uel.ac.uk/hrservices/hs/handbook/ and a comprehensive guide to risk assessment is available on the Health & Safety Executive's web site at http://www.hse.gov.uk/risk/casestudies/index.htm. An example risk assessment is also included below.

APPENDIX C – NOTICE OF ETHICS REVIEW DECISION

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: Marita Morahan

SUPERVISOR: Amy Bartlett

STUDENT: Julia Keleher

Course: Prof Doc in Clinical Psychology

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY

(Please indicate the decision according to one of the 3 options above)

Approved with minor amendments.

Minor amendments required *(for reviewer)*:

An interesting piece of work. Please attend to the following minor amendments and return the completed ethics application form to your supervisor.

3.5

You mention eligibility twice in this section. What is their eligibility?

4.3 and 4.4

Please answer section 4.3 and 4.4 separately as requested in the form.

4.6

Section 4.6 and participant information sheet and debrief letter all indicate that the data will be stored until a pass mark is achieved. What happens to the data if a pass mark is never achieved?

5.16

Is this answer no or N/A?

5.17

Please confirm whether you have informed your participants about whether the data is collected anonymously. Also whether you have informed your participants about the steps taken to ensure the confidentiality and protect the identity of participants.

5.18

Is this no or N/A?

6.3

It would be useful to signpost participants to their workplace services in the debrief letter. This is the purpose of a debrief letter, should any issues arise after participation in the interview.

6.4

This should read yes. No and not applicable are not suitable here. (They are also separate answers). It should read yes, the research will take place online. Online is not on campus.

6.5

Please answer either No, or N/A.

Appendix B

This needs your details at the end of the email. (name and email).

Appendix C

This states the interview will take place either by video or phone. You have stated in the ethics application that it is only by video on MS Teams. Please be consistent.

Once again you need to include your details, name email address at the places indicated on this pro forma.

Major amendments required *(for reviewer)*:

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature)*: [redacted]
Student number: u1945472

Date: 21.10.2021

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES / ~~NO~~

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

☐ MEDIUM (Please approve but with appropriate recommendations)

☒ LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: *Marita Morahan*

Date: 12/10/2021

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

APPENDIX D – REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION FORM

School of Psychology Ethics Committee

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of the School Research Ethics Committee).

How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

Required documents

A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	**YES** ☒
Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc.	**YES** ☒

A copy of the approval of your initial ethics application.	**YES** ☒

Details

Name of applicant:	**Julia Keleher**
Programme of study:	**Professional Doctorate in Clinical Psychology**
Title of research:	How can clinical psychologists best support their MDT colleagues in addressing the emotional outcomes associated with working with people with aphasia?
Name of supervisor:	**Amy Bartlett**

Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	**Rationale**
To publicise recruitment for the research via social media platforms (Twitter, Instagram and Linkedin) using a recruitment poster.	To help with recruitment for the research
Proposed amendment	Rationale for proposed amendment
Proposed amendment	Rationale for proposed amendment
Proposed amendment	Rationale for proposed amendment

Confirmation

Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?	**YES** ☒	**NO** ☐

Student's signature

Student: (Typed name to act as signature)	**Julia Keleher**
Date:	**13/12/2021**

Reviewer's decision		
Amendment(s) approved:	**YES** ☒	**NO** ☐
Comments:	Please enter any further comments here	
Reviewer: (Typed name to act as signature)	**Trishna Patel**	
Date:	**14/12/2021**	

APPENDIX E – REQUEST FOR TITLE CHANGE TO AN ETHICS FORM

University of East London

School of Psychology Ethics Committee

REQUEST FOR TITLE CHANGE TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for a proposed title change to an ethics application that has been approved by the School of Psychology

By applying for a change of title request, you confirm that in doing so, the process by which you have collected your data/conducted your research has not changed or deviated from your original ethics approval. If either of these have changed, then you are required to complete an 'Ethics Application Amendment Form'.

How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	Using your UEL email address, email the completed request form along with associated documents to Dr Jérémy Lemoine (School Ethics Committee Member): j.lemoine@uel.ac.uk
4	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.

Required documents

A copy of the approval of your initial ethics application.	**YES** ☒

Details

Name of applicant:	**Julia Keleher**
Programme of study:	**Professional Doctorate in Clinical Psychology**
Title of research:	**How can clinical psychologists best support their MDT colleagues in addressing the emotional**

	outcomes associated with working with people with aphasia?
Name of supervisor:	**Amy Bartlett**

Proposed title change

Briefly outline the nature of your proposed title change in the boxes below

Old title:	"How can clinical psychologists best support their MDT colleagues in addressing the emotional outcomes associated with working with people with aphasia?"
New title:	**Clinical psychologists' experiences of supporting people with aphasia as part of a multidisciplinary team**
Rationale:	The newly proposed title is felt to better reflect findings from the research

Confirmation

Is your supervisor aware of your proposed change of title and in agreement with it?	**YES** ☒	**NO** ☐
Does your change of title impact the process of how you collected your data/conducted your research?	**YES** ☐	**NO** ☒

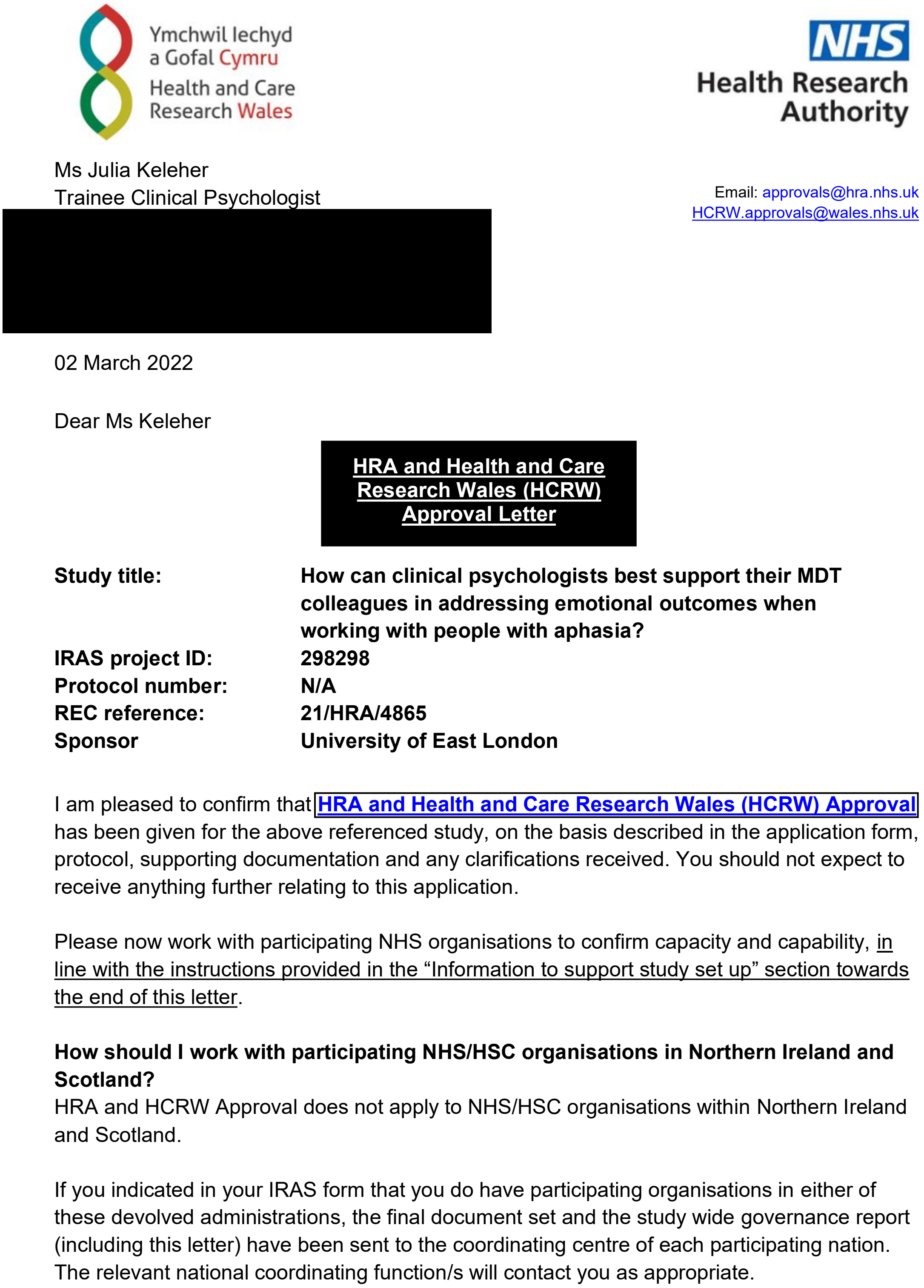
Student's signature

Student: (Typed name to act as signature)	**Julia Keleher**
Date:	**24/03/2023**

Reviewer's decision

Title change approved:	**YES** ☒	**NO** ☐
Comments:	**The new title reflects better the research study and will not impact the process of how the data are collected or how the research is conducted.**	
Reviewer: (Typed name to act as signature)	**Dr Jérémy Lemoine**	
Date:	**27/03/2023**	

APPENDIX F – HRA APPROVAL LETTER



Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Ms Julia Keleher
Trainee Clinical Psychologist
[redacted]

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

02 March 2022

Dear Ms Keleher

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**How can clinical psychologists best support their MDT colleagues in addressing emotional outcomes when working with people with aphasia?**
IRAS project ID:	**298298**
Protocol number:	**N/A**
REC reference:	**21/HRA/4865**
Sponsor	**University of East London**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The *"After HRA Approval – guidance for sponsors and investigators"* document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **298298**. Please quote this on all correspondence.

Yours sincerely,
Chris Kitchen

Email: approvals@hra.nhs.uk

Copy to: *Catherine Hitchens*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor Indemnity]		04 August 2021
Interview schedules or topic guides for participants [Interview Question Guide]	0.1	14 June 2021
IRAS Application Form [IRAS_Form_04022022]		04 February 2022
Letters of invitation to participant [Recruitment Emails]	0.2	21 October 2021
Other [Participant Debrief Letter]	0.2	13 December 2021
Other [model Non-Commercial PIC agreement (mNC-PICA sponsor to PIC)]	0.1	15 January 2022
Participant consent form [Consent Form]	1.2	15 January 2022
Participant information sheet (PIS) [PIS]	1.3	17 February 2022
Research protocol or project proposal [Study Protocol]	0.1	28 June 2021
Summary CV for Chief Investigator (CI) [Summary CV for CI]		
Summary CV for supervisor (student research) [Summary CV for Supervisor]		09 May 2019
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary Diagram of Protocol]	0.1	28 June 2021

IRAS project ID	298298

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
This is a non-commercial study with two participating NHS organisations functioning as Participant Identification Centres.	PIC activities should not commence until a PIC Agreement is in place. HRA and HCRW recommend use of the standard Participating NHS Organisation to PIC agreement available here.	Since the study only involves PICs, sites should make appropriate arrangements with the NHS trusts involved using the model PIC agreement available at https://www.myresearchproject.org.uk/help/hlpsitespecific.aspx#PIC	No application for external funding has been made.	Neither a Principal Investigator nor a Local Collaborator is expected to be in place at Participant Identification Centres.	The sponsor has stated that local staff in participating organisations in England who have a contractual relationship with the organisation will undertake the expected activities. Therefore no honorary research contracts or letters of access are expected for this study.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion in the NIHR Clinical Research Network Portfolio.

APPENDIX G – PARTICIPANT INFORMATION SHEET

PARTICIPANT INFORMATION SHEET

How can clinical psychologists best support their MDT colleagues in addressing emotional outcomes when working with people with aphasia?

You are being invited to participate in the above-named research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

Who am I?

I am a postgraduate student studying for a doctorate in Clinical Psychology at the University of East London. As part of my studies I am conducting the research you are being invited to participate in.

What is the research?

The research aims to find out more about clinical psychologists' understandings of the emotional outcomes associated with aphasia and their experiences of working in MDTs that support people with aphasia.

You have been invited to participate because you are a clinical psychologist or a clinical neuropsychologist who has experience of working with people with aphasia as part of an MDT. I am not looking for 'experts' on the topic I am studying, but simply wish to find out more about your experiences in your work.

The research has been approved by the School of Psychology Research Ethics Committee, which is guided by the standards of research ethics set by the British Psychological Society (BPS).

What will your participation involve?

If you agree to participate you will be asked to attend a one-off interview lasting around one hour. The kinds of topics you will be asked about in the interview include:

- How you make sense of the emotional or psychosocial aspects of aphasia
- Your experiences of working psychologically with people with aphasia

- Any other types of work you do as a member of the MDT
- Your experiences of working with other professionals in your team (e.g. Speech and Language Therapists, Occupational Therapists etc.)
- What you find helpful/unhelpful when working with your MDT colleagues

This interview will take place via video or audio on Microsoft (MS) Teams. Interviews will be informal and conversational in nature. You do not have to answer all of the questions asked of you and can choose to stop the interview at any time if you would like to.

Payment

I will not be able to pay you for participating in my research, but your participation would be very valuable in helping to develop knowledge and understanding of the research topic.

What will happen to the information that you provide?

Interviews will take place online and in private and will be recorded on MS Teams. Any identifiable information you provide (names, workplaces etc.) will be changed when transcribing the interview to protect your anonymity. Any MS Teams interview recordings will be stored securely in the researcher's UEL networked H: Drive service. Anonymised transcriptions will be stored in a separate folder on the researcher's UEL networked H: Drive, on a password protected computer. Only the researcher will be able to listen back to the interview and only they and the research supervisor will have access to the anonymised transcription. Any hard copies of consent forms will be scanned in and stored in the same way before being destroyed.

Anonymised extracts from the interview may be included in the write up of the research to be used in presentations, reports, publications and any other ways in which the finding will be disseminated. However, any extracts used will be chosen carefully to ensure the anonymity of participants is respected. It is hoped that this research will be useful to professionals such as yourself and may be published and appear in academic journals. The thesis will be publicly accessible on UEL's institutional repository.

Interview recordings and consent forms will be stored securely up until the research has been examined and has been awarded a pass mark or a maximum of 12 months from 01.06.2022 (whichever comes first); at which point they will be destroyed. The anonymised transcriptions will be retained for three years.

What if you want to withdraw?

You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. Separately, you may also request to withdraw your data even after you have participated, provided that this request is made within 3 weeks of the interview. After this point analysis will have started and it will not be possible to withdraw your data.

How will we use information about you?

We will need to use information from you for this research project. This information will include your name, email address and job title held by the researcher. The researcher will use this information to do the research. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information in used?

You can find out more about how we use your information by asking one of the research team using the contact details on this document

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me:

Julia Keleher
U1945472@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor:

Amy Bartlett
School of Psychology, University of East London, Water Lane, London E15 4LZ,
a.l.bartlett@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel,
School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

APPENDIX H – RECRUITMENT POSTER

Call for research participants

University of East London

How can clinical psychologists best support their MDT colleagues in addressing emotional outcomes when working with people with aphasia?

Are you a qualified clinical psychologist or clinical neuropsychologist?

Do you work in an MDT that supports people with aphasia in their rehabilitation?

Can you give up to an hour of your time to participate in an interview?

Who am I?
My name is Julia and I am a trainee clinical psychologist at the University of East London (UEL).
I am inviting you to participate in my doctoral research project by taking part in a one-off interview over Microsoft Teams.

The research aims to find out more about clinical psychologists' understandings of the emotional outcomes associated with aphasia, and their experiences of working in MDTs that support people with aphasia.

Participation will involve taking part in an online interview over Microsoft Teams. In the interview, you might be asked about the following topics:

- How you make sense of the emotional or psychosocial aspects of aphasia
- Your experiences of working psychologically with people with aphasia
- Any other types of work you do as a member of the MDT
- Your experiences of working with other professionals in your team (e.g. Speech and Language Therapists, Occupational Therapists etc.)
- What you find helpful/unhelpful when working with your MDT colleagues

I'm interested. What next?
If you are interested in participating or would like more information please contact me using the email address below. I will be happy to answer any questions you may have and will send over a participant information sheet.

Julia Keleher
U1945472@uel.ac.uk

Please note this research project has been ethically approved by the UEL School of Psychology Research Ethics Committee.

APPENDIX I – CONSENT FORM

UNIVERSITY OF EAST LONDON

Consent to participate in a research study

How can clinical psychologists best support their MDT colleagues in addressing emotional outcomes when working with people with aphasia?

	Mark X to indicate consent
I confirm that I have read the information sheet dated 20.03.2021 (V1.0) for the above study and that I have been given a copy to keep. (**NB**: all consent forms should show the date on which they were agreed and have a version number in order to keep track of any changes that might occur over the course of the study).	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation in the study is voluntary and that I may withdraw at any time, without providing a reason for doing so.	
I understand that I have 3 weeks from the date of the interview to withdraw my data from the study. If I choose to withdraw my data within 3 weeks it will not be included in the analysis.	
I understand that the interview will be recorded using Microsoft Teams.	
I understand that my interview data will be transcribed from the recording and anonymised to protect my identity.	
I understand that my personal information and data, including audio recordings from the research will be securely stored and remain strictly confidential. Only the research team will have access to this information, to which I give my permission.	
It has been explained to me what will happen to the data once the research has been completed.	
I understand that short, anonymised quotes from my interview may be used in the thesis and that these will not personally identify me.	
I understand that the thesis will be publicly accessible in the University of East London's Institutional Repository (ROAR).	

I understand that short, anonymised quotes from my interview may be used in material such as conference presentations, reports, articles in professional and academic journals resulting from the study and that these will not personally identify me.	
I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to. If yes, please provide an email address:	
I agree to take part in the above study.	

Signed: **Date:**

Filing instruction: Once signed, one copy to be provided to the research participant and one copy to be stored securely by the researcher

APPENDIX J – DEBRIEF LETTER

University of East London

PARTICIPANT DEBRIEF LETTER

Thank you for participating in my research study about how clinical psychologists best support their MDT colleagues in addressing emotional outcomes when working with people with aphasia. This letter offers information that may be relevant in light of you having now taken part.

What will happen to the information that you have provided?
The following steps will be taken to ensure the confidentiality and integrity of the data you have provided.

Any identifiable information you provide (names, workplaces etc.) will be changed when transcribing the interview to protect your anonymity. Any MS Teams interview recordings will be stored securely in the researcher's UEL networked H: Drive service. Anonymised transcriptions will be stored in a separate folder on the researcher's UEL networked H: Drive, on a password protected computer. Only the researcher will be able to listen back to the interview and only they and the research supervisor will have access to the anonymised transcription. Any hard copies of consent forms will be scanned in and stored in the same way before being destroyed.

Anonymised extracts from the interview may be included in the write up of the research to be used in presentations, reports, publications and any other ways in which the finding will be disseminated. However, any extracts used will be chosen carefully to ensure the anonymity of participants is respected. It is hoped that this research will be useful to professionals such as yourself and may be published and appear in academic journals. The thesis will be publicly accessible on UEL's institutional repository.

Interview recordings and consent forms will be stored securely up until the research has been examined and has been awarded a pass mark or a maximum of 12 months from 01.06.2022 (whichever comes first); at which point they will be destroyed. The anonymised transcriptions will be retained for three years.

What if you want to withdraw?
You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. Separately, you may also request to withdraw your data even after you have participated, provided that this request is made within 3 weeks of the interview. After this point analysis will have started and it will not be possible to withdraw your data.

What to do if participating in this research study has raised issues for you?

I hope that participating in my research study has been an interesting experience. However, it may have brought up concerns or challenges relating to your work. If this is the case, I would advise you to speak with your line manager/appropriate supervisor to discuss any concerns you may have.

If you have any concerns about the study its self, please feel welcome to use the contact details below to get in touch.

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me:

Julia Keleher
U1945472@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor:

Amy Bartlett
School of Psychology, University of East London, Water Lane, London E15 4LZ,
a.l.bartlett@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel,
School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

APPENDIX K – RESEARCH DATA MANAGEMENT PLAN

UEL Data Management Plan: Full

For review and feedback please send to: researchdata@uel.ac.uk

If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).

Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts, prototypes, and multimedia objects that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects.

Administrative Data	
PI/Researcher	Julia Keleher
PI/Researcher ID (e.g. ORCiD)	0000-0003-2450-9592
PI/Researcher email	U1945472@uel.ac.uk
Research Title	“How can clinical psychologists best support their MDT colleagues in addressing the emotional outcomes associated with working with people with aphasia?”
Project ID	IRAS Project ID: 298298
Research Duration	April 2021 – Sept 2022
Research Description	In line with the research questions and epistemological stance, the proposed research will comprise of individual semi-structured interviews with 8-12 qualified clinical psychologists and/or clinical neuropsychologists who have current or recent experience of working with people with aphasia as part of an MDT in NHS settings, such as stroke units or community teams.
Funder	n/a – no external funding

Grant Reference Number (Post-award)	n/a
Date of first version (of DMP)	01.04.2021
Date of last update (of DMP)	15.04.2021
Related Policies List any other relevant funder, institutional, departmental or group policies on data management, data sharing and data security. Some of the information you give in the remainder of the DMP will be determined by the content of other policies. If so, point/link to them here.	Research Data Management Policy
Does this research follow on from previous research? If so, provide details	no
Data Collection	
What data will you collect or create?	- Interview recordings in .mp4 format - Transcriptions of the interviews will be created and saved as Microsoft Word files. - Consent forms (electronic versions – Microsoft word) - .docx - Reflexive thematic analysis (TA) will be undertaken by the researcher using Microsoft Word and Excel and files saved in these formats accordingly (.docx & .xlsx) Personal/identifying data: - Names and signatures will be collected on consent forms, which will be stored securely and separately

	to interview recordings and transcriptions - Responses to the questions in the recorded interview may contain direct or indirect identifying data about the participants (e.g. names of services or locations). All identifying information will be changed/anonymised at the point of transcription through the use of pseudonyms or generic descriptors
How will the data be collected or created?	- Semi-structured interviews lasting approximately one hour will be used to gather data relevant to the proposed research questions. - For interviews Microsoft Teams will be used and will be recorded using the in-app recording feature. - Interviews will be transcribed by hand by the researcher and will be anonymised at the point of transcription.
Documentation and Metadata	
What documentation and metadata will accompany the data?	- A proposed interview schedule has been developed and is included in the proposed plan of work (MS Word) - Blank consent form (MS Word) - Participant information sheet (MS Word) - Participant debrief letter (MS Word) - Password protected anonymisation log (MS Word) Folder structure: Files will be stored in folders on the researcher's password protected computer based on the phase of research/subject matter. For instance:

	- Anonymised interview transcriptions will be stored in their own folder titled 'Interview Transcripts'). - Files relating to the analysis containing anonymised data (codes, themes, thematic maps) will be stored in a separate folder titled 'Analysis' - Password protected anonymisation log will be stored in a separate folder on OneDrive for Business and backed up on the UEL H: Drive File naming: Nameoffile – versionnumber YYYYMMDD - e.g. RDM Plan – V1.1 20210401
Ethics and Intellectual Property	
How will you manage any ethical issues?	- Participants will be informed of the nature of the interview and how their data will be stored prior to consenting to participate and will have a copy of the participant information sheet. It is not anticipated that interviews will cover any sensitive topics and therefore unlikely that they would give rise to any distress from either the participant or the researcher. However, participants can choose to discontinue the interview at any time and will be reminded of this at the start of the interview. - Participants will be given a unique code, which they can use to have their data withdrawn from the study (within 3 weeks of interviews). Codes will be stored in the password protected anonymisation log to link the data to the participant. - The nature of the research (asking about professional issues) means it is unlikely that the data collected will

	contain information that could be deemed 'sensitive'. In the event that participants choose to discuss sensitive topics, the researcher will ensure any specific or indirect identifying details are changed to protect the anonymity of the participant. -
How will you manage copyright and Intellectual Property Rights issues?	**n/a**
Storage and Backup	
How will the data be stored and backed up during the research?	- Interviews will be recorded via Microsoft (MS) Teams and recordings will be downloaded from MS Teams Stream Library and stored securely on (1) the UEL networked H: Drive and (2) OneDrive for Business. Following this any local copies will be deleted to ensure there are just two copies stored securely. No files will be stored outside of this (e.g. on iCloud). - Anonymised transcriptions of interviews will be stored in a separate folder on the researcher's UEL networked H: Drive. Transcriptions will be backed up in a separate folder on OneDrive for Business. - Consent forms will be administered and collected electronically and will be stored on (1) the UEL networked H: Drive and (2) OneDrive for Business. Any local copies (e.g. that were emailed and downloaded) will be deleted.

How will you manage access and security?	- The researchers H:Drive and OneDrive are both password protected. - Raw data will not be shared with anyone aside from the researcher's director of studies (DoS). OneDrive for Business' filed sharing facility will be used to share any data between the researcher and the DoS.
Data Sharing	
How will you share the data?	Anonymised extracts may feature in the write up of the research, which may be shared in the following ways: • UEL's Research Repository • Conference presentations. • Publishing in peer and non-peer reviewed journals. • Peer-reviewed books. • Publication in media and on project websites. • Promotional reports and materials on research. • Reports compiled on behalf of external organisations.
Are any restrictions on data sharing required?	Raw data will not be shared with anyone outside of the research team. Anonymised transcriptions may need to be shared with markers upon request.
Selection and Preservation	
Which data are of long-term value and should be retained, shared, and/or preserved?	- Anonymised interview transcriptions will be retained by the researcher's director of studies (DoS) (supervisor) for 3 years on their password protected OneDrive for Business in case of future publication

What is the long-term preservation plan for the data?	- Original interview recordings will be stored securely as described above up until the research has been examined and has been awarded a pass mark; at which point they will be destroyed. - Anonymised interview transcriptions will be retained by the researcher's director of studies (DoS) (supervisor) for 3 years on their password protected OneDrive for business in case of future publication.
Responsibilities and Resources	
Who will be responsible for data management?	Researcher (Julia Keleher) Amy Bartlett (DoS)
What resources will you require to deliver your plan?	A secure internet connection A laptop with the following software installed: • MS Office • MS Teams
Review	
DMP should be reviewed regularly and suggest review on review by ethics **Plan should be updated with what will happen to consent forms PJ.**	**Send any updates to researchdata@uel.ac.uk**
Date: 15/04/2021	Reviewer name: Penny Jackson Research Data Management Officer

Guidance

Brief information to help answer each section is below. Aim to be specific and concise. For assistance in writing your data management plan, or with research data management more generally, please contact: **researchdata@uel.ac.uk**

Administrative Data

Related Policies

List any other relevant funder, institutional, departmental or group policies on data management, data sharing and data security. Some of the information you give in the remainder of the DMP will be determined by the content of other policies. If so, point/link to them here.

Data collection

Describe the data aspects of your research, how you will capture/generate them, the file formats you are using and why. Mention your reasons for choosing particular data standards and approaches. Note the likely volume of data to be created.

Documentation and Metadata

What metadata will be created to describe the data? Consider what other documentation is needed to enable reuse. This may include information on the methodology used to collect the data, analytical and procedural information, definitions of variables, the format and file type of the data and software used to collect and/or process the data. How will this be captured and recorded?

Ethics and Intellectual Property

Detail any ethical and privacy issues, including the consent of participants. Explain the copyright/IPR and whether there are any data licensing issues – either for data you are reusing, or your data which you will make available to others.

Storage and Backup

Give a rough idea of data volume. Say where and on what media you will store data, and how they will be backed-up. Mention security measures to protect data which are sensitive or valuable. Who will have access to the data during the project and how will this be controlled?

Data Sharing

Note who would be interested in your data, and describe how you will make them available (with any restrictions). Detail any reasons not to share, as well as embargo periods or if you want time to exploit your data for publishing.

Selection and Preservation

Consider what data are worth selecting for long-term access and preservation. Say where you intend to deposit the data, such as in UEL’s data repository (data.uel.ac.uk) or a subject repository. How long should data be retained?

APPENDIX L – RECRUITMENT EMAIL TEMPLATES

Email to be circulated to organisations

Subject header: Call for research participants

“Dear [name of service gatekeeper],

I am a trainee clinical psychologist at UEL and wish to interview clinical psychologists/clinical neuropsychologists who support people with aphasia as part of an MDT. I am hoping this research will improve our understanding of how clinical psychologists can best support their MDT colleagues in addressing emotional outcomes when working with people with aphasia.

As [name of service] employs clinical psychologists with experience in this area, I would be grateful if you could help with recruitment by circulating the below email and attached information sheet to relevant members of your team.

This research project has been ethically approved by UEL [insert approval details] and has been granted Health Research Authority (HRA) approval [insert IRAS project ID] to recruit. You do not need to reply to this email but if you have any questions about the research please do not hesitate to get in touch with me using the email address below.

Many thanks in advance for your cooperation and support.

Kind Regards,

[name]
Trainee Clinical Psychologist
University of East London”

Email to be circulated to prospective participants

Subject header: Call for research participants

"

- Are you a clinical psychologist?
- Do you work in an MDT that supports people with aphasia in their rehabilitation?
- Can you give up to an hour of your time to participate in an interview?

I am a trainee clinical psychologist studying for my doctorate at the University of East London and am inviting you to participate in a research project by taking part in a one-off interview.

The research aims to find out more about clinical psychologists' understandings of the emotional outcomes associated with aphasia and their experiences of working in MDTs that support people with aphasia.

Participation will involve taking part in an online interview over Microsoft Teams. In the interview, you might be asked about the following topics:

- How you make sense of the emotional or psychosocial aspects of aphasia
- Your experiences of working psychologically with people with aphasia
- Any other types of work you do as a member of the MDT
- Your experiences of working with other professionals in your team (e.g. Speech and Language Therapists, Occupational Therapists etc.)
- What you find helpful/unhelpful when working with your MDT colleagues

I'm interested. What next? If you are interested in participating it is advised that you take some time to read the attached participant information sheet. If you would like to express your interest and/or have any questions, please contact:

[name of researcher]
[UEL email address]

Please note this research project has been ethically approved by UEL [insert approval details] and has been granted Health Research Authority (HRA) approval [insert IRAS project ID]. You do not need to reply to this email but if you have any questions about the research please do not hesitate to get in touch with me using the email address below.

Thank you for taking the time to read this email. Please feel welcome to share this email with anyone you think may be interested in participating.

Kind Regards

[name]
Trainee Clinical Psychologist
University of East London"

APPENDIX M – INTERVIEW GUIDE

Introduction

- Greeting
- Checking consent - did they have any questions about anything on the form?
- Reminders:
    - Stopping the interview - *"Just to remind you, we can stop the interview at any point. You don't need to give a reason, just tell me you'd like to stop or pause."*
    - Debrief letter - *"Once we've finished I'll send over a debrief letter with some details on it. But you have my contact details and my supervisors already on the participant information sheet"*

- Any questions
- Start recording

Interview

General questions about service and length of time worked there:

1. Can you tell me a bit about the service you work in where you have worked with people with aphasia?

2. How long have you worked in the service for?

3. Is this the first role you have been in where you have worked with people with aphasia?

Work with people with aphasia:

4. Could you tell me a little bit about the type of work you do or have done with people with aphasia and how you have found it?

5. What is your understanding of the emotional and/or psychosocial impact of aphasia for some of the people you have worked with?

- What kinds of things do PWA tell you about how they experience their aphasia?

6. What is it like for you working as part of an MDT with people with aphasia?

7. Do you feel this understanding is shared with other professionals in your team?

- How/how not?
- Do you feel that other professionals in your team share your understanding/have an understanding of the emotional impact of

aphasia?

8. Do you ever work jointly with other people in the MDT?
- If so, how have you found this?
- If not, why not?

9. Is there anything challenging about working in this way?
- If so, what?
- If not, what has made it successful/helpful?

10. What do you feel is important when working as a team/jointly with people with aphasia?

11. *If not already addressed in responses to previous questions*: Does your work ever involve supporting other members of the MDT in their work with people with aphasia?

- If yes, what does this support look like?

12. *If not already addressed in responses to previous questions:* Do you find other members of the MDT supportive of your work with people with aphasia?

- If so, what does this look like?
- If not, would you like to feel more supported? What would this look like?

13. Is there anything else that you would like to share about the work you do with people with aphasia or about working in an MDT

Ending

- Thank you for giving your time for this interview
- Do you have any questions for me?
- Withdrawing data – *"If you did want to withdraw your data after the interview, you have 3 weeks from today to do so*"

APPENDIX N – REFLEXIVE JOURNAL EXTRACTS

Familiarisation

...For instance, I wondered whether there was a pattern by which participants with less experience felt more anxious about working with people with aphasia. Or whether people working in acute settings had to rely more on family members to get to know the person as they have less time to work therapeutically. I started to notice when participants across interviews said the same things about their work with people with aphasia – e.g., that they find it rewarding, or that working with frustration is always a factor.

At this stage (and perhaps during transcription) I also noticed my own tendency to follow up on aspects of the interviewee's answers to questions. For instance, being particularly driven to ask about differences in their work with people with aphasia compared to other populations highlighted my bias towards seeing aphasia as having unique emotional consequences. Recognising this allowed me to step back during later parts of the analysis, and be driven more by the data, producing themes which hopefully reflect the clinicians' experiences and views, and correspond to the research's aim.

Coding

I have noticed myself becoming more selective with data segments I am applying codes to from when I coded my first interview. I have also noticed that the way I am coding the data is becoming more interpretive and I am becoming more confident in making more latent interpretations of the data.

APPENDIX O – EXTRACTS OF NOTES MADE DURING ANALYSIS

<u>During reading, transcription, and coding:</u>

- *Participants seem to have worked therapeutically less with people with receptive difficulties or very severe aphasia– have less strategies for this*

    - *And harder to assess – e.g. both in acquired and PPA (i.e. semantic)*
    - *Can leave therapist psychologist helpless (Georgia)*

- *Difference in role within acute and community services*
    - *Do those working in acute or inpatient settings notice more difficulties with people getting basic needs met? And frustration around this, lack of control*
        - *Lisa and Ashley*
    - *Do those working in acute settings need to rely more on other staff, who have more time with patients with aphasia?*

- *Frustration nearly always a factor*
    - *Can make therapy more difficult/challenging – importance of openness and honesty*
    - *Understanding can be a challenge for the clinician – managing frustration during sessions when you are not able to understand. Can be hard to balance*
    - *But therapy offers chance to work with/overcome issues with frustration*
    - *Loved ones also experience frustration – for themselves and on behalf of the PWA*

- *Social isolation/anxiety often an issue – people become withdrawn. Psych has a role in supporting people to put themselves out there and practice their communication – e.g. in community*
    - *Optimising social participation (Aimee) – and linking in with wider system as supporting this work*

<u>Phase 3: Generating initial themes</u>

<u>Moving beyond language</u>

- *With time and through working with significant others you can get a sense of what is important to the person and this allows you to move beyond barriers that having limited language presents for working psychologically*
    - *E.g. connecting with values*
    - *Understanding body language, gesture etc.*
    - *Using the person's idiosyncratic communication style*
    - *Connecting with colleagues who can help you ascertain what is important to the person – e.g. SLTs, OTs*

<u>Therapy dependent on language ability vs. language ability doesn't matter</u>

- *This cluster came about through realising there were some conflicting statements about how people with more severe forms of aphasia are able to access talking therapy/psychology interventions – rather than separating these views out thought would be interesting to explore these ideas as sitting along a spectrum; particularly as some conflicting statements were observed within data items (e.g. Lisa)*
- *Some people discuss that talking therapy will be limited and there being a need to 'be realistic', in favour of adopting more indirect methods of treatment; whilst others discussed how people with even severe aphasia can be more included in therapy process – e.g., through use of more values based therapies and inclusion of family members/loved ones*

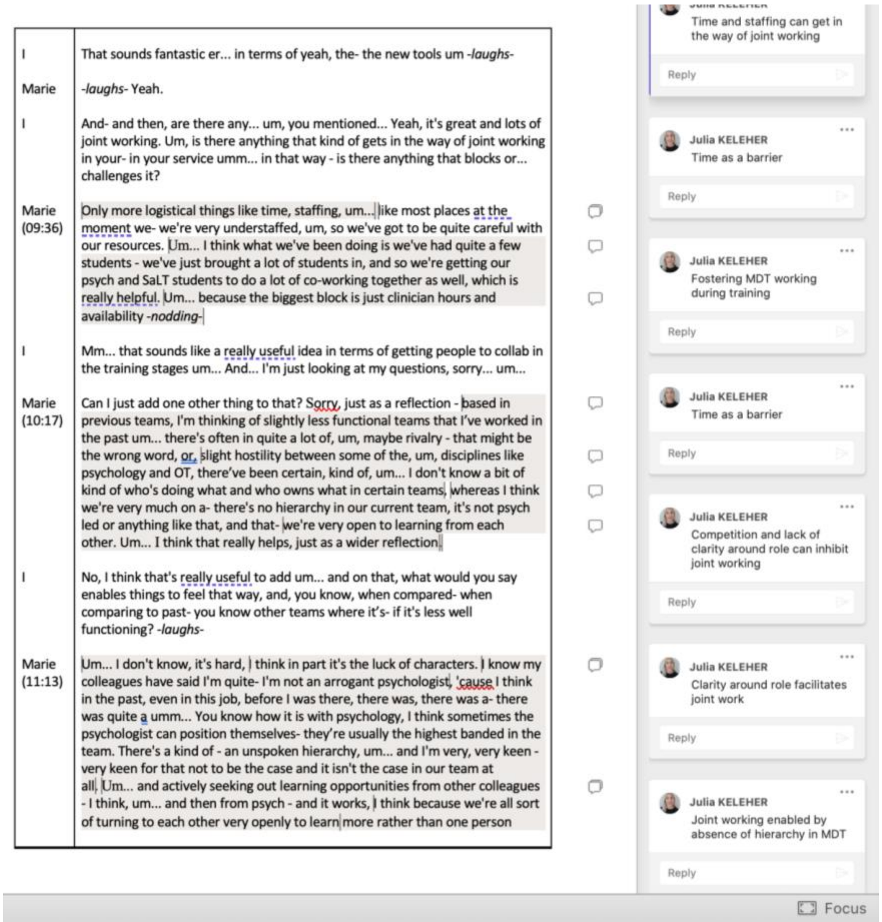
<u>Something about how psychologists view their position within the team</u>

- *Some interesting extracts from interview with Marie where she was reflecting on not being an 'arrogant' psychologist and the absence of a hierarchy being a positive thing. This felt like an important bit of data relevant to research question 3.*
- *But couldn't see anything else within the dataset reflecting this at first*
    - *Then came across an extract of interview with Ashley about it being 'nice' to get to work with everyone, and importance to them of sitting on the ward with the MDT and not 'up in the psychology dept.' despite having this 'unique' role and higher banding*

APPENDIX P – CODED INTERVIEW EXTRACT

Figure 3

Coded Interview Extract



I	That sounds fantastic er... in terms of yeah, the- the new tools um *-laughs-*
Marie	*-laughs-* Yeah.
I	And- and then, are there any... um, you mentioned... Yeah, it's great and lots of joint working. Um, is there anything that kind of gets in the way of joint working in your- in your service umm... in that way - is there anything that blocks or... challenges it?
Marie (09:36)	Only more logistical things like time, staffing, um... like most places at the moment we- we're very understaffed, um, so we've got to be quite careful with our resources. Um... I think what we've been doing is we've had quite a few students - we've just brought a lot of students in, and so we're getting our psych and SaLT students to do a lot of co-working together as well, which is really helpful. Um... because the biggest block is just clinician hours and availability *-nodding-*
I	Mm... that sounds like a really useful idea in terms of getting people to collab in the training stages um... And... I'm just looking at my questions, sorry... um...
Marie (10:17)	Can I just add one other thing to that? Sorry, just as a reflection - based in previous teams, I'm thinking of slightly less functional teams that I've worked in the past um... there's often in quite a lot of, um, maybe rivalry - that might be the wrong word, or, slight hostility between some of the, um, disciplines like psychology and OT, there've been certain, kind of, um... I don't know a bit of kind of who's doing what and who owns what in certain teams, whereas I think we're very much on a- there's no hierarchy in our current team, it's not psych led or anything like that, and that- we're very open to learning from each other. Um... I think that really helps, just as a wider reflection.
I	No, I think that's really useful to add um... and on that, what would you say enables things to feel that way, and, you know, when compared- when comparing to past- you know other teams where it's- if it's less well functioning? *-laughs-*
Marie (11:13)	Um... I don't know, it's hard, I think in part it's the luck of characters. I know my colleagues have said I'm quite- I'm not an arrogant psychologist, 'cause I think in the past, even in this job, before I was there, there was, there was a- there was quite a umm... You know how it is with psychology, I think sometimes the psychologist can position themselves- they're usually the highest banded in the team. There's a kind of - an unspoken hierarchy, um... and I'm very, very keen - very keen for that not to be the case and it isn't the case in our team at all. Um... and actively seeking out learning opportunities from other colleagues - I think, um... and then from psych - and it works, I think because we're all sort of turning to each other very openly to learn more rather than one person

Time and staffing can get in the way of joint working

Julia KELEHER
Time as a barrier

Julia KELEHER
Fostering MDT working during training

Julia KELEHER
Time as a barrier

Julia KELEHER
Competition and lack of clarity around role can inhibit joint working

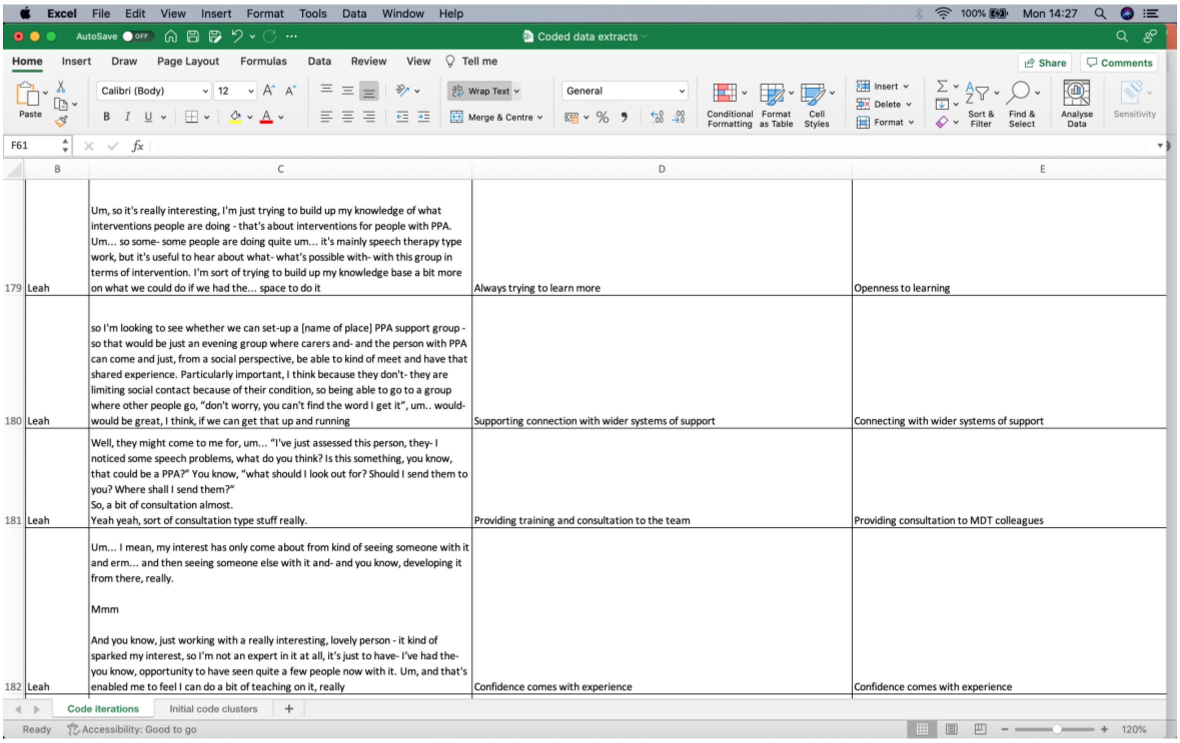
Julia KELEHER
Clarity around role facilitates joint work

Julia KELEHER
Joint working enabled by absence of hierarchy in MDT

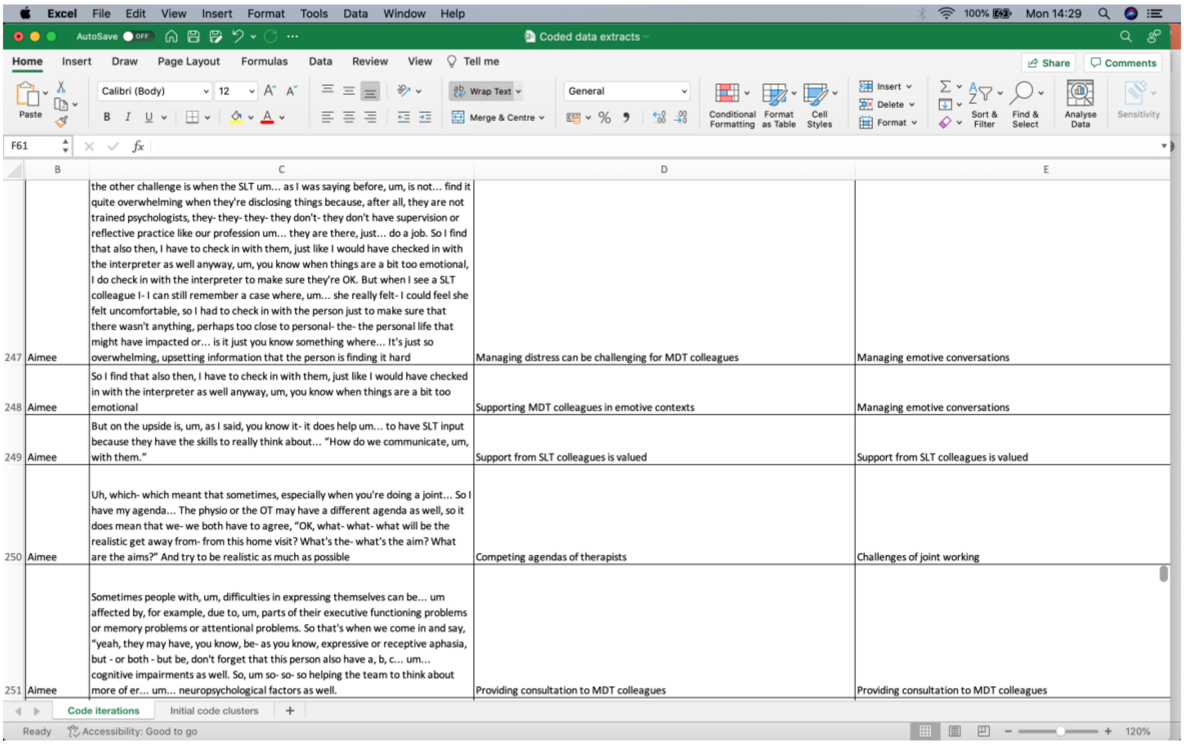
APPENDIX Q – EXTRACTS OF EXCEL SPREADSHEET WITH DATA EXTRACTS AND CODE ITERATIONS

Figure 4

Data Extracts and Code Iterations



	B	C	D	E
179	Leah	Um, so it's really interesting, I'm just trying to build up my knowledge of what interventions people are doing - that's about interventions for people with PPA. Um... so some- some people are doing quite um... it's mainly speech therapy type work, but it's useful to hear about what- what's possible with- with this group in terms of intervention. I'm sort of trying to build up my knowledge base a bit more on what we could do if we had the... space to do it	Always trying to learn more	Openness to learning
180	Leah	so I'm looking to see whether we can set-up a [name of place] PPA support group - so that would be just an evening group where carers and- and the person with PPA can come and just, from a social perspective, be able to kind of meet and have that shared experience. Particularly important, I think because they don't- they are limiting social contact because of their condition, so being able to go to a group where other people go, "don't worry, you can't find the word I get it", um.. would-would be great, I think, if we can get that up and running	Supporting connection with wider systems of support	Connecting with wider systems of support
181	Leah	Well, they might come to me for, um... "I've just assessed this person, they- I noticed some speech problems, what do you think? Is this something, you know, that could be a PPA?" You know, "what should I look out for? Should I send them to you? Where shall I send them?" So, a bit of consultation almost. Yeah yeah, sort of consultation type stuff really.	Providing training and consultation to the team	Providing consultation to MDT colleagues
182	Leah	Um... I mean, my interest has only come about from kind of seeing someone with it and erm... and then seeing someone else with it and- and you know, developing it from there, really. Mmm And you know, just working with a really interesting, lovely person - it kind of sparked my interest, so I'm not an expert in it at all, it's just to have- I've had the- you know, opportunity to have seen quite a few people now with it. Um, and that's enabled me to feel I can do a bit of teaching on it, really	Confidence comes with experience	Confidence comes with experience



	B	C	D	E
247	Aimee	the other challenge is when the SLT um... as I was saying before, um, is not... find it quite overwhelming when they're disclosing things because, after all, they are not trained psychologists, they- they- they- they don't- they don't have supervision or reflective practice like our profession um... they are there, just... do a job. So I find that also then, I have to check in with them, just like I would have checked in with the interpreter as well anyway, um, you know when things are a bit too emotional, I do check in with the interpreter to make sure they're OK. But when I see a SLT colleague I- I can still remember a case where, um... she really felt- I could feel she felt uncomfortable, so I had to check in with the person just to make sure that there wasn't anything, perhaps too close to personal- the- the personal life that might have impacted or... is it just you know something where... It's just so overwhelming, upsetting information that the person is finding it hard	Managing distress can be challenging for MDT colleagues	Managing emotive conversations
248	Aimee	So I find that also then, I have to check in with them, just like I would have checked in with the interpreter as well anyway, um, you know when things are a bit too emotional	Supporting MDT colleagues in emotive contexts	Managing emotive conversations
249	Aimee	But on the upside is, um, as I said, you know it- it does help um... to have SLT input because they have the skills to really think about... "How do we communicate, um, with them."	Support from SLT colleagues is valued	Support from SLT colleagues is valued
250	Aimee	Uh, which- which meant that sometimes, especially when you're doing a joint... So I have my agenda... The physio or the OT may have a different agenda as well, so it does mean that we- we both have to agree, "OK, what- what- what will be the realistic get away from- from this home visit? What's the- what's the aim? What are the aims?" And try to be realistic as much as possible	Competing agendas of therapists	Challenges of joint working
251	Aimee	Sometimes people with, um, difficulties in expressing themselves can be... um affected by, for example, due to, um, parts of their executive functioning problems or memory problems or attentional problems. So that's when we come in and say, "yeah, they may have, you know, be- as you know, expressive or receptive aphasia, but - or both - but be, don't forget that this person also have a, b, c... um... cognitive impairments as well. So, um so- so- so helping the team to think about more of er... um... neuropsychological factors as well.	Providing consultation to MDT colleagues	Providing consultation to MDT colleagues

APPENDIX R – THEMATIC MAPPING USED IN ANALYSIS

Figure 5

Clustering Codes into Themes

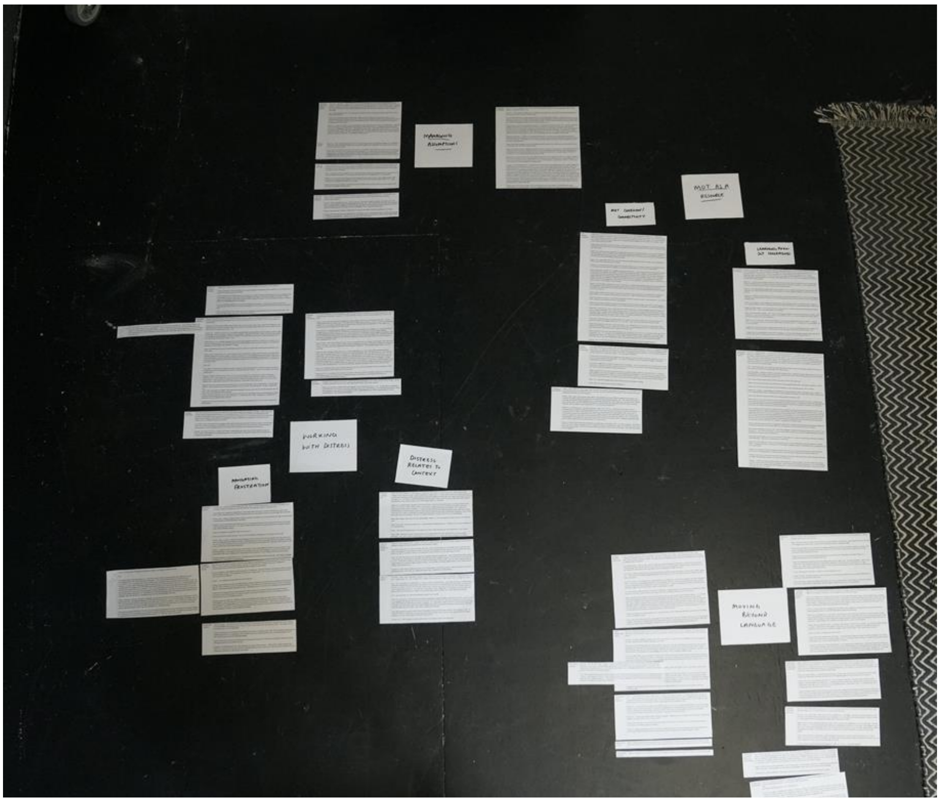


Figure 6

Thematic Map 1

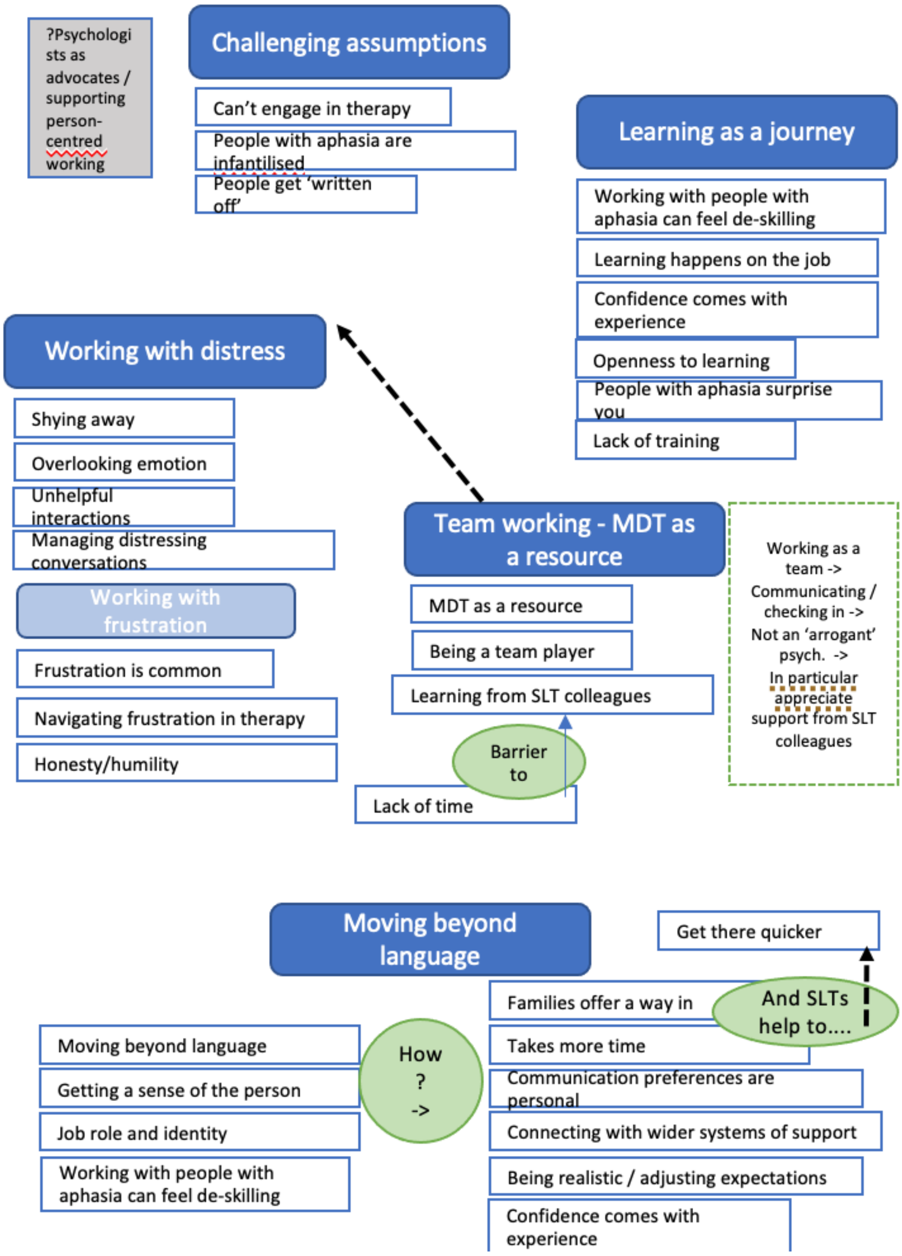


Figure 7

Thematic Map 2

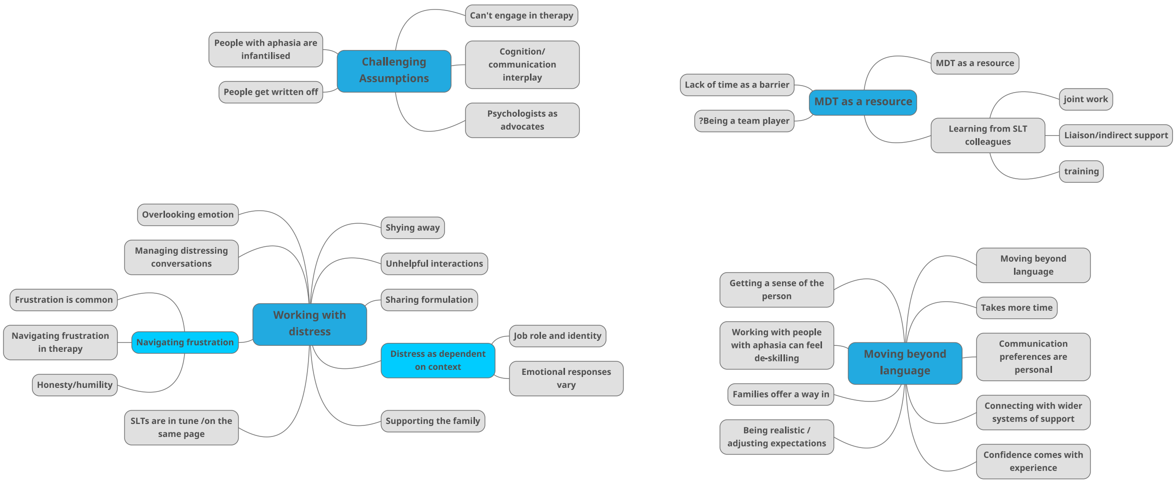
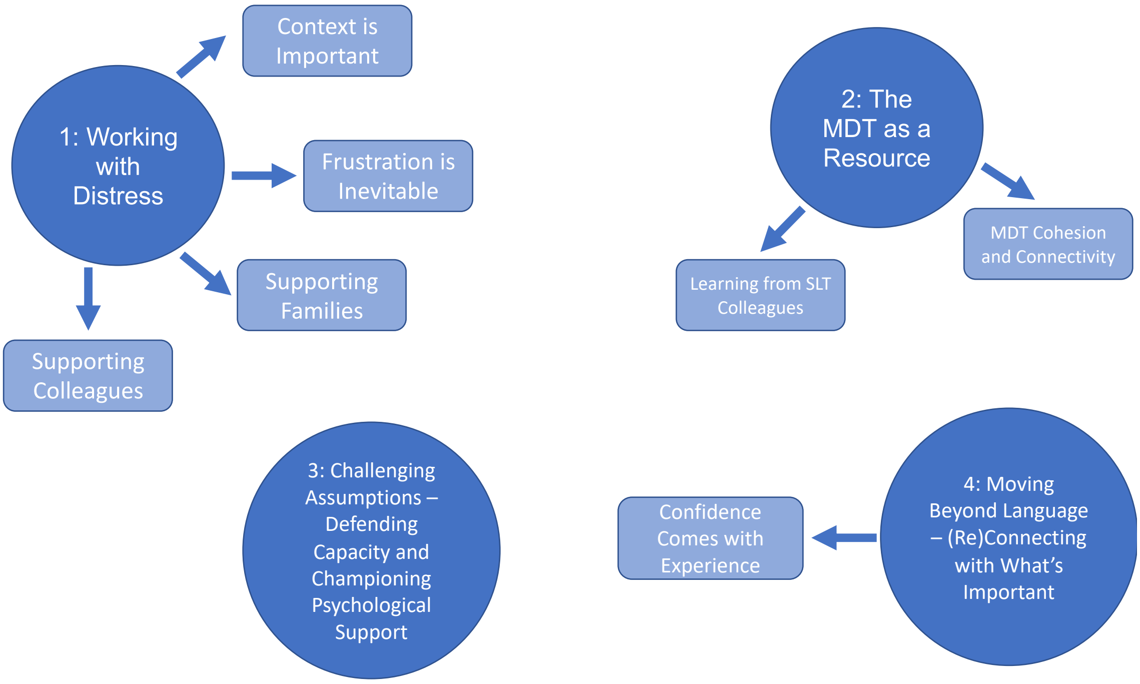


Figure 8

Final Thematic Map



APPENDIX S – CODES CLUSTERED INTO CANDIDATE THEMES

Challenging assumptions	
People with aphasia are infantilised	Lisa: So I think this- you know, people can sometimes infantilise erm... people with aphasia. Erm... and sort of think that there's- there's more cognitive problems than there actually is because of the way that they present with the communication problems. Lisa: this I think is something that erm... I think people who... people who maybe are younger or who have a very- who were very active, maybe very high functioning before their stroke... erm... and they will often tell me that- how frustrating it is that people think they're stupid. Erm, and I hate to say it like that but that's how they- that's how patients will vocalise it, you know, and this real sort of I'm fine, you know, I'm intelligent, I can- I remember things, I know. Georgia: How people say- I feel like it- people think I'm stupid or I feel stupid. I feel like my intelligence has changed Georgia: Sometimes what you find, is people speak in a patronizing way and it is literally the worst. It's that patronizing way or feeling like or sounding like... Almost the person is a bit 'stupid' because of their communication and like, obviously that is completely awful in the worst, and that's when you have to sort of feed back
Embarrassment	Aimee: Uh, particularly with the higher functioning people, they tend to, um, find it embarrassing to actually try and go... so what their strategy is, will be trying to go round rather- so rather than describing the target word they go round the words to describe something... uh, and they find it really... frustrating and humiliating and embarrassing... Leah: ...so people can have a- have a good go at a conversation, but they just can't get their words out very well, so they'll be stumbling and stuttering over their words. And they know what.. things are, they can find the words but they just can't get them out. And they can be quite- that can be quite socially awkward for people...
People get written off	Lisa: ...and I think it- it's... that's- that can be very challenging for nursing staff. Erm... for all staff really but I think more so nursing staff where, you know, you see someone who just- who just can't get their message across and then there's this assumption that well they can't remember things or you know... that they- they just can't talk so they don't sort of maybe stop and try, and try other things Lisa: It's important to think of cognition as well as aphasia and then- but also not to make assumptions- I suppose it's not to make assumptions about people. Erm, just based on the fact that they're struggling with their communication Ashley: Erm, I'm not sure that the physios or the OTs really think about it that much. Um... yeah. Maybe though. I think sometimes people might just get written off a bit because they can't say what it is that's bothering them. Um... maybe there's just an assumption that they're fine, or not fine. Marie: um but I do find sometimes... particularly with this population they are maybe a little bit quicker to prescribe and write off... the possibility of talking therapy

People with aphasia can't engage in therapy / therapy is possible	Lisa: Yeah... yeah. Well, I- I suppose I try and see it as not all that different from working with people who don't have aphasia. So I suppose I'm trying to make it equitable in the sense that, you know, I- I- I think sometimes- I think sometimes the ther- so most of my referrals for psychology input come from the therapists on the ward. Erm, and I often... I might not get a referral sometimes cos people might make the assumption, well this person isn't going to be able to engage in... in psychology Lisa: ...I think the reality is often... is if someone has a receptive aphasia I'm probably not doing a longer piece of sort of clinical work with them. Ashley: Erm, but at the same time I think there's a slightly unrealistic expectation of psychology in terms of our- I'll sometimes get referrals for talking therapy and it's... it's sort of like, it's going to be limited. Erm, we obviously try as best as we can to... to manage that. But you just can't do talking therapy in the same way that you might with someone who's completely fluent in their speech Marie: Um... I think an overall sort of systemic challenge to start [inaudible] when someone has aphasia there's a belief that they can't engage in, um, talking therapy or psychology, and they I find that the um... [inaudible] are often quite quick to jump to um... antidepressant medication, and things like that and so that's- that's a kind of quite a uniform issue I've seen and something that I have to fight quite strongly against - often I'm not anti prescription where I think it's appropriate and there is a lot of times where it is...um but I do find sometimes... particularly with this population they are maybe a little bit quicker to prescribe and write off... the possibility of talking therapy... Donna: Erm... And... whilst people might not think that psychological therapy is appropriate for people, um, with aphasia, that isn't true because there are ways that you can adapt your approach to working with those people to make sure that they're able to access it as well Marie: there's so much that's so complex and unique about...[inaudible]...with aphasia how much you rely on language and actually how much you can communicate, even without language... For someone who, assuming that they've got receptive language intact, or at least to a degree, then there's loads- there's loads you can actually do to work with someone who's struggling with aphasia. And even if even if they're receptive, language is impaired and you're creative and you use different modalities, there- there's is tons you can do

Psychologists as advocates	Lisa: Erm... erm... so I think my role is in a way, it's sort of advocating a little bit for- for how psychology might be able to support in a particular situation... erm... Lisa: Erm... I think as well with aphasia erm... It's difficult because often times I get involved with capacity assessments on the ward as well – that's a sort of, a part of my role. Lisa: And I think often times, and quite appropriately, it's a speech therapist who might do a capacity assessment or one of the other- you know, one of the other medics or one of the other therapists erm... But I- I'd be keen to not not get involved just because someone has a communication difficulty and I think- I- I've often done joint capacity assessments with myself and a speech and language therapist around a- around a particular issue. Ashley: Yeah, just I think that recognition that people can't advocate for themselves as easily. Erm... so for example we had a patient recently who um, we knew, well I knew because we spoke to her friend, that she had just really important structure and routine that was like so integral to her, she gets really stressed if things aren't like, to plan, she'd always be up and ready and we were finding that she would often still like in her night gown at like 10am... and because she couldn't really ask to get up and get ready and it hadn't been offered to her... so...um... just making sure that actually we're thinking about the patient in a quite a person centred way and maybe being a bit more pre-emptive of their needs... Ashley: And I think also – it comes up a bit in capacity assessments – you know, not assuming someone doesn't have capacity because they're aphasic. Like, taking the time to really like try and help them communicate their kind of thoughts and wishes if they can and if another way... um, just some of those things not to yeah, just writing someone off because they can't say anything, yeah... Ashley: I think there's definitely a specific role for psychology and speech in that - within our team I think we're the ones who tend to be the- who think of that sort of stuff Ashley: Erm, I find as well that... people obviously find it harder to advocate for themselves so maybe a bit of work with the team as well. And our team are very good to be fair but erm, kind of thinking about alternative ways to communicate so, you know, can they write something down erm... err... can they kind of, gesture...err... just other, other communication methods erm... and sometimes doing that with partners as well. Aimee: Um, but he also has quite a few other cognitive impairments as well, which meant that, um... trying to advocate for him - because he also has a lot of medical appointments - trying to advocate for him that um... and also advocate for him, but also empowering him to be to be able to say, "no, you can only attend one... appointment each time... and that you needs a gap because the person gets very fatigued as well Georgia: I'm a real champion for um, making sure that everyone has like, the equivalent service. So, I might be going a bit off topic here [name of interviewer] so stop me if I am, but um,I think a really important point to mention is part of the [name of project], we have to use a bunch of outcome measures and the two mood measures are the GAD-7 and the PHQ-9, which aren't appropriate for people who have communication difficulties. So, right at the start of this project, before I was even involved and I saw that they were using those measures, I said, "that's completely unacceptable to use for people with communication difficulties. You need to have one like the DISC, or whatever we choose, that is appropriate so people can engage and rate their mood." And then the top person said, "Oh no, no, but this is what we've decided on now. So if it doesn't work, if you can't use it with them then use it with the carer", and so then I was like, "absolutely not you can not ask the carer to fill in that form to rate the persons mood". So, it's a real bugbear of mine and so, um, when we come to the end of this project, that's going to be one of my recommendations. If these outcome measures are to continue, you need an appropriate measure for people with communication difficulties, because it's such a huge proportion, [name of interviewer], even cognitive difficulties Georgia: And it's like, well, that's again a lack of understanding about what aphasia and other difficulties around communication are. So, I think there's a bit of like, upskilling that's needed to then appreciate what that might mean for someone

Working with distress	
Overlooking emotions	Lisa: cos I think often times the MDT will think, well this is- this is just speech and language therapy, erm, but- but there are so many- there are so many psychological aspects of living with aphasia that- that it's useful for, erm, for psychology to be involved with... Ashley: Erm, I think people probably rely a bit more on like, are they crying in every session rather than thinking too much about the impact on mood and things. I think that also because there's psychologists within the team that might be kind of, just, left to us to consider and less their... role. Ashley: Erm... I think there's often an un- unrealistic expectation from psychology that we can solve things, we have a magic wand [laugh] and we just 'know everything and fix everything'... which can be unhelpful. I think a lot of times when people are- patients are having difficulties, whatever it might be, it's very much like, 'go and speak to your psychologist about it' but actually, like, we can't work miracles... yeah. Marie: Physio... um... our physio colleagues are very kind of psychologically informed in our team, um... and keen to learn, but I know there are often... uh, maybe not quite as much understanding in physio and you can often see- see frustration building in communication there sometimes. -nodding- Marie: and then there's the mood, mental health, adjustment side as well, which often I find has been overlooked in, um, neuro-rehab Aimee: I guess it may not be as um... at the forefront of their mind because... people may have aphasia only, which meant that there might not be as much, well there won't be any physio input, so the physiotherapist would maybe thinking more... I don't think aphasia- someone with aphasia will really pop into their minds [inaudible], but having said that, I think there is a overall understanding that someone with a neurological condition tends to have common themes about... adjustment or their quality of life. Mm... Ok... They might not recognise- they might not be able to recognise in the individual patient, but they are aware of the themes so they- there- there is a theoretical understanding, but whether they will be able to... see it in front of them, that might be a different story Georgia: Sometimes, like the speech- I mean, I'm sorry if this sounds bad, but sometimes this speech and language therapists, I think... they're quite- they're so focused on their like specific goals and like their specific sort of tasks that they're doing... I- I feel like that they sometimes don't appreciate the psychological element and like the loss and what it actually means, 'cause they're so focused on their specific um... intervention, if that makes sense Georgia: there was a comment yesterday actually, from one of the stroke buddies that I'm working with... Someone asked him um... Does the person have communication difficulties and in- and then the buddy was like, "oh yeah, I should think so." And it's like, "what are you on about?" Like, I feel like he totally got the wrong end of the stick and then they were like, "oh does- does he have difficulties with his speech?" He said, "Oh no, he's fine, he's- it's- he's slurred though". And it's like, well, that's again a lack of understanding about what aphasia and other difficulties around communication are. So, I think there's a bit of like, upskilling that's needed to then appreciate what that might mean for someone Georgia: So in answer your question, no, I don't- I don't think they always appreciate that sort of loss and that adjustment and frustration

SLTs are in tune with emotions	Ashley: Erm... [pause]. I'm not sure actually. Our speech therapists are very kind of, in tune with that. Ashley: I think a lot of it does come back on the speech therapists though because they spend the most time with them so they're more likely to pick up on anything. Lisa: I would say the only thing that [audio unclear] is that... I think- I think speech therapists are- are very skilled with this and actually I'd say a lot of my speech therapy colleagues, they might've even had very similar conversations or talked about very similar topics w-with, with people that they've met on the wards. Erm, and probably have a level of confidence about- about attempting that communication Lisa: it can build frustration and I think speech therapists are very good at... at being able to kind of hold that and understand that and use that and I've seen my colleagues do that in sessions and in joint sessions with speech therapists as well. Aimee: we do get quite a few referrals from my SLT colleagues uh, about people whom they- they, you know, um... they want psychological input. They- they- they do refer people to us.
Managing emotive conversations	Lisa: I think sometimes, and understandably, the MD- the other members of the MDT can sometimes shy away from, sort of being involved in those sort of moments – I've found that they've found it useful to have psychology sort of support with that. Ashley: we got a guy who's got quite a moderate- err- severe aphasia and he was very emotionally labile. Erm... but the therapist- like the OTs and physios weren't really sure how to manage that in sessions or couldn't... couldn't really discuss it with him um... very easily so, maybe giving some tips and ideas oh kind of how to manage that, um... that might be an example of kind of something that we come up with Donna: but um... the speech language therapist was kind of finding that really tricky to navigate and... on her own trying to manage it and, so, I joined her and, um... we did some- we did some work with them around, you know, different communication styles and turn-taking and... um... and we videoed um, a conversation - all of us having a conversation – and then we all looked back and reflected on our own communication and, um... that sort of thing... But... certainly I know from the speech and language therapist she felt much better supported not having to do those sessions on her own because it was a challenging piece of work Aimee: Aimee: I- I think some of them are very... they're not sure what to do. Uh, because... Yeah, because their- their- their role is to actually, uh, well try to enhance, or give- provide strategies to, you know, to alleviate the symptoms of aphasia, but however, uh, when people start crying I think- I think they find it really hard... Not everybody, though, that's-so- so- it's a mixed bag Aimee: the other challenge is when the SLT um... as I was saying before, um, is not... find it quite overwhelming when they're disclosing things because, after all, they are not trained psychologists, they- they- they- they don't- they don't have supervision or reflective practice like our profession um... they are there, just... do a job. So I find that also then, I have to check in with them, just like I would have checked in with the interpreter as well anyway, um, you know when things are a bit too emotional, I do check in with the interpreter to make sure they're OK. But when I see a SLT colleague I- I can still remember a case where, um... she really felt- I could feel she felt uncomfortable, so I had to check in with the person just to make sure that there wasn't anything, perhaps too close to personal- the- the personal life that might have impacted or... is it just you know something where... It's just so overwhelming, upsetting information that the person is finding it hard Aimee: So I find that also then, I have to check in with them, just like I would have checked in with the interpreter as well anyway, um, you know when things are a bit too emotional Georgia: So, it's- I'm not doing it at the moment, but I think we did like six months of monthly training and, um, those were around different topics. So, one was sort of managing distressing conversations, so anything like that around, um, communication difficulties would have come up

Sharing formulation	Georgia: Just your general formulation, I guess if you've got psychologists in your MDT to pick up on these things... just sort of general comments about how, you know, difficult that must be or you know, whatever Marie: we in our MDT meetings with, as you'd expect, kind of sharing formulations... Um... sharing different perspectives, particularly where we've got, um, you know, difficulties with families understanding or if it's high expressed emotion, things like that going on, we've got that sort of aspect, as well as supporting the team in their understanding of a client's presentation um... But particularly with aphasia
Subtheme 1: Frustration is common	
Frustration is common / Frustration as Inevitable	Lisa: But erm... sort of in the acute setting I think what- what is overwhelmingly obvious is the sense of frustration, erm... you know, of real, sort of deep frustration with- with just not being able to get your message across Lisa: And just not- maybe not – being able to communicate about that and the- and the frustration as a result of that. That's, that's mainly what I see in my work and mainly what I see with people at that sort of acute stage after their stroke Ashley: Yeah... I think one thing that often comes up is people's frustration. Erm, so because they can't get across their point or communicate as effectively as they could before Marie: um and so with that kind of aphasia you're then seeing people become very frustrated and then the more kind of irritation and confusion aspect of it... Um, where as with the clients who do have that awareness of, um, again frustration with- with word finding perhaps Marie: the frustration is huge, that's- that's really common Leah: but also real frustration because... we see a lot of frustration and people just can't get their point across. Donna: I think... I mean I- I think for everyone language is such a key part to how we communicate with one another, that when you suddenly lose the ability to do that, it's devastating and, um, it can cause huge amounts of frustration and anger, erm and- and a lot of sadness as well. Erm, and then to not be able to communicate that - easily with other people, just you know, it's kind of layer upon layer of frustration Donna: ...sometimes they're experiencing so much emotion, it's just really difficult for them. Erm, and, you know, I would find it frustrating if I was trying to tell someone something and they just weren't getting it. Erm, and I've tried every way I could and they still weren't getting it and I really wanted to communicate it, I can't imagine anything more frustrating... Georgia: Dependent on the extent of it and... how they perceive it and how it's affecting their life... but I think, um, people have said to me... Frustration is a massive thing

Navigating frustration in therapy	Lisa: there are often a lot of barriers so you know, you might go in thinking about, you know, wanting to ask about a certain topic or... have a certain conversation and you- you just can’t get there and, you know there’s just a breakdown in communication and a lot of it is kind of dealing with that frustration in the moment Lisa: so actually you- your attempt to have a session sort of brings up... this- this is kind of a live example of what- you know of the frustration and erm... this change that I’m gonna have to get used to. This is it here in action and I think, you kind of have to sit with that difficulty Ashley: ... just managing the frustration that comes with that Donna: I have worked with people with aphasia who’re really not tolerant at all and they find it really hard when you don't get what they're trying to communicate quickly, and that's a lot harder to work with because then it's that sort of delicate balance of wanting to properly understand but not... agitating them even more that you're repeatedly misunderstanding Donna: Erm, but I guess from the therapist point of view it's about not reacting to that frustration and not taking it personally and not thinking right, I'm a useless therapist, but it's just being able to sit with it and thinking, look, this is a normal reaction to a very frustrating situation Georgia: I guess the other, um, challenge is maybe how frustrated some people get. When they're trying to have a conversation, so you're thinking about, you know, while they're trying to either express themselves or understand what you're saying. So it's thinking about, um... Just reassuring, you know, “take your time”... “We can have a break whenever you want”, um... and a lot of, “can I just check I've understood what you said” a lot of sort of checking that I've understood them correctly. So, I do that a lot with people with aphasia.
Honesty and empathy	Leah: And it was... And myself and my trainee were like, “we don't know what this means”, and you know, you're trying to be really empathic with people and not- not say, “I'm sorry I don't know what you mean too much”... But equally, not just saying yes when you don't understand Donna: I mean for me, it's just kind of being really honest about it and saying, “look, I can see this is really annoying you and winding you up that I'm not getting this and I'm really sorry, but it's really important that I understand properly 'cause I don't want us to go on with the misunderstanding” Donna: I mean as a professional, you know you're trained to be patient and to take time and really try and work out how that person wants to communicate with you... Georgia: So it's thinking about, um... Just reassuring, you know, “take your time”... “We can have a break whenever you want”, um... and a lot of, “can I just check I've understood what you said” a lot of sort of checking that I've understood them correctly. So, I do that a lot with people with aphasia
Subtheme 2: Distress relates to context	

Emotional responses vary	Ashley: But yeah, I suppose... it’s individual. It- it depends on the person. I’ve seen people with aphasia who’ve really struggled with it because they get so kind of wound up in trying to say... er... like a certain word or get a certain point across and get really frustrated but other people might be much more relaxed and just be like “phh” take a breath, and then they’ll start again. Erm... so I think it’s really individualised as to the impact it has on them. And you know, some people progress... really quickly in terms of their recovery, erm, other people might be a bit slower... Ashley: Um... I think it’s so individualised as to what the person values or needs and how that impact on them moving forward in their kind of rehab and recovery. So, I think I’ve definitely met people who have aphasia but also now are wheelchair dependent and are much more upset about the wheelchair than they are about the aphasia... and vice versa. Erm, it’s so individualised Marie: Yeah, hugely, I don’t have any one understanding, I think it’- it, you know, different clients present in such different ways Marie: there’s that- that fear and anxiety um... and depression and adjustment, um... So there’s no- no there’s definitely no one understanding. Marie: ...then kind of bringing it down a bit more sort of micro I think obviously each client experience is very unique. Marie: I think I go client by client and what they’re presenting with and trying to work through with them where possible what they’re- they’re sort of prese- they’re understanding of what it is they’re going through and how they’re responding to it
Impact of aphasia depends on context	Ashley: Um, I suppose really it depends a lot on, kind of, how it relates to functional outcome. You know, someone who... I dunno... for want of a better example, works in a call centre, is going to be much more affected by aphasia than like a [inaudible] left sided weakness perhaps... Lisa: yeah, I would say erm... just the- just the idea that... I think a lot of people are, at that stage when people are more acute, are getting their head around the idea of, you know, I’m not going to be able to go back and do the job I was doing before, because it’s actually so reliant on me being able to sort of express erm, you know express vocally. Lisa: I see- I see people I’ve worked with er- a couple of patients recently where... where their job role is so closely linked to being able to being able to communicate and actually, processing that loss and getting their head around, you know, who they are as a person if they’re not, you know, if they’re not, a lecturer, you know that- that was- that’s someone who I’ve very recently worked with. Erm... you know, that’s their job so it’s just a huge shift... to think about, you know, what’s life gonna be like, you know who am I without this particular type of role in my life. Erm... yeah, those kinds of things Leah: Um, and in fact had, uh, uh, one patient was a teacher with that condition and... when something was going wrong on a school trip, she couldn't get out, “stop, don't cross the road” quick enough for them to- the children to not cross the road so... um... so she sort of started to drop out of things like that because it had an effect- she just couldn't get the words out quick enough to- in a, kind of, highly charged situation... So it can affect, you know, people’s work, 'cause it often presents... earlier... pre-retirement. Um... Georgia: So I think yeah, it's definitely varied, isn't it? Dependent on the extent of it and... how they perceive it and how it's affecting their life... but I think, um, people have said to me... Frustration is a massive thing

Impact on identity	Lisa: Yeah, I think- I think a big thing for people is erm- is sort of a loss of role, and loss of identity... I probably shouldn't say loss – change really. Erm... and m-maybe loss is actually how they will see it in that moment and it is a huge loss I think... Lisa: I see- I see people I've worked with er- a couple of patients recently where... where their job role is so closely linked to being able to being able to communicate and actually, processing that loss and getting their head around, you know, who they are as a person if they're not, you know, if they're not, a lecturer, you know that- that was- that's someone who I've very recently worked with. Erm... you know, that's their job so it's just a huge shift... to think about, you know, what's life gonna be like, you know who am I without this particular type of role in my life. Erm... yeah, those kinds of things Lisa: ...you know who am I without this particular type of role in my life Leah: OK. I was just um... thinking about the impact of language on peoples identity, really, and how much... how much of our...language skills identify, kind of, who we are and get across who we are as a person. So certainly for- for the teacher that I worked with her whole life was around... language. Um... being able to speak in front of a class and that was her role in identity and I think when people were really struggling to be able to speak and communicate what they are, what they- you know what they want to say... there comes a massive loss with that Leah: Yeah, and they've got the kind of label of dementia with that and the impact of that on their identity as well... So there's the kind of... being able to communicate their needs and their wishes, and you know physically with the speech problems... Um, but also the label of dementia on top of that. Georgia: Um... I don't feel like the same person 'cause I can't express myself in the same way.
MDT as a resource	
Subtheme 1: MDT cohesion/connectivity	

MDT cohesion/connectivity	Ashley: Yeah... so we kind of all cross over so I'll do lots of joint work with occupational therapists, erm... occasionally physiotherapists like, for example if someone is feeling really anxious every time they go to a walk and it's a barrier to their rehab, then I might come and join a session for that. Erm, and that might be someone with aphasia. Erm, rehab assistants, erm... there are medical and nursing staff around – occasionally do bits together but not as much. Um... dietician... yeah. Loads of joint working in our MDT. Ashley: we have those day-to-day ad hoc chats so I think a large part of my role is consultation so I purposefully sit on the ward with the team rather than up in the psychology department so you can have sort of ad hoc chats so... yeah that works both ways I guess Marie: Yeah, I think very much especially in our MDT at the moment, it's a really lovely MDT and very sort of, a healthy and well functioning, but all in one office, which is quite good, because then there's lots of sort of cross talking and- and this... we've got three speech language therapists and so speech, psych and OT... I think very much we're all on the same page and we're all kind of constantly checking in with one another. Marie: ...it's a really lovely MDT and very sort of, a healthy and well functioning, but all in one office, which is quite good, because then there's lots of sort of cross talking Marie: Um... I think what we've been doing is we've had quite a few students - we've just brought a lot of students in, and so we're getting our psych and SaLT students to do a lot of co-working together as well, which is really helpful. Ashley: Well I guess, I feel like I'm in a slightly weird position in that erm... I work in very much in the same way as the other therapists do, like the physios, OTs, speech, so we all kind of timetable our sessions together and we all kind of sit in the same place but because I'm a band 8 and they tend to- well they are more junior, I also go to like the senior meetings and... meetings with like the consultant medical staff, things like that, so I sort of sit in the middle it feels. Kind of a weird limbo position. And also, I'm employed by a different trust to the trust I sit in so I have a lot of kind of different procedures for things and I'm not line managed by anyone there so no one can tell me off [laughs], so, things like that so... I think we're in kind of a weird... a weird position to be in the MDT Ashley: So it's a bit easier maybe for me to have a chat with our consultant about something but also know how kind of the OTs are getting on with someone because we have those day-to-day ad hoc chats so I think a large part of my role is consultation so I purposefully sit on the ward with the team rather than up in the psychology department so you can have sort of ad hoc chats so.. Marie: whereas I think we're very much on a- there's no hierarchy in our current team, it's not psych led or anything like that, and that- we're very open to learning from each other. Um... I think that really helps, just as a wider reflection Marie: Yeah, like it's honestly, it's been the best experience I've had of working in an MDT - for those reasons... um, and just learn- constantly learning from each other and constantly, Marie: And we're forever being surprised by a client where we think we might have figured out, sort of... what's going on communicatively, then something changes um... and I think having that to and fro conversation, lots of joint working erm... Marie: Um... I don't know, it's hard, I think in part it's the luck of characters. I know my colleagues have said I'm quite- I'm not an arrogant psychologist, 'cause I think in the past, even in this job, before I was there, there was, there was a- there was quite a umm... You know how it is with psychology, I think sometimes the psychologist can position themselves- they're usually the highest banded in the team. There's a kind of - an unspoken hierarchy, um... and I'm very, very keen - very keen for that not to be the case and it isn't the case in our team at all. Donna: Um... and I think being in a multidisciplinary team is part of that, because I know that I can access resources if I need to via speech and language therapy. Um... So... no, I don't... Yeah, I don't really have any concerns with that

	Donna: In my experience, joint work is just really positive... um... positive for me as a therapist, but also positive for the person that we're going to see um... because you know they get a coordinated approach and, as I've said before, that they don't have to keep repeating themselves or going over the same stuff Aimee: we tend to have quite a lot of MDT discussions. Um... because it's- it's quite it's- it's- it's quite complex, we do tend to need this... Um... SLT... to guide us not just psychology, but other disciplines as well. And likewise, um, we psychology then share information. Um... with them. So- so no, I think it's better in a way of again, might be my naive thinking, but I- I do feel that, um, we as a team in general, um, we do communicate quite well, um, to try and work more holistically Georgia: I think it obviously does depend on the person, doesn't it? And like, the type of therapist they are
Practical barriers to joint working	Lisa: Often times we can't- we don't- we're not able to coordinate to have joint sessions... Erm, it- it's... I suppose it's staffing and it's erm... err, I suppose time pressure, so... that particular person who I had in mind so, we just sort of happened to be there at the same time. That's on a hyper acute stroke unit, so typically people are there for... it can be anywhere between 24 hours and sort of 2-3 days max. So that's... it's a very quick turnaround Lisa: Because it's a medical ward and things move quite quickly, you sort of, you take a bit of time where you can. Erm... so it can be hard to coordinate working jointly ... So, I think it's the setting more than anything that makes it- can make it challenging to do the joint working Lisa: like you might have in a rehab unit where you have a timetable – and I've had this when I've worked in inpatient rehab units where... you know, you know in advance and you can sit down the week before with the speech therapist and you can say, "let's see this person together at this particular time". Ashley: Yeah, and on a more sort of practical level erm, everyone's so busy, sometimes having the time to- to maybe sit down together or see someone together... and we're really good at timetabling it in but you know, if one person's off sick then that kind of throws the- all of the rest of the OTs if one of them's in there or.. the patient's often being taken for scans or just aren't there when you go to see them or, just some of those practical things that come with working in hospital Marie: Um... because the biggest block is just clinician hours and availability -nodding Marie: Only more logistical things like time, staffing, um...

Challenges of joint working	Donna: I mean I think one of the dangers when you work with someone with aphasia and you go in for a joint session is that you and the therapist start talking all the time... because, you know, and that that conversation starts and then the person, potentially, you know, can be a bit excluded Donna: I mean, I guess the only other thing might be that potentially you've got different agendas for the session, erm... and then the patients agenda kind of gets lost, 'cause there's three competing agendas erm... and thinking about how do you make sure that the patients agenda is the one at the top of the list? But, I would hope that... you know, we do address that and that we do- you know that both therapists go in with you know, the notion that we want to find out first and foremost, what the patient wants to talk about, um... not- not what we want to do Aimee: So- so that's good, uh.... but I also remember... then... um... the- um... me feeling a bit conscious that she's disclosing thing - the patient is disclosing things in front of a SLT, which she may not necessarily would have done that - if it is only just SLT- ther- rehab, if you know what I mean. Um... because obviously as psychologists, they- they do tell us everything and we don't put everything in the- in the progress notes but now, with another person, you know, having to work as a- almost as an interpreter, but also obviously trying to help us understand one another is, um... It can feel a bit uncomfortable, um, to begin with, because you never know how much actually the patient is telling you what they really want to tell you because there's another person in the room as well. Aimee: Uh, which- which meant that sometimes, especially when you're doing a joint... So I have my agenda... The physio or the OT may have a different agenda as well, so it does mean that we- we both have to agree, “OK, what- what- what will be the realistic get away from- from this home visit? What's the- what's the aim? What are the aims?” And try to be realistic as much as possible
Subtheme 2: Learning from SLT colleagues	

Learning from SLT colleagues	Lisa: Erm... the only other thing in working with speech and language therapists, erm, that I've found really useful in the past is using talking mats. I don't know if that's something you've come across from other people talking about it or in your own work. But erm I- I think maybe... because in the acute unit – because things tend to happen so fast – I- I think sometimes it falls a bit by the wayside. Erm but I've found, sort of having more meaningful and more rich conversations with- with people using the talking mats. I find them really, really helpful. Erm, and... it's sort of reminding me to go back to thinking about using them again Marie: Um... it's been quite interesting actually for me because this is the job where I've had the most um – please forgive my lack of coherence here – the most inter- joined up working with SLT and so they've taught me... a lot – way more than I've learnt on training or other neuro jobs – about aphasia and working with it Leah: So I- so we have something called [name of support service], which is a national organization for rare dementia, and they have, um, a speech therapist within that, and she specializes in primary progressive aphasia. So, I've had conversations with her. Donna: um... and from my point of view, you know, observing her and how she supported the, um, man with the language difficulties to communicate with his wife was- it was really interesting to kind of be there and observe that and see what her strategies were. Ashley: Erm, so I guess...so the strategies they might get from speech therapy, so with a... like speak slower, or louder, or erm... specific aids like an iPad or a whiteboard and a pen that they've been given or... things like that I guess, make it easier Aimee: But on the upside is, um, as I said, you know it- it does help um... to have SLT input because they have the skills to really think about... "How do we communicate, um, with them." Aimee: I guess the difference will be I will- I- One of the challenges sometimes is that because they can be so severe... that I do need um... a SLT to be in the therapy... of course, with patient's consent. Um, certainly to begin with because I need to understand and observe how the interaction is. Aimee: Uh so not- if they don't- they can do it indirectly as well, so we are talking about the more milder um... aphasia, where... checking with them to see what kind of technology or strategies they use... to facilitate the, um, conversations, um, so I do rely on them Georgia: Or if I speak to the speech language therapist before and I say, you know, what techniques do you usually do? What should I be thinking about? Cos obviously they're, you know, often working with the patients before I am Georgia: Yeah, I've only picked that up from like the language around speech and language therapists really using that and how they work with the communication partner and then you sort of go in and see the patient as well, no Georgia: Like, I would love some training actually. Yeah, it's all just come from experience um... I remember the uh... speech and language therapist in [name of borough], she used to run a session for the rehab assistants on aphasia and things but I could never make that

Support from SLT colleagues is valued	Lisa: Erm... I really like it when... I can work with a speech therapist who is sort of happy to come alongside me and we do a piece of work together. Erm... an example I'm just sort of thinking about is- is about two weeks ago. Erm, I went onto one of the wards to speak with a lady who I'd met for the second time... Erm... and the speech therapist just happened to be there.... And it was- it was really helpful, because I was able to sit with her and sort of ask questions and bring up the topics I wanted to bring up that I thought were relevant, erm... while she was sort of, thinking – she was exclusively thinking about their communication needs. And she was helping by writing particular things down or... sort of asking us to pause so she could check the persons understanding Lisa: ...and the patient felt, sort of, better supported when there was like another brain thinking- thinking exclusively, you know, about communicatio n and what might help a little bit more. Lisa: And I will do... I will do a lot of that in my sessions anyway, but you- I feel like I was able to get somewhere quicker and the patient felt, sort of, better supported when there was like another brain thinking- thinking exclusively, you know, about communication and what might help a little bit more. Lisa: So when we get the opportunity to kind of work jointly I think it works really well. Ashley: I do a lot of, kind of, joint work stuff with speech and language therapy as well - just trying to unpick some of that Ashley: yeah, it's nice to have the support from our colleagues so, yeah, especially speech in that... Situation Ashley: Erm, so I guess...so the strategies they might get from speech therapy, so with a... like speak slower, or louder, or erm... specific aids like an iPad or a whiteboard and a pen that they've been given or... things like that I guess, make it easier Ashley: Yeah, and I think having someone just reminding people to use them as well Donna: Yeah, um, and I think actually, you know, working particularly in the early stages of recovery from something like stroke, it's really important to work jointly with speech and language therapy... Um, because you know, obviously, they have lots- detailed information and they'll be exploring with the person, what are the strategies that work for you? And then sharing that information so that we can use it in our therapies Donna: I think particularly when you're getting to know somebody new, if the speech and language therapist has already worked with them and is already familiar with their communication, then that's really helpful, it's kind of a bit of a shortcut to getting to know the person and, um... working in the way that they want to work. And I think, you know, rather than the patient having to explain to every new therapist how to communicate... um... It- it's helpful if we do those joint sessions so that that information about how that person would like to communicate is quickly communicated between all of us and they don't have to keep repeating themselves or going through the really painful process of every time they start with a new therapist not being understood. Um... Which... is obviously not- not fair on them Donna: I think you know the speech and language therapists that I've worked with have always been extremely skilled and very good at making sure that the person that we're working with is very much included in the conversation Aimee: I guess the difference will be I will- I- One of the challenges sometimes is that because they can be so severe... that I do need um... a SLT to be in the therapy... of course, with patient's consent. Um, certainly to begin with because I need to understand and observe how the interaction is. Aimee: But on the upside is, um, as I said, you know it- it does help um... to have SLT input because they have the skills to really think about... "How do we communicate, um, with them."

	Aimee: Uh so not- if they don't- they can do it indirectly as well, so we are talking about the more milder um... aphasia, where... checking with them to see what kind of technology or strategies they use... to facilitate the, um, conversations, um, so I do rely on them Georgia: Or if I speak to the speech language therapist before and I say, you know, what techniques do you usually do? What should I be thinking about? Cos obviously they're, you know, often working with the patients before I am Georgia: I think if there are certain techniques and strategies that the speechies have used, or other therapists have found are helpful then definitely knowing to use those and what they are Georgia: ...and she was having individual sessions with the patient - so speech specific - and then I would have sessions, with her, focused on the sort of emotional element... And she would just be absolutely fantastic in... um...sort of breaking down the information, thinking about key- keywords. Um... it's just- it was just really, really helpful. So that's just a really successful one, that I can think of
Moving beyond language	
Getting to know the person is key	Lisa: Err... and it, you know I think, you know one of the key things is sort of build... you know, because when I meet someone on the stroke ward I'm trying to build – the first I'm trying to do is build a sense of who this person is, you know, who are they? What's important to them? You know, how has this particular event- how has this disrupted their normal way of being and their normal life? Lisa: And when you – when you get a picture and you get a sense of someone, who they are, what their personality, you know what they like and what they don't like, you know you sort of- you get pulled in quicker and you- you get a sense of you know, what direction you want to go with in terms of setting goals... jointly with them. Lisa: if you're always relying on them to provide information and tell you about the person, what they think might be going on... I think then you're probably neglecting trying to do that- that one-to-one work with the person and figure out what- what's important. Lisa: But I've had- I've had feedback from people before sort of saying that... you know the people on the ward understand them – so the speech and language therapist or the psychologist or the OT or who are working with them, they will have got to the stage where they've figured out a way to communicate or... people can anticipate, the staff can anticipate what the person might need and help to get to them communicating a message Lisa: the nurses are often around for a long shift, so they have a really good sense of how this person is making their needs known. So you know, I think the nurses I've worked with are very skilled in picking up on non-verbal cues Marie: Watching people who get to know a client well...So once you get to know a client well with aphasia... um... that bit about body language, intonation, connection, understanding, and being able to involve the family and get to know someone is so key, because actually I found myself having what feel like full blown conversations with someone and what- what they're saying is making no sense at all, but through knowing them so well and underst- if they've got quite good intonation, even if it's jargon aphasia and they're coming out with the same word over and over and over... you really can... You- you really can understand... some of the time and - particularly if they've got some receptive language you can- you can test what you think someone is saying and they can... They can tell you Donna: and because I've worked with her such a long time now, I kind of understand what she's saying without her having to say it sometimes –laughs- Donna: You know, obviously with the young lady that was talking about who had the stroke, and then the um, non-epileptic seizures... That was real multidisciplinary working and we all kind of understood and knew her communication difficulties and we all kind of used her language for things 'cause she- she has particular language that she likes to use

Family members offer a way in (& over-reliance on family members)	Lisa: Erm... when that's absent and you can't do that in the kind of quick way you would normally do, you know, I think we often rely on family members to give us that sort of information and then you can build on that then when you work with people Lisa: Erm... so there's definitely a balance to be struck there but erm, I know that we- Uh definitely in the acute phase we rely quite heavily on family members helping us out really . Lisa: and a bit more thinking about the persons system. Because you can't get everything from sitting down with them for... 50 minutes, 60 minutes erm, and just asking them about how they're doing, how they're feeling, what they're thinking about the new stroke, all- all of the other potential difficulties they might be having, whether it's physical or cognitive... You know, that sort of information and that knowledge has to come... from... working in a different way Lisa: cos I might meet someone perhaps for the first time and then I go away and speak with their family member and then I come back... and... I might say, you know, "I spoke with.." you know, "I spoke with your partner and they told me this". You know and it's the basis of being able to work on something and talk about something and structure a session... erm... so I think working with families... that- that's really key. Leah: So, um... I think, um... The challenge is... is... understanding them in the room -nodding- Um, so some people, unless they've got, a partner with them it can be really hard to know... what they're saying Aimee: the person tends to have their- their own inner language, if you like, some slangs or some- some way of - I'm just thinking now the cultural elements as well, not just racial culture, but family culture - the way of communication may be different. Certain things may mean different things. So I- I sometimes also... I find that usu- yes I, I find that family members, or whoever are close to them um... help... to kind of think about actually how- how is- is it- is it- is- you know, what are the ways they um... Yeah, what- what other ways will help to facilitate communication? Georgia: Or, you know, any family member that knows the patient better than I do and are more familiar with their interaction style Lisa: Erm... the- the other thing... -laughs- I'm not contradicting myself I promise. It's just another end of the spectrum. I think also... that's a bit of a double edged sword in that, I think on the stroke ward, what can happen is that then, when someone can't communicate, or- or can't fully communicate or erm... is struggling with that erm... that we can sometimes end up overly reliant on the family member. Lisa: I think sometimes that can put a lot of pressure on the family member and cause distress- sort of unwarranted distress in them as well. Because if you are- if you're always relying on them to provide information and tell you about the person, what they think might be going on... I think then you're probably neglecting trying to do that- that one-to-one work with the person and figure out what- what's important.

Connecting to what's important	Leah: ...so the gentleman I've been talking about - he loves to talk about his garden – it's really important to him. But he can't... get across what he needs to say. So we've just talked about having a few words in a notebook for him to help him socially communicate a few keywordsSo we're- we're just thinking about practical things around - for him - what he could have to take out to aid communication with him about things that are important to him. Marie: Um... with particularly our clients with aphasia, because for- for me I'm slightly going off piste, but I will come back, I promise, but one of the interventions if someone is struggling with the talking therapy, um, would be to liaise very heavily with OT and go for more values driven approach in terms, of you know, connecting values connected with hobbies, connecting with things like that which we can explore in psych with visual prompts um... Marie: Um... And you can explore values and you can explore... identity and you can explore connecting back to things that will give someone a sense of, um, a sense of self Marie: And I think that's one of the most powerful pieces of the work... it's really the- the richness comes with that re-connection to something outside of language. Donna: it's really rewarding work and, you know, it's really lovely when you see the changes and you see people able to communicate better and getting back to their old lives and all the things that are really important to them
Takes more time	Lisa: Erm, I think- I think you have work very- you have to work very hard and you have to be very invested. Erm... and you probably have to put in a bit more time Leah: ...you have to kind of... talk round stuff and you just need to allow a lot more time... with people to be able to, um, get to the things that you need to get... 'cause they're not going to get there...[inaudible] really... Donna: Erm, and I think it's just as well about managing expectations of how much you're gonna achieve in a session - that you're not going to get through the same volume of work, erm, in a 50 minute session that you might otherwise with someone for whom aphasia isn't an issue Donna: For me, the most important thing is taking time, um, with the person with aphasia and really seeking... to understand how they wish to communicate with you... Aimee: The difference would be how I work with them rather than um, rather than... the way they present... Well, I mean obviously the way they present will be the communication difficulties, if that's what you are referring to um... Yeah... which... No, I- I think- I think- I think they're similar, it's just- it's just the communication bit does require more time um, so I would say that they- they can have similar themes... Aimee: It does require more time... to really try and understand the person Aimee: Particular- particularly because of their communica- if we know that someone has communication difficulties, it's more- even more important to allow time Aimee: that's fine, at least I know that I don't have to rush. So- so- so that's what I- I tend to keep in mind and- and when I do a- and- and then when I do joints with- with same again, I'll never one hour, it's- it's just impossible

Connecting with wider systems of support	Leah: Um, and just helping people to get out to groups, so coming to different dementia groups or, er, signposting people to different um, webinars to have that... care or support and- and the peer support Leah: so I'm looking to see whether we can set-up a [name of place] PPA support group - so that would be just an evening group where carers and- and the person with PPA can come and just, from a social perspective, be able to kind of meet and have that shared experience. Particularly important, I think because they don't- they are limiting social contact because of their condition, so being able to go to a group where other people go, “don't worry, you can't find the word I get it”, um.. would- would be great, I think, if we can get that up and running Leah: um... there's lots of carer support events and there's lots of webinars and information and research, and there's a speech therapist as well, so- so we definitely signpost people into that group. Donna: um, just helping her to... see that it's really important to put herself back out there, and that friends are actually very understanding, and she started carrying a card, so she's in the supermarket, she could show people saying that I have difficulty with my speech and then having really positive experiences where people were helping her to get a taxi, and you know, just... really building up her confidence and reducing that... sense of social isolation... Aimee: because sometimes I think... Just being in a group helps, and that you're not alone... And usually sometimes people in a group - stroke survivors with aphasia, comes with, you know, diverse backgrounds and different diverse um... impairment, but they also have different strategies as well. So that usually is quite a good support network Aimee: You know, so thinking about wider system Aimee: my therapy, I'm not just doing therapy, I'm also thinking about wider system - is that if we know that a person has communication problems, we know that this person will have difficulties communicating with the wider system. And if um... neuro rehab's aim is to increase and optimise someone’s um... functioning, be it from a social, vocational, uh... you know, daily, uh, perspective, then... we gotta look at the wider system. Because if not, neuro rehab is not doing their job.
Understanding the person’s communication preferences	Donna: I think once you've adjusted your expectations and you've worked out what are the best things for that person - 'cause I do think it's very individual... Some people still like to use their speech as much as possible and they don't like to use pictures or... written word or cues, they- you know they want to do it their way - that's fine, whereas other people... you know, much prefer writing words down or, er... using visual illustrations...um, so yeah, it's also about kind of getting to know the person and working out what- what they prefer doing. Donna: and really seeking... to understand how they wish to communicate with you, and just being aware that that might change over time as well, that what works for them at the beginning might not be what works for them later on Donna: Um, and so, just checking in with them um... and... making sure that they - you know, 'cause I think one of the dangers is that they might feel patronised or... or misunderstood and nobody’s like, taking the time to check in and, have I understood? Is that right? Is that correct? Erm, so, just making sure that... you do that so that... any communication that you have with them is as they would want it to be Georgia: Asking the patient what's the best way to communicate, asking the communication partner, you know what's best for you here? Do we need to take certain breaks? Do I need to write things down for you? I'm- I'm assuming it’d be helpful if I use short sentences, but please tell me if not, you know it's- it's having that sort of rapport from the start, isn't it? And making them feel like they are an equal partner in your assessment rather than just you asking questions

Confidence comes with experience	Lisa: Erm... but I think as time has gone on and I've had more experience and more exposure to working with- with people and with families erm... I actually, I find the work really, really rewarding Lisa: Erm... and... yeah I think- I think now I feel more confident and... and I think I- I genuinely was thinking back on some of the cases I've worked with and actually the work sometimes is- is- some of the more rewarding pieces of work I've done is- is with people with erm with people with aphasia after their stroke -nodding-. Marie: and I've- I almost learned that too late, I think. I think in my early post qualification - sort of 10 years ago - I was like really... Quite um... anxious about working with clients even when I newly qualified, um, who didn't have language 'cause it was- I saw it as the tool to psychology, and it's only sort of in the last five years or so that I've really, really become confident in realizing it's so- there's so much that can be done... helpful, that's not just medication...to support someone with aphasia. Leah: And you know, just working with a really interesting, lovely person - it kind of sparked my interest, so I'm not an expert in it at all, it's just to have- I've had the- you know, opportunity to have seen quite a few people now with it. Um, and that's enabled me to feel I can do a bit of teaching on it, really Donna: I mean, I've been doing this job a long time –laughs- so I- I don't- I- I feel quite confident.
Working with people with aphasia can feel de-skilling	Lisa: I mean I think when I first started in my career I found it incredibly challenging. Erm... and if I'm honest I probably felt a sense of... felt myself avoiding work with people with aphasia if I'm being completely honest and I think that comes off the back of... because as psychologists, you know, we're in the business of talking to people and we're in the business of trying to make sense of people's emotions that- that's primarily what we do... Erm... and when someone doesn't have the ability to, you know, to share via means of communication erm that, I think that can feel quite de-skilling. Marie: I think in my early post qualification - sort of 10 years ago - I was like really... Quite um... anxious about working with clients even when I newly qualified, um, who didn't have language 'cause it was- I saw it as the tool to psychology Georgia: Um... so then sometimes I think that can leave you as a therapist feeling sort of quite helpless actually
Adapting your communication	Leah: Um... because they may not... understand the question, so I've had to really begin to think about my own communication style and how I... try not to give really long sentences – Mm... [inaudible] break things down or write things down Leah: Um, so again, it's being quite creative in a session, sometimes you might want to show a picture, but they might not recognize the picture either, so you might have to describe – "well it's one of those things that rings a bell if you have a fire", and you have to kind of... talk round stuff and you just need to allow a lot more time... with people to be able to, um, get to the things that you need to get... 'cause they're not going to get there...[inaudible] really... Donna: Yeah, I mean one of the things is that you might have- you can't ask the same kind of open-ended questions that you might normally ask, um, because that might be very difficult for them to respond to, so you might be asking more kind of closed questions. Um... but also using kind of, er, written material, drawings, pictures Aimee: I guess as a clinician, therapist's own worries about am I actually really understanding the person? But of course to counter that would be to keep checking in... um... But yeah, always trying to be very conscious that I'm really understanding the person and hearing the person.

APPENDIX T – DATA EXTRACTS RELEVANT TO EACH THEME

Theme 1: Working with Distress	
Subtheme: Context is Important	
Georgia	*So I think yeah, it's definitely varied, isn't it? Dependent on the extent of it and... how they perceive it and how it's affecting their life...*
Marie	*Yeah, hugely, I don't have any one understanding, I think it'- it, you know, different clients present in such different ways [...] there's that- that fear and anxiety um... and depression and adjustment, um... So there's no- no there's definitely no one understanding.*
Marie	*there's that- that fear and anxiety um... and depression and adjustment, um... So there's no- no there's definitely no one understanding.*
Marie	*...then kind of bringing it down a bit more sort of micro I think obviously each client experience is very unique.*
Marie	*I think I go client by client and what they're presenting with and trying to work through with them where possible what they're- they're sort of prese- they're understanding of what it is they're going through and how they're responding to it*
Ashley	*Ashley: But yeah, I suppose... it's individual. It- it depends on the person. I've seen people with aphasia who've really struggled with it because they get so kind of wound up in trying to say... er... like a certain word or get a certain point across and get really frustrated but other people might be much more relaxed and just be like "phh" take a breath, and then they'll start again. Erm... so I think it's really individualised as to the impact it has on them. And you know, some people progress... really quickly in terms of their recovery, erm, other people might be a bit slower...*
Ashley	*Um... I think it's so individualised as to what the person values or needs and how that impact on them moving forward in their kind of rehab and recovery. So, I think I've definitely met people who have aphasia but also now are wheelchair dependent and are much more upset about the wheelchair than they are about the aphasia... and vice versa. Erm, it's so individualised*

Ashley	*You know, someone who... I dunno... for want of a better example, works in a call centre, is going to be much more affected by aphasia than like a [inaudible] left sided weakness perhaps...*
Donna	*...one of the difficulties that someone might be experiencing is aphasia and word finding difficulties, and this can often obviously have a very profound effect on their life and their relationships. Maybe their ability to return to work...*
Donna	*Erm...and... I guess in terms of work, well, I mean there are just some jobs where it just wouldn't be safe. Um, if- if you have aphasia, to continue working, um... you know, 'cause you could potentially put other people at risk, um...* *And I think, you know, again, workplaces are very dependent on language. Erm... they don't really... have ways to compensate for that, many places and so... I think it can make returning to work very difficult depending on what the roles do- the role that the person is doing but I would say that nearly all jobs involve some form of language at some point*
Leah	*Um, and in fact had, uh, uh, one patient was a teacher with that condition and... when something was going wrong on a school trip, she couldn't get out, "stop, don't cross the road" quick enough for them to- the children to not cross the road so... um... so she sort of started to drop out of things like that because it had an effect- she just couldn't get the words out quick enough to- in a, kind of, highly charged situation... (Leah)*
Lisa	*...yeah, I would say erm... just the- just the idea that... I think a lot of people are, at that stage when people are more acute, are getting their head around the idea of, you know, I'm not going to be able to go back and do the job I was doing before, because it's actually so reliant on me being able to sort of express erm, you know express vocally.*
Lisa	*I see- I see people I've worked with er- a couple of patients recently where... where their job role is so closely linked to being able to being able to communicate and actually, processing that loss and getting their head around, you know, who they are as a person if they're not, you know, if they're not, a lecturer, you know that- that was- that's someone who I've*

	very recently worked with. Erm... you know, that's their job so it's just a huge shift... to think about, you know, what's life gonna be like, you know who am I without this particular type of role in my life.
Leah	*I was just um... thinking about the impact of language on people's identity, really, and how much... how much of our...language skills identify, kind of, who we are and get across who we are as a person. So certainly for- for the teacher that I worked with her whole life was around... language. Um... being able to speak in front of a class and that was her role in identity and I think when people were really struggling to be able to speak and communicate what they are, what they- you know what they want to say... there comes a massive loss with that (Leah)*
Subtheme: Frustration is Inevitable	
Donna	*I think for everyone language is such a key part to how we communicate with one another, that when you suddenly lose the ability to do that, it's devastating and, um, it can cause huge amounts of frustration and anger, [...] and a lot of sadness as well. Erm, and then to not be able to communicate that - easily with other people, just you know, it's kind of layer upon layer of frustration*
Lisa	*But erm... sort of in the acute setting I think what- what is overwhelmingly obvious is the sense of frustration, erm... you know, of real, sort of deep frustration with- with just not being able to get your message across*
Marie	*...the frustration is huge, that's- that's really common*
Leah	*...but also real frustration because... we see a lot of frustration and people just can't get their point across.*
Ashley	*Yeah... I think one thing that often comes up is people's frustration. Erm, so because they can't get across their point or communicate as effectively as they could before*
Lisa	*And just not- maybe not – being able to communicate about that and the- and the frustration as a result of that. That's [...] mainly what I see in my*

	work and mainly what I see with people at that sort of acute stage after their stroke
Donna	*...sometimes they're experiencing so much emotion, it's just really difficult for them. Erm, and, you know, I would find it frustrating if I was trying to tell someone something and they just weren't getting it. Erm, and I've tried every way I could and they still weren't getting it and I really wanted to communicate it, I can't imagine anything more frustrating...*
Georgia	*but I think, um, people have said to me... Frustration is a massive thing*
Lisa	*...there are often a lot of barriers so you know, you might go in thinking about, you know, wanting to ask about a certain topic or... have a certain conversation and you- you just can't get there and, you know there's just a breakdown in communication and a lot of it is kind of dealing with that frustration in the moment*
Lisa	*...so actually you- your attempt to have a session sort of brings up... this- this is kind of a live example of what- you know of the frustration and erm... this change that I'm gonna have to get used to. This is it here in action and I think, you kind of have to sit with that difficulty*
Ashley	*... just managing the frustration that comes with that*
Donna	*I have worked with people with aphasia who're really not tolerant at all and they find it really hard when you don't get what they're trying to communicate quickly, and that's a lot harder to work with because then it's that sort of delicate balance of wanting to properly understand but not... agitating them even more that you're repeatedly misunderstanding*
Leah	*And it was... And myself and my trainee were like, "we don't know what this means", and you know, you're trying to be really empathic with people and not- not say, "I'm sorry I don't know what you mean too much"... But equally, not just saying yes when you don't understand*
Donna	*I mean for me, it's just kind of being really honest about it and saying, "look, I can see this is really annoying you and winding you up that I'm not getting this and I'm really sorry, but it's really important that I understand properly 'cause I don't want us to go on with the misunderstanding*

Georgia	*I guess the other, um, challenge is maybe how frustrated some people get. When they're trying to have a conversation, so you're thinking about, you know, while they're trying to either express themselves or understand what you're saying. So it's thinking about, um... Just reassuring, you know, "take your time"... "We can have a break whenever you want", um... and a lot of, "can I just check I've understood what you said" a lot of sort of checking that I've understood them correctly. So, I do that a lot with people with aphasia.*
Donna	*Erm, but I guess from the therapist point of view it's about not reacting to that frustration and not taking it personally and not thinking right, I'm a useless therapist, but it's just being able to sit with it and thinking, look, this is a normal reaction to a very frustrating situation*
Donna	*I mean as a professional, you know you're trained to be patient and to take time and really try and work out how that person wants to communicate with you...*
Subtheme: Supporting Colleagues - 'When people start crying, they find it really hard'	
Lisa	*I think sometimes, and understandably, the MD- the other members of the MDT can sometimes shy away from, sort of being involved in those sort of moments– I've found that they've found it useful to have psychology sort of support with that.*
Lisa	*....cos I think often times the MDT will think, well this is- this is just speech and language therapy, erm, but- but there are so many- there are so many psychological aspects of living with aphasia that- that it's useful for, erm, for psychology to be involved with...*
Ashley	*Erm, I think people probably rely a bit more on like, are they crying in every session rather than thinking too much about the impact on mood and things. I think that also because there's psychologists within the team that might be kind of, just, left to us to consider and less their... role.*
Ashley	*Erm... I think there's often an un- unrealistic expectation from psychology that we can solve things, we have a magic wand [laugh] and we just 'know everything and fix everything'... which can be unhelpful. I think a lot of*

	times when people are- patients are having difficulties, whatever it might be, it's very much like, 'go and speak to your psychologist about it' but actually, like, we can't work miracles... yeah.
Marie	*Physio... um... our physio colleagues are very kind of psychologically informed in our team, um... and keen to learn, but I know there are often... uh, maybe not quite as much understanding in physio and you can often see- see frustration building in communication there sometimes. -nodding-*
Aimee	*I guess it may not be as um... at the forefront of their mind because... people may have aphasia only, which meant that there might not be as much, well there won't be any physio input, so the physiotherapist would maybe thinking more... I don't think aphasia- someone with aphasia will really pop into their minds [inaudible], but having said that, I think there is a overall understanding that someone with a neurological condition tends to have common themes about... adjustment or their quality of life.* *...* *They might not recognise- they might not be able to recognise in the individual patient, but they are aware of the themes so they- there- there is a theoretical understanding, but whether they will be able to... see it in front of them, that might be a different story*
Marie	*...and then there's the mood, mental health, adjustment side as well, which often I find has been overlooked in, um, neuro-rehab*
Lisa	*I think speech therapists are- are very skilled with this and actually I'd say a lot of my speech therapy colleagues, they might've even had very similar conversations or talked about very similar topics w-with, with people that they've met on the wards. Erm, and probably have a level of confidence about- about attempting that communication*
Ashley	*Erm... -pause- I'm not sure actually. Our speech therapists are very kind of, in tune with that.*
Ashley	*I think a lot of it does come back on the speech therapists though because they spend the most time with them so they're more likely to pick up on anything.*

Aimee	*we do get quite a few referrals from my SLT colleagues uh, about people whom they- they, you know, um... they want psychological input. They- they- they do refer people to us.*
Georgia	*...there was a comment yesterday actually, from one of the stroke buddies that I'm working with... Someone asked him um... Does the person have communication difficulties and in- and then the buddy was like, “oh yeah, I should think so.”* *And it's like, “what are you on about?” Like, I feel like he totally got the wrong end of the stick and then they were like, “oh does- does he have difficulties with his speech?”* *He said, “Oh no, he's fine, he's- it's- he's slurred though”. And it's like, well, that's again a lack of understanding about what aphasia and other difficulties around communication are. So, I think there's a bit of like, upskilling that's needed to then appreciate what that might mean for someone [...] So in answer your question, no, I don't- I don't think they always appreciate that sort of loss and that adjustment and frustration*
Georgia	*... sometimes the speech and language therapists, I think [...] they're so focused on their like specific goals and like their specific sort of tasks that they're doing... I- I feel like that they sometimes don't appreciate the psychological element and like the loss and what it actually means, 'cause they're so focused on their specific um... intervention, if that makes sense*
Aimee	*I- I think some of them are very... they're not sure what to do. Uh, because... Yeah, because their [...] role is to actually, uh, well try to enhance, or give- provide strategies to, you know, to alleviate the symptoms of aphasia, but [...] when people start crying I think- I think they find it really hard... Not everybody, though, that’s- so- so- it's a mixed bag*
Marie	*...we in our MDT meetings with, as you'd expect, kind of sharing formulations... Um... sharing different perspectives, particularly where we've got, um, you know, difficulties with families understanding or if it's high expressed emotion, things like that going on, we've got that sort of aspect, as well as supporting the team in their understanding of a client’s presentation um... But particularly with aphasia*

Georgia	*So, it's- I'm not doing it at the moment, but I think we did like six months of monthly training and, um, those were around different topics. So, one was sort of managing distressing conversations, so anything like that around, um, communication difficulties would have come up*
Donna	*the speech language therapist was kind of finding that really tricky to navigate and... on her own trying to manage it and, so, I joined her [...] But... certainly I know from the speech and language therapist she felt much better supported not having to do those sessions on her own because it was a challenging piece of work*
Ashley	*...we got a guy who's got quite a moderate- err- severe aphasia and he was very emotionally labile. Erm... but the therapist- like the OTs and physios weren't really sure how to manage that in sessions or couldn't... couldn't really discuss it with him um... very easily so, maybe giving some tips and ideas oh kind of how to manage that, um... that might be an example of kind of something that we come up with*
Aimee	*...the other challenge is when the SLT um... as I was saying before, um, is not... find it quite overwhelming when they're disclosing things because, after all, they are not trained psychologists, they- they- they- they don't- they don't have supervision or reflective practice like our profession um... they are there, just... do a job. So I find that also then, I have to check in with them, just like I would have checked in with the interpreter as well anyway, um, you know when things are a bit too emotional, I do check in with the interpreter to make sure they're OK.But when I see a SLT colleague I- I can still remember a case where, um... she really felt- I could feel she felt uncomfortable, so I had to check in with the person just to make sure that there wasn't anything, perhaps too close to personal- the- the personal life that might have impacted or... is it just you know something where... It's just so overwhelming, upsetting information that the person is finding it hard*
Lisa	*....it can build frustration and I think speech therapists are very good at... at being able to kind of hold that and understand that and use that and*

	I’ve seen my colleagues do that in sessions and in joint sessions with speech therapists as well.
Georgia	*Just your general formulation, I guess if you've got psychologists in your MDT to pick up on these things... just sort of general comments about how, you know, difficult that must be or you know, whatever*
Marie	*...we in our MDT meetings with, as you'd expect, kind of sharing formulations... Um... sharing different perspectives, particularly where we've got, um, you know, difficulties with families understanding or if it's high expressed emotion, things like that going on, we've got that sort of aspect, as well as supporting the team in their understanding of a client’s presentation um... But particularly with aphasia*
Subtheme: Supporting families	
Donna	*And I think also for loved ones and for relatives and, um, people involved in the person’s life, it's also really frustrating because they desperately want to understand... erm, but then all- it- experience that frustration at not being able to understand*
Georgia	*and then I think on the flip side to that, it's the loss that, um, the caregivers or family members experience as well, and saying that they feel so... frustrated for them that they can't express themselves in the same way. And sometimes they say they feel like, obviously, there's- there's- sort of a- a different person, and then that they've lost that sort of... the person that they were before*
Lisa	*but the erm... his wife, she was really protective of his sons, she was really concerned about how they might react, sort of seeing their father so different from how he was before and a big part of that was sort of, him not being able to communicate and to sort of express, erm... and as a result he himself was incredibly frustrated and he would try to vocalise things and then he would just get, you know, so frustrated, he would just burst into tears and th- that was happening really frequently so I could really understand why she didn’t- why she was reluctant to bring her kids in to see him.*

Donna	*Erm... you know, to have other people finishing sentences, and, you know, predicting what you're gonna say, especially when they get it wrong. Um, so you know, I think it- it has massive implications for relationships and it takes a really long time to adjust to that*
Aimee	*Uh, because of the aphasia problems, um... The partner doesn't seem to understand that these difficulties are very frustrating and the- and- and the husband is feeling well, "I can't express myself, what do you want me to do?"*
Ashley	*So speech therapy do a large part of this but may- like I've done sessions before with a partner there where we might role model kind of alternative communication styles erm for them to be able to kind of use that when the person's discharged or in their time with them.*
Aimee	*So [...] we got them into a room and then where we just got them to communicate one another [...] almost like doing a systemic therapy, but at the same time the SLT will... um... interrupt by going, "OK, so I think what he's trying to say is XYZ and how do you think you can say in such a way that will mean that you don't have to be so frustrated [...] And then how can the partner try and be a bit more patient? You know, things like that. So trying to improve the communication [...] sometimes we do a bit of facilitation with that.*
Donna	*...we did some work with them around, you know, different communication styles and turn-taking and... um... and we videoed um, a conversation - all of us having a conversation – and then we all looked back and reflected on our own communication...*
Lisa	*Erm, I was just sort of thinking there about... I know I probably mentioned at the top about working with families... well I know I mentioned it in other contexts. But, erm... I think uh – I have- I have a couple of cases just where I've worked where there's been a lot of involvement in... kind of... supporting and educating family members about people's aphasia.*
Lisa	*we did a piece of work where the kids came in at different times and, you know, sat with their mum and dad and saw their dad for the first time and, you know, we did sort of work with talking to them in advance of this*

	meeting and talking about some of their expectations and their hopes and their fears
Lisa	*Erm, but also it- it- it seemed to be very helpful for this kind of family system, erm... and I think that's where, erm... I think that's where- where we can – psychologists – I think can add a bit of value, in terms of working with people with aphasia cos I think often times the MDT will think, well this is- this is just speech and language therapy, erm, but- but there are so many- there are so many psychological aspects of living with aphasia that- that it's useful for, erm, for psychology to be involved with...*
Marie	*working with the wider systems, and the families, and helping their adjustment in order to help the client*
Leah	*I see my role as supporting families to understand what this condition is...*
Leah	*Um, so I think a lot about education and just - people have valued the opportunity to just talk and ask questions. Erm, "how is this different to Alzheimer's?" Er... And, "should I fill in the gaps for him?" You know, is an often question, "when- when they're struggling for a word, what do I do?" "Is it helpful for me to fill it in or should I leave them to try and find it?" This- this being able to navigate some of those queries that carers can often have about how best to help their loved one when they're struggling. Erm... yeah*
Georgia	*Um... he's got, you know, severe communication difficulties. Um, really severe emotional lability - so with him it was working with his wife, who's an incredible communication partner. Um, and we were thinking about education around the emotional lability, thinking about whether there's a role for medication. This had pr- been previously discussed with them, but they were quite against medication 'cause they hadn't had the chance to ask questions about it. Um... so we yeah- sort of education, exploring things that might help, and then thinking about um, strategies in terms of helping him to manage in that moment*
The MDT as a Resource	
Subtheme: MDT Cohesion and Connectivity	

Aimee	*...we tend to have quite a lot of MDT discussions. Um... because [...] it's quite complex, we do tend to need this... Um... SLT... to guide us not just psychology, but other disciplines as well. And likewise, um, we psychology then share information. [...] So [...] no, I think it's better in a way of again, might be my naive thinking, but I- I do feel that, um, we as a team in general, um, we do communicate quite well, um, to try and work more holistically*
Marie	*...whereas I think we're very much on a- there's no hierarchy in our current team, it's not psych led or anything like that, and that- we're very open to learning from each other. Um... I think that really helps, just as a wider reflection*
Marie	*Yeah, like it's honestly, it's been the best experience I've had of working in an MDT - for those reasons... um, and just learn- constantly learning from each other...*
Marie	*And we're forever being surprised by a client where we think we might have figured out, sort of... what's going on communicatively, then something changes um... and I think having that to and fro conversation, lots of joint working erm...*
Ashley	*Yeah... so we kind of all cross over so I'll do lots of joint work with occupational therapists, erm... occasionally physiotherapists like, for example if someone is feeling really anxious every time they go to a walk and it's a barrier to their rehab, then I might come and join a session for that. Erm, and that might be someone with aphasia. Erm, rehab assistants, erm... there are medical and nursing staff around – occasionally do bits together but not as much. Um... dietician... yeah. Loads of joint working in our MDT.*
Marie	*Yeah, I think very much especially in our MDT at the moment, it's a really lovely MDT and very sort of, a healthy and well-functioning, but all in one office, which is quite good, because then there's lots of sort of cross talking and [...] we've got three speech language therapists and so speech, psych and OT... I think very much we're all on the same page and we're all kind of constantly checking in with one another.*

Marie	*...I know my colleagues have said I'm quite- I'm not an arrogant psychologist, 'cause I think in the past, even in this job, before I was there, there was [...] You know how it is with psychology, I think sometimes the psychologist can position themselves- they're usually the highest banded in the team. There's a kind of - an unspoken hierarchy, um... and I'm very, very keen - very keen for that not to be the case and it isn't the case in our team at all.*
Marie	*Marie: Um... I think what we've been doing is we've had quite a few students - we've just brought a lot of students in, and so we're getting our psych and SaLT students to do a lot of co-working together as well, which is really helpful.*
Ashley	*Well I guess, I feel like I'm in a slightly weird position in that erm... I work in very much in the same way as the other therapists do, like the physios, OTs, speech, so we all kind of timetable our sessions together and we all kind of sit in the same place but because I'm a band 8 and they tend to- well they are more junior, I also go to like the senior meetings and... meetings with like the consultant medical staff, things like that, so I sort of sit in the middle it feels. Kind of a weird limbo position*
Ashley	*But it's nice, because we kind of get to work with- with everyone as well. So it's a bit easier maybe for me to have a chat with our consultant about something but also know how kind of the OTs are getting on with someone because we have those day-to-day ad hoc chats so I think a large part of my role is consultation so I purposefully sit on the ward with the team rather than up in the psychology department so you can have sort of ad hoc chats so...*
Donna	*Um... and I think being in a multidisciplinary team is part of that, because I know that I can access resources if I need to via speech and language therapy. Um... So... no, I don't... Yeah, I don't really have any concerns with that*
Lisa	*Often times we can't- we don't- we're not able to coordinate to have joint sessions... Erm, it- it's... I suppose it's staffing and it's erm... err, I suppose time pressure, so... that particular person who I had in mind so, we just*

	sort of happened to be there at the same time. That's on a hyper acute stroke unit, so typically people are there for... it can be anywhere between 24 hours and sort of 2-3 days max. So that's... it's a very quick turnaround
Lisa	*Because it's a medical ward and things move quite quickly, you sort of, you take a bit of time where you can. Erm... so it can be hard to coordinate working jointly ... So, I think it's the setting more than anything that makes it- can make it challenging to do the joint working*
Lisa	*...like you might have in a rehab unit where you have a timetable – and I've had this when I've worked in inpatient rehab units where... you know, you know in advance and you can sit down the week before with the speech therapist and you can say, 'let's see this person together at this particular time'.*
Ashley	*Yeah, and on a more sort of practical level erm, everyone's so busy, sometimes having the time to- to maybe sit down together or see someone together... and we're really good at timetabling it in but you know, if one person's off sick then that kind of throws the- all of the rest of the OTs if one of them's in there or.. the patient's often being taken for scans or just aren't there when you go to see them or, just some of those practical things that come with working in hospital*
Marie	*Um... because the biggest block is just clinician hours and availability - nodding*
Marie	*Only more logistical things like time, staffing, um...*
Subtheme: Learning from SLT colleagues	
Marie	*Um... it's been quite interesting actually for me because this is the job where I've had the most um – please forgive my lack of coherence here – the most inter- joined up working with SLT and so they've taught me... a lot – way more than I've learnt on training or other neuro jobs – about aphasia and working with it*
Donna	*Donna: In my experience, joint work is just really positive... um... positive for me as a therapist, but also positive for the person that we're going to see um... because you know they get a coordinated approach and, as I've*

	said before, that they don't have to keep repeating themselves or going over the same stuff
Georgia	*Or if I speak to the speech language therapist before and I say, you know, what techniques do you usually do? What should I be thinking about? Cos obviously they're, you know, often working with the patients before I am*
Ashley	*yeah, it's nice to have the support from our colleagues so, yeah, especially speech in that...*
Ashley	*Erm, so I guess...so the strategies they might get from speech therapy, so with a... like speak slower, or louder, or erm... specific aids like an iPad or a whiteboard and a pen that they've been given or... things like that I guess, make it easier*
Georgia	*Yeah, I've only picked that up from like the language around speech and language therapists really using that and how they work with the communication partner and then you sort of go in and see the patient as well*
Aimee	*... checking with them to see what kind of technology or strategies they use... to facilitate the, um, conversations, um, so I do rely on them*
Donna	*Yeah, um, and I think actually, you know, working particularly in the early stages of recovery from something like stroke, it's really important to work jointly with speech and language therapy... Um, because you know, obviously, they have lots- detailed information and they'll be exploring with the person, what are the strategies that work for you? And then sharing that information so that we can use it in our therapies*
Leah	*So I- so we have something called [name of support service], which is a national organization for rare dementia, and they have, um, a speech therapist within that, and she specializes in primary progressive aphasia. So, I've had conversations with her.*
Donna	*um... and from my point of view, you know, observing her and how she supported the, um, man with the language difficulties to communicate with his wife was- it was really interesting to kind of be there and observe that and see what her strategies were.*

Aimee	*I guess the difference will be I will- I- One of the challenges sometimes is that because they can be so severe... that I do need um... a SLT to be in the therapy... of course, with patient's consent. Um, certainly to begin with because I need to understand and observe how the interaction is.*
Georgia	*...and she was having individual sessions with the patient - so speech specific - and then I would have sessions, with her, focused on the sort of emotional element... And she would just be absolutely fantastic in [...] sort of breaking down the information, thinking about key- keywords. [...] it's just- it was just really, really helpful.*
Lisa	*Erm, I went onto one of the wards to speak with a lady who I'd met for the second time [...] and the speech therapist just happened to be there... And it was [...] really helpful, because I was able to sit with her and sort of ask questions and bring up the topics I wanted to bring up that I thought were relevant, erm... while she was sort of, thinking – she was exclusively thinking about their communication needs. And she was helping by writing particular things down or... sort of asking us to pause so she could check the persons understanding*
Lisa	*...and the patient felt, sort of, better supported when there was like another brain thinking- thinking exclusively, you know, about communicatio n and what might help a little bit more.*
Lisa	*I will do a lot of that in my sessions anyway, but you- I feel like I was able to get somewhere quicker and the patient felt, sort of, better supported when there was like another brain thinking- thinking exclusively, you know, about communication and what might help a little bit more.*
Donna	*Donna: I think particularly when you're getting to know somebody new, if the speech and language therapist has already worked with them and is already familiar with their communication, then that's really helpful, it's kind of a bit of a shortcut to getting to know the person and, um... working in the way that they want to work. And I think, you know, rather than the patient having to explain to every new therapist how to communicate... um... It- it's helpful if we do those joint sessions so that that information about how that person would like to communicate is quickly*

	communicated between all of us and they don't have to keep repeating themselves or going through the really painful process of every time they start with a new therapist not being understood. Um... Which... is obviously not- not fair on them
Donna	*I think you know the speech and language therapists that I've worked with have always been extremely skilled and very good at making sure that the person that we're working with is very much included in the conversation*
Aimee	*But on the upside is, um, as I said, you know it- it does help um... to have SLT input because they have the skills to really think about... "How do we communicate, um, with them."*
Challenging Assumptions - Defending Capacity and Championing Psychological Support	
Lisa	*So I think this- you know, people can sometimes infantilise erm... people with aphasia. Erm... and sort of think that there's- there's more cognitive problems than there actually is because of the way that they present with the communication problems.*
Lisa	*...this I think is something that erm... I think people who... people who maybe are younger or who have a very- who were very active, maybe very high functioning before their stroke... erm... and they will often tell me that- how frustrating it is that people think they're stupid. Erm, and I hate to say it like that but that's how they- that's how patients will vocalise it, you know, and this real sort of I'm fine, you know, I'm intelligent, I can- I remember things, I know.*
Georgia	*How people say- I feel like it- people think I'm stupid or I feel stupid. I feel like my intelligence has changed...*
Aimee	*Uh, particularly with the higher functioning people, they tend to, um, find it embarrassing to actually try and go... so what their strategy is, will be trying to go round rather- so rather than describing the target word they go round the words to describe something... uh, and they find it really... frustrating and humiliating and embarrassing...*
Leah	*...so people can have a- have a good go at a conversation, but they just can't get their words out very well, so they'll be stumbling and stuttering*

	over their words. And they know what.. things are, they can find the words but they just can't get them out. And they can be quite- that can be quite socially awkward for people...
Georgia	*Sometimes what you find, is people speak in a patronizing way and it is literally the worst. It's that patronizing way or feeling like or sounding like... Almost the person is a bit 'stupid' because of their communication and like, obviously that is completely awful in the worst, and that's when you have to sort of feed back*
Lisa	*It's important to think of cognition as well as aphasia and then- but also not to make assumptions- I suppose it's not to make assumptions about people. Erm, just based on the fact that they're struggling with their communication*
Ashley	*Erm, I'm not sure that the physios or the OTs really think about it that much. Um... yeah. Maybe though. I think sometimes people might just get written off a bit because they can't say what it is that's bothering them. Um... maybe there's just an assumption that they're fine, or not fine.*
Lisa	*...and I think it- it's... that's- that can be very challenging for nursing staff [...] where, you know, you see someone who just- who just can't get their message across and then there's this assumption that well they can't remember things or you know... that they- they just can't talk so they don't sort of maybe stop and try, and try other things.*
Donna	*...whilst people might not think that psychological therapy is appropriate for people, um, with aphasia, that isn't true because there are ways that you can adapt your approach to working [...] to make sure that they're able to access it as well*
Lisa	*...I think the reality is often... is if someone has a receptive aphasia I'm probably not doing a longer piece of sort of clinical work with them.*
Ashley	*Erm, but at the same time I think there's a slightly unrealistic expectation of psychology in terms of our- I'll sometimes get referrals for talking therapy and it's... it's sort of like, it's going to be limited. Erm, we obviously try as best as we can to... to manage that. But you just can't do talking*

	therapy in the same way that you might with someone who's completely fluent in their speech
Marie	*Um... I think an overall sort of systemic challenge to start [inaudible] when someone has aphasia there's a belief that they can't engage in, um, talking therapy or psychology, and they I find that the um... [inaudible] are often quite quick to jump to um... antidepressant medication, and things like that and so that's- that's a kind of quite a uniform issue I've seen and something that I have to fight quite strongly against - often I'm not anti-prescription where I think it's appropriate and there is a lot of times where it is...um but I do find sometimes... particularly with this population they are maybe a little bit quicker to prescribe and write off... the possibility of talking therapy...*
Marie	*...there's so much that's so complex and unique about...[inaudible]...with aphasia how much you rely on language and actually how much you can communicate, even without language... For someone who, assuming that they've got receptive language intact, or at least to a degree, then there's loads- there's loads you can actually do to work with someone who's struggling with aphasia. And even if even if they're receptive, language is impaired and you're creative and you use different modalities, there- there's is tons you can do*
Lisa	*Yeah... yeah. Well, I- I suppose I try and see it as not all that different from working with people who don't have aphasia. So I suppose I'm trying to make it equitable in the sense that, you know, I- I- I think sometimes- I think sometimes the ther- so most of my referrals for psychology input come from the therapists on the ward. Erm, and I often... I might not get a referral sometimes cos people might make the assumption, well this person isn't going to be able to engage in... in psychology*
Lisa	*Erm... erm... so I think my role is in a way, it's sort of advocating a little bit for- for how psychology might be able to support in a particular situation... erm...*
Ashley	*Yeah, just I think that recognition that people can't advocate for themselves as easily. Erm... so for example we had a patient recently who*

	um, we knew, well I knew because we spoke to her friend, that she had just really important structure and routine that was like so integral to her, she gets really stressed if things aren't like, to plan, she'd always be up and ready and we were finding that she would often still like in her night gown at like 10am... and because she couldn't really ask to get up and get ready and it hadn't been offered to her... so...um... just making sure that actually we're thinking about the patient in a quite a person centred way and maybe being a bit more pre-emptive of their needs...
Ashley	*And I think also – it comes up a bit in capacity assessments – you know, not assuming someone doesn't have capacity because they're aphasic. Like, taking the time to really like try and help them communicate their kind of thoughts and wishes if they can and if another way... um, just some of those things not to yeah, just writing someone off because they can't say anything, yeah...*
Lisa	*And I think often times, and quite appropriately, it's a speech therapist who might do a capacity assessment or one of the other- you know, one of the other medics or one of the other therapists erm... But I- I'd be keen to not not get involved just because someone has a communication difficulty and I think- I- I've often done joint capacity assessments with myself and a speech and language therapist around a- around a particular issue.*
Ashley	*I think there's definitely a specific role for psychology and speech in that - within our team I think we're the ones who tend to be the- who think of that sort of stuff*
Theme 4: Moving Beyond Language – (Re)Connecting with What's Important	
Lisa	*And when you – when you get a picture and you get a sense of someone, who they are, what their personality, you know what they like and what they don't like, you know you sort of- you get pulled in quicker and you- you get a sense of you know, what direction you want to go with in terms of setting goals... jointly with them.*
Lisa	*Err... and it, you know I think, you know one of the key things is sort of build... you know, because when I meet someone on the stroke ward I'm trying to build – the first I'm trying to do is build a sense of who this person*

	is, you know, who are they? What's important to them? You know, how has this particular event- how has this disrupted their normal way of being and their normal life?
Lisa	*...and a bit more thinking about the persons system. Because you can't get everything from sitting down with them for... 50 minutes, 60 minutes erm, and just asking them about how they're doing, how they're feeling, what they're thinking about the new stroke, all- all of the other potential difficulties they might be having, whether it's physical or cognitive... You know, that sort of information and that knowledge has to come... from... working in a different way*
Lisa	*Erm, I think- I think you have work very- you have to work very hard and you have to be very invested. Erm... and you probably have to put in a bit more time*
Leah	*...you have to kind of... talk round stuff and you just need to allow a lot more time... with people to be able to, um, get to the things that you need to get... 'cause they're not going to get there...[inaudible] really...*
Donna	*Erm, and I think it's just as well about managing expectations of how much you're gonna achieve in a session - that you're not going to get through the same volume of work, erm, in a 50 minute session that you might otherwise with someone for whom aphasia isn't an issue*
Aimee	*The difference would be how I work with them rather than um, rather than... the way they present... Well, I mean obviously the way they present will be the communication difficulties, if that's what you are referring to um... Yeah... which... No, I- I think- I think- I think they're similar, it's just- it's just the communication bit does require more time um, so I would say that they- they can have similar themes...*
Donna	*...and because I've worked with her such a long time now, I kind of understand what she's saying without her having to say it sometimes – laughs-*
Marie	*So once you get to know a client well with aphasia... um... that bit about body language, intonation, connection, understanding, and being able to involve the family and get to know someone is so key, because actually I*

	found myself having what feel like full blown conversations with someone and what- what they're saying is making no sense at all, but through knowing them so well and underst- if they've got quite good intonation, even if it's jargon aphasia and they're coming out with the same word over and over and over... you really can... You- you really can understand... some of the time and - particularly if they've got some receptive language you can- you can test what you think someone is saying and they can... They can tell you
Lisa	*Erm... when that's absent and you can't do that in the kind of quick way you would normally do, you know, I think we often rely on family members to give us that sort of information and then you can build on that then when you work with people*
Lisa	*Erm... so there's definitely a balance to be struck there but erm, I know that we- Uh definitely in the acute phase we rely quite heavily on family members helping us out really.*
Lisa	*I find it really useful to go to the nurse to begin with and say... you know, how have things been over the past, sort of 24 hours? [...] So sort of that helps me to understand a little bit more and helps me to know [...] what some of the issues might be for this person, but also helps me with approaching them and communicating with them as well if I have a sense of what they are and what they aren't struggling with*
Lisa	*But I've had- I've had feedback from people before sort of saying that... you know the people on the ward understand them – so the speech and language therapist or the psychologist or the OT or who are working with them, they will have got to the stage where they've figured out a way to communicate or... people can anticipate, the staff can anticipate what the person might need and help to get to them communicating a message*
Lisa	*...the nurses are often around for a long shift, so they have a really good sense of how this person is making their needs known. So you know, I think the nurses I've worked with are very skilled in picking up on non-verbal cues*

Lisa	*I think sometimes that can put a lot of pressure on the family member and cause distress- sort of unwarranted distress in them as well. Because if you are- if you're always relying on them to provide information and tell you about the person, what they think might be going on... I think then you're probably neglecting trying to do that- that one-to-one work with the person and figure out what- what's important.*
Aimee	*...the person tends to have their- their own inner language, if you like, some slangs or [...] I'm just thinking now the cultural elements as well, not just racial culture, but family culture - the way of communication may be different. Certain things may mean different things. So I find that family members, or whoever are close to them help... to kind of think about actually [...] what other ways will help to facilitate communication?*
Donna	*You know, obviously with the young lady that was talking about who had the stroke, and then the um, non-epileptic seizures... That was real multidisciplinary working and we all kind of understood and knew her communication difficulties and we all kind of used her language for things 'cause she- she has particular language that she likes to use*
Georgia	*Or, you know, any family member that knows the patient better than I do and are more familiar with their interaction style*
Marie	*And I think that's one of the most powerful pieces of the work... it's really the- the richness comes with that re-connection to something outside of language.*
Marie	*Um... with particularly our clients with aphasia, because for- for me I'm slightly going off piste, but I will come back, I promise, but one of the interventions if someone is struggling with the talking therapy, um, would be to liaise very heavily with OT and go for more values driven approach in terms, of you know, connecting values connected with hobbies, connecting with things like that which we can explore in psych with visual prompts um...*
Marie	*Um... And you can explore values and you can explore... identity and you can explore connecting back to things that will give someone a sense of, um, a sense of self*

Leah	*...so the gentleman I've been talking about - he loves to talk about his garden – it's really important to him. But he can't... get across what he needs to say. So we've just talked about having a few words in a notebook for him to help him socially communicate a few keywords. So we're- we're just thinking about practical things around - for him - what he could have to take out to aid communication with him about things that are important to him.*
Leah	*...so I'm looking to see whether we can set-up a [name of place] PPA support group - so that would be just an evening group where carers and- and the person with PPA can come and just, from a social perspective, be able to kind of meet and have that shared experience. Particularly important, I think because they don't- they are limiting social contact because of their condition, so being able to go to a group where other people go, "don't worry, you can't find the word I get it", um.. would- would be great, I think, if we can get that up and running*
Leah	*Um, and just helping people to get out to groups, so coming to different dementia groups or, er, signposting people to different um, webinars to have that... care or support and- and the peer support*
Donna	*...um, just helping her to... see that it's really important to put herself back out there, and that friends are actually very understanding, and she started carrying a card, so she's in the supermarket, she could show people saying that I have difficulty with my speech and then having really positive experiences where people were helping her to get a taxi, and you know, just... really building up her confidence and reducing that... sense of social isolation...*
Aimee	*...because sometimes I think... Just being in a group helps, and that you're not alone... And usually sometimes people in a group - stroke survivors with aphasia, comes with, you know, diverse backgrounds and different diverse um... impairment, but they also have different strategies as well. So that usually is quite a good support network*
Aimee	*...my therapy, I'm not just doing therapy, I'm also thinking about wider system - is that if we know that a person has communication problems, we*

	know that this person will have difficulties communicating with the wider system. And if um... neuro rehab's aim is to increase and optimise someone’s um... functioning, be it from a social, vocational, uh... you know, daily, uh, perspective, then... we gotta look at the wider system. Because if not, neuro rehab is not doing their job.
Subtheme: Confidence comes with Experience	
Lisa	*...I mean I think when I first started in my career I found it incredibly challenging. Erm... and if I’m honest I probably felt a sense of... felt myself avoiding work with people with aphasia if I’m being completely honest and I think that comes off the back of... because as psychologists, you know, we’re in the business of talking to people and we’re in the business of trying to make sense of people’s emotions that- that’s primarily what we do... Erm... and when someone doesn’t have the ability to, you know, to share via means of communication erm that, I think that can feel quite de-skilling. (Lisa)*
Marie	*...and I've- I almost learned that too late, I think. I think in my early post qualification - sort of 10 years ago - I was like really... Quite um... anxious about working with clients even when I newly qualified, um, who didn't have language 'cause it was- I saw it as the tool to psychology, and it's only sort of in the last five years or so that I’ve really, really become confident in realizing it’s so- there's so much that can be done... helpful, that's not just medication...to support someone with aphasia.*