Stroke professionals’ views and experiences of supporting Young Stroke Survivors (YSS) who have dependent children

SALLY GASCOINE

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ABSTRACT

Background

Stroke is a leading cause of disability both in the UK and worldwide. One in four strokes happen to people under 65 and the incidence is rising. Young stroke survivors with dependent children may experience difficulty in their ability to parent their children, with disruption felt across the whole family system. There is a paucity of research on the experiences of rehabilitation staff working with young stroke survivors with dependent children leading to a lack of understanding about their views and experiences, and how supported they feel in their work. A better understanding of the experience of rehabilitation staff will contribute to offering effective family focused rehabilitation for this population.

Aim

The study aimed to contribute to the limited evidence base by gaining an understanding of how staff members of a stroke service experience working with young stroke survivors who have dependent children and how they experience support that facilitates their work.

Method

Semi-structured interviews were carried out with ten members of an Early Supported Discharge (ESD) stroke team, including Psychologists, Physiotherapists, Speech & language Therapists and Occupational Therapists. A critical realist thematic analysis was used to analysis the data.

Results

The analysis generated three higher-order themes; “There is More to Hold,” “Working into the Complexity,” and “Impact on Staff”. The study found staff from ESD teams experience working with young stroke survivors with dependent children as unique. They noticed loss and change in the parenting of young stroke survivors and their role within their family. Staff described including parenting related treatment goals into rehabilitation and including the children of young stroke survivors into therapy sessions. Working with young stroke survivors with dependent children may elicit a difficult emotional response for ESD team staff. They talked about valuing and utilising the support provided by the Multi-Disciplinary Team (MDT).

Conclusion

This study contributes to a small body of literature on family-centred rehabilitation practises. Recommendations for practice, policy and research have been proposed.

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LIST OF ABBREVIATIONS

ABI	Acquired Brain Injury
ESD	Early Supported Discharge
FSF	Family Systems Framework
GDPR	General Data Protection Regulation
HCP	Health Care Provider
HD	Huntingdon’s Disease
HRA	Health Research Authority
IRAS	Integrated Research Application System
LTP	Long Term Plan
MDT	Multi-disciplinary Team
MS	Multiple Sclerosis
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OT	Occupation Therapist
PIS	Participant Information Sheet
R&D	Research & Development
SLP	Speech-Language Pathologists
SLT	Speech and Language Therapist
TBI	Traumatic Brain Injury
UEL	University of East London
UK	United Kingdom

1. INTRODUCTION

1.1. Overview

The present study explores how staff from a stroke team experience working with young stroke survivors who have dependent children. In this chapter, key terminology will be discussed, followed by an outline of stroke and stroke services. This is followed by a narrative review of the literature focusing on the experience of young stroke survivors, including young stroke survivors parenting after stroke, and the support needs of young stroke survivors. A scoping review of the literature around staff perspectives of working with young stroke survivors with dependent children will attempt to contextualise the research questions and study aims.

1.2. Terminology

1.2.1. Stroke Survivors

Stroke survivors is the term commonly used in stroke research to describe an individual who has survived a stroke. The heterogeneity of this group is acknowledged and discussed throughout the study.

This study uses the terms older stroke survivors for those who experience a stroke when over the age of 65; and young stroke survivors to describe those who experience a stroke under the age of 65. This is the most widely accepted definition within stroke research, fitting the rationale of young stroke survivors being those who are over the age of 18 and thus considered an adult, but under the traditional age of retirement, (Morris, 2011). Although the default age of retirement was removed in the UK in 2011, 65 is associated with retirement and ‘older age,’ and is adopted as such by services in the National Health Service (NHS), such as ‘older adult’ mental health services. It is important to note however, the inclusiveness of the 18-65 age range does not take into account the different living conditions, life activities, roles and expectations that are likely between those at the lower and upper end of the age boundaries, (Harris Walker., 2021a; Lincoln et al., 2012).

1.2.2. Stroke/Acquired Brain Injury

Stroke accounts for 35% of individuals living with an Acquired Brain Injury (ABI) (Headway Essex, n.d.). Although the majority of research discussed in this study is related to stroke survivors, in an attempt to ensure all relevant literature is considered, some research focused on parenting after an ABI is included.

1.3. Stroke

A stroke occurs every five minutes in the UK, equating to over 100,000 people experiencing a stroke each year; with rates increasing globally, (Stroke Association, n.d; Feigin et al. 2014). The majority of people survive their first stroke, with around two thirds experiencing disability (Different Strokes, n.d.). The effects of stroke are heterogeneous, depending on the location of brain injury and severity of damage to neural pathways (Different Strokes, n.d.). However, stroke is a leading cause of disability with difficulties often experienced with movement, cognition, and communication, (Smajlović, 2015; Stroke Association, n.d.). The current economic cost of stroke for the UK is calculated to be £26 billion each year, with costs to the NHS and social care calculated as £8.6 billion, (Patel et al., 2020).

1.4. NHS Services for Stroke Survivors

In the UK, stroke services provided by the NHS consist of urgent and acute inpatient care and rehabilitation services. The NHS Long Term Plan (LTP) published in 2019 identified stroke as a clinical priority. Specific goals of the LTP include increasing efforts at the prevention of stroke and increasing the quality and availability of rehabilitation services.

1.4.1. Acute Services

Acute services provide daily and continuous specialist multi-disciplinary input, (NHS England, 2021). Stroke survivors in acute care should receive physiological monitoring and inpatient rehabilitation by specialist therapies including Speech and Language Therapy (SLT) and occupational Therapy (OT), (NHS England, 2021).

1.4.2. Rehabilitation Services

Stroke survivors receive rehabilitation in inpatient services and/or community teams, (NHS England, 2021). Rehabilitation is offered in the community for stroke survivors considered to be medically stable and with access to a safe and appropriate environment for rehabilitation, (NHS England, 2022). In the UK, approximately half of young stroke survivors will be discharged from acute care to community rehabilitation, (Walters et al., 2020).

Rehabilitation is provided by a specialised Multi-Disciplinary Team (MDT), comprised of OTs, physiotherapists, SLTs, social workers, consultant physicians and clinical psychologists, (NICE, 2013). Rehabilitation should be needs focused, with person-centred rehabilitation goals, regularly reviewed in collaboration with stroke survivors and their support network, (NHS England, 2022).

In the community, rehabilitation is offered by community stroke teams and Early Supported Discharge (ESD) teams. Stroke survivors are referred for ESD if they have mild to moderate disability, (NICE, 2013). ESD is therefore suitable for approximately 40% of stroke survivors in the UK, (Fisher et al., 2011, 2013). Rehabilitation offered as part of ESD should maintain the same intensity as that offered in inpatient settings, (NSH England, 2022). It is therefore typically more intense than that offered by community services, and offered over a shorter period of time, (NHS England, 2022). Stroke survivors are usually seen by an ESD team within 24 hours of discharge from acute services and may receive up to four visits per day, seven days per week, (Cobley et al., 2013).

1.4.2.1. Role of clinical psychology: Clinical guidance is clear that the entire MDT should address the neuropsychological, emotional, cognitive, and psychological needs of stroke survivors and consider the impact on engagement with rehabilitation, (NHS England, 2021). However, clinical psychologists have a key role within the MDT in supporting the development of psychological skills, providing supervision, and offering direct psychological interventions for stroke survivors who require it, (Gillham & Clark, 2011).

1.4.3. Benefits of Early Supported Discharge

ESD teams have been found to accelerate discharge home for stroke survivors, reducing their length of stay in inpatient settings and increasing longer term independence from institutional care, (Langhorne et al., 2007; Langhorne & Baylan, 2017). The growing and supportive evidence base for ESD has seen its implementation both in the UK and internationally, (Hitch et al., 2020; Walters et al., 2020). However, there is some variation in service provision both in England and globally, (Cameron et al., 2022; Chouliara et al., 2023; Walters et al., 2020).

ESD is generally perceived positively by stroke survivors, carers, and staff. Stroke survivors have reported that they value being at home and working on personalised, ecologically valid goals, empowering them to re-establish desired life roles, (Chouliara et al., 2023; Cobley et al., 2013). Stroke survivors have also expressed their sense of security resulting from having access to their social support network and involving family in their care, (Cameron et al., 2022; Cobley et al., 2013). Staff have reported that the ESD service model aligns with their professional and personal beliefs and values about the benefits of client-centred care, flexibility and equity, (Hitch et al., 2020). Staff have highlighted the opportunity provided by regular home visits to develop a better understanding of the stroke survivor and form a trusting therapeutic relationship, (Martinsen et al., 2021). Staff have described that being at home means family members are often present during sessions providing an opportunity to observe family relationships, (Martinsen et al., 2021). Working at home also provides staff with the opportunity to observe the transition from acute services to home. Although often eagerly anticipated, this can often present unexpected challenges for stroke survivors, especially when reality differs from expectation, (Banks & Pearson, 2004; Lawrence, 2010).

1.5. Stroke in Younger and Middle-Aged Adults

1.5.1.Epidemiology

Although the risk of having a stroke rises with age, one in four strokes happen to people under 65, (Different Strokes, n.d.), with 10-20% of strokes occurring in people aged 18-50, (Boot et al., 2020). Furthermore, the incidence of stroke in those under 65 is increasing globally, becoming a growing public health concern (Boot et al., 2020; Sultan & Elkind, 2013).

Most strokes occurring in those under 65 are ischemic resulting from a blockage in an artery supplying blood to the brain, (Mehndiratta et al., 2004). Ischemic strokes are linked to modifiable cardiovascular risk factors such as smoking, diabetes, hypertension, and alcohol and drug use, (Mehndiratta et al., 2004). Recently, infection of the COVID-19 virus has also been linked to strokes in those under 65, both with and without traditional risk factors, (Oxley, 2020).

Strokes occur in young adults of all races, ethnicities and gender, (Boot et al., 2020). However, the cause of stroke varies across geographical region, gender and ethnic group, (Boot et al., 2020). Despite the relatively lower incidence and better outcomes, young stroke survivors still require significant resources from health services, (Lincoln et al., 2012).

1.5.2. Underrepresentation in Research Literature

Young stroke survivors have been relatively neglected in stroke literature, (Banks & Pearson, 2004; Hutton & Ownsworth, 2019). The lack of research reflects the commonly held perception of stroke as a health event that happens in older age, therefore few studies have focused on strokes in younger people (Banks & Pearson, 2004; Harris & Bettger, 2018). Consequences of this include misdiagnosis, a lack of understanding of the needs of young stroke survivors, and stroke services that do not reflect the needs of this client group, (Different Strokes, n.d.).

1.5.3.The Experience of Stroke at a Younger Age

A stroke may be particularly disruptive for young stroke survivors due to the greater diversion from the anticipated life trajectory of younger and middle aged adults, (Banks & Pearson, 2004; Hutton & Ownsworth, 2019). Adults at this stage are typically in employment with financial and family commitments, alongside a busy schedule of social and community activities (Wolfenden & Grace, 2015). Stroke at a younger age is therefore likely to carry a greater burden of disability, (Harris & Bettger, 2018).

Stroke survivors can experience a range of impairments across physical, cognitive and emotional domains including mobility issues, weakness, speech difficulties, fatigue, difficulty focusing, emotional lability, anxiety, anger, and low mood, (Harris Walker, et al., 2021b). The experience of stroke and process of stroke recovery is unique for each young stroke survivor, with some feeling they have recovered fully a short time after their stroke, and others experiencing lifelong residual impairments, (Kuluski et al., 2014a; Walters et al., 2020). However, there are some aspects of experience that appear to be widely shared across young stroke survivors.

1.5.3.1.Stroke as a sudden and traumatic event: Young stroke survivors often have no history of ill health and so the stroke is experienced as a shocking and traumatising event, (Banks & Pearson, 2004; Harris Walker et al., 2021a; Kuluski et al., 2014a; Lawrence, 2010; Stone, 2005).

This is highlighted by a young stroke survivor in Stone's (2005) study:

> *"I said, 'what do you mean, I've had a stroke?' And, and you know, that was the first I'd heard of it. Um, I was horrified that I'd had a stroke and I was like 37."*

The suddenness and unexpectedness of disability is often difficult for young stroke survivors to make sense of and many feel frustrated and unprepared for the sudden changes to their life, (Coppock et al., 2018; Kuluski et al., 2014a; Lawrence, 2010; Shipley et al., 2018).

> *"[It's as if somebody came in the middle of the night.. and stole part of me and I have never got it back."*

(Kuluski et al., 2014a, participant 7).

The shock of experiencing a stroke at a younger age is often compounded by a delay in recognition and diagnosis of stroke due to the misconception of stroke as a problem of older age only, (Banks & Pearson, 2004; Harris Walker et al., 2021a, 2021b; Kuluski et al., 2014; Stone, 2005; Teasell et al., 2000; Wolfenden & Grace, 2015).

1.5.3.2. Impact on the self, life roles and relationship to others: Young stroke survivors have reported an overwhelming fatigue and exhaustion completing day to day tasks and consequently withdrawing participation or taking a more passive role in social activities, work and family life (Coppock et al., 2018; Röding et al., 2003; Toglia et al., 2019; Yilmaz et al., 2015). The loss of valued life roles and activities can have a negative effect on an individual's sense of self, their quality of life, and economic consequences for self and family (Kuluski et al., 2014a; Yilmaz et al., 2015).

The nature of close relationships may also change following a stroke. Relationships may shift as young stroke survivors find themselves suddenly needing care from partners or once again from their parents, (Teasell et al., 2000). Young stroke survivors may experience feelings of burden and dependency on their partner, (Ford et al., 2021; Kuluski et al., 2014a).

Outside of the family, the social worlds of young stroke survivors may shrink as they withdraw from social activities for fear of how they are perceived by others, feelings of shame associated with residual physical impairment, or avoidance of being reminded about their former selves (Ford et al., 2021; Kuluski et al., 2014a; Lawrence, 2010).

Importantly however, not all changes for young stroke survivors appear to be negative. Some young stroke survivors have described a newfound appreciation and gratitude for life, with higher value placed on spending time with loved ones, (Harris Walker et al., 2021a; Röding et al., 2003), and for some, a feeling of relief that they were not more severely affected by the stroke, (Röding et al., 2003).

1.5.3.3. The problem of invisibility: A compounding difficulty, exacerbating the effects of residual impairments of stroke for young stroke survivors can be the problem of invisibility, (Morris, 2011; Röding et al., 2003; Stone, 2005). Cognitive difficulties such as fatigue can pose serious difficulties for young stroke survivors during interactions with others and when contemplating a return to work, (Morris, 2011; Stone, 2005). However, due to the invisibility of cognitive difficulty, young stroke survivors are tasked with continually having to decide if they want to disclose their difficulties to others, often in situations where they did not perform according to social norms and expectations for a non-disabled person of their age group, (Stone, 2005).

1.6. Parenting After Stroke

Parenting involves supporting and preparing children to become compassionate, productive and able members of society, (Bornstein, 2007). On a wider scale, parenting in its various forms, i.e. biological, adoptive, lone or step-parenting, ensures survival of the human race, as children cannot grow and thrive in solitary conditions, (Luster & Okagaki, 2005). Thus, when considered in terms of its significance, parenting can be viewed as a fundamental and universal concern of society (Hoghughi, 2004).

On a day to day basis, parenting may take place across multiple domains in the provision of physical, social, emotional, and spiritual care, (Hoghughi, 2004). To successfully complete parenting tasks, parents require diverse resources including knowledge, skills, material resources, and social and emotional support, (Hoghughi, 2004). Parenting is therefore a complex and demanding occupation that often requires managing conflicting burdens and responsibility in the context of various life roles including parent, partner, worker and friend, (Pituch et al., 2020; Hoghughi, 2004).

Unlike other life roles such as employment, parenting is unique in the sense that upon discharge from hospital, young stroke survivors are likely to return to household responsibilities and to parenting in some capacity, regardless of any residual impairment and readiness to return to these roles, (Harris & Bettger, 2018).

Although the degree and range of impairment experienced by young stroke survivors will influence the extent to which parenting practices are affected, (Coppock et al., 2018; Harris Walker, et al., 2021b); the possible breath of impairment has the potential to cause wide-ranging disruption to the young stroke survivors' capacity to complete day to day parenting tasks and provide a nurturing environment that fosters child development, (Edwards et al., 2014; Holloway & Tyrrell, 2016).

1.6.1. Young Stroke Survivors Experiences of Parenting After Stroke

Research exploring the experiences of parents following stroke assists in gaining an understanding of aspects of stroke recovery for this population, alongside how parenting can be supported, (Edwards et al., 2014; Harris & Bettger, 2018). Unfortunately, research to date has been limited in this area, (Edwards et al., 2014; Harris & Bettger, 2018; Harris Walker et al., 2021a; Holloway & Tyrrell, 2016). However, some qualitative research literature has explored the experiences of young stroke survivors with dependent children and some common themes have been highlighted.

1.6.1.1.Loss and change to parenting following stroke: Young stroke survivors have described feeling changed as a parent and noticing a shift in their parental role following a stroke, leading to a feeling of loss and mourning for the parent they were before their stroke, (Coppock et al., 2018; Edwards et al., 2014; Gawulayo et al., 2021; Harris Walker, et al., 2021b). Loss has been described in terms of being unable to fulfil particular tasks related to parenting such as being able walk children to school, (Edwards et al., 2014; Harris Walker et al., 2021b; Kitzmuller et al., 2012; Kuluski et al., 2014a; Pituch et al., 2020).

Loss has also been described in terms of a loss of parental identity, for instance, being an 'active' or 'strong' parent, (Edwards et al., 2014; Harris Walker et al., 2021b; Martinsen et al., 2012; Röding et al., 2003). The feeling of loss around parental identity was described by a participant in the study by Harris Walker, et al., (2021a, p. 130):

> *"I think that's the hardest, I can't be me, and I feel like the stroke took away from my children the mom who I would have been. It's like the mom that I would have been didn't have all these mood swings, the mom that they would have had was never late…" (Mother, age 39 at time of her stroke).*

Loss to parental authority also appears to be a particularly challenging experience for young stroke survivors who are parenting. This may be as a consequence of fatigue causing undesired leniency with boundary setting, or difficulties communicating requests, (Edwards et al., 2014; Harris Walker et al., 2021b; Killmer et al., 2022).

1.6.1.2. Loss and change to the parent-child relationship following stroke: Young stroke survivors have also described changes in the parent-child relationship following stroke. This may arise from a physical separation from children during a hospital stay, leading to a sense of disconnection, (Edwards et al., 2014; Harris Walker et al., 2021). Furthermore, struggling to communicate with each other in the way they were able to before the stroke may lead to conflict and disengagement between parent and child, (Kitzmuller et al., 2012; Kuluski et al., 2014a). In addition, emotional changes such as irritability and frustration may negatively alter interactions, (Gawulayo et al., 2021; Harris Walker et al., 2021b). This could be further compounded by physical difficulties restricting how parents can display physical affection, (Hutton & Ownsworth, 2019; Kuluski et al., 2014a).

1.6.1.3. Emotional impact: Negative beliefs around not being a good enough parent can negatively affect the emotional wellbeing of young stroke survivors with dependent children, (Lawrence, 2010; Pituch et al., 2020). Young stroke survivors have described feelings of sadness and frustration at the impact of stroke on parenting, (Kitzmuller et al., 2012; Yilmaz et al., 2015) and discomfort and guilt associated with being physically absent whilst receiving treatment, (Edwards et al., 2014; Harris Walker et al., 2021a). Feelings of uncertainty and worry about recurrence of stroke might also be experienced, contributing to the overall emotional toil of the experience, (Edwards et al., 2014; Harris Walker et al., 2021a).

However, young stroke survivors with dependent children have also described experiences of hope, creativity and finding strategies to adapt to the changes in parenting, ensuring they were still able to participate as a parent, (Edwards et al., 2014; Harris Walker et al., 2021a; Pituch et al., 2020).. Furthermore, some of the changes to family life following stroke have been described positively. For instance, being able to slow down and spend more time at home with family, (Martinsen et al., 2012; Röding et al., 2003). A participant from Martinsen’s et al. (2012) study describes this as follows:

> *[To be at home] has been positive. [..] Not all the fathers have that opportunity. I’ve had the opportunity to be there for my kids, pick them up at school and make dinner. […] That’s somehow the great, positive part of this (father 43, nine years since stroke).*

Furthermore, young stroke survivors have described children as a motivating factor in their recovery, creating a drive to restore pre-existing roles, (Coppock et al., 2018; Kitzmuller et al., 2012; Kuluski et al., 2014a).

1.6.1.4. Balancing parenting tasks with own recovery: Another challenge reported by young stroke survivors with dependent children is finding a balance between childcare and making time for their recovery, (Harris & Bettger, 2018; Harris Walker et al., 2021a; Martinsen et al., 2012; Röding et al., 2003). Both internal and external pressures may exist for young stroke survivors with dependent children who may be less able to adopt a lifestyle that prioritises their recovery leading to feeling overwhelmed, and increasing their vulnerability for further difficulties, (Harris & Bettger, 2018; Harris Walker et al., 2021b; Martinsen et al., 2012; Röding et al., 2003).

1.6.1.5. Social cultural influences on parenting after stroke: Despite the shared experiences that have been reported for young stroke survivors with dependent children, there will inevitably be important differences, shaped by personal, cultural, and societal context. The experience of parenting is influenced by both macro- level processes such as financial stressors, and micro-level influences, which include day to day stressors such as relationship between co-parents, (Belsky, 1984; Conley et al. 2004). Macro-and micro-level processes are shaped by social cultural factors such as ethnicity and class and the associated discrimination, (Belsky, 1984; Conley et al. 2004). Parental perceptions are unlikely to look the same across intersecting identities, however most research and thinking into parenting privileges white, middle class and heterosexual values and practices as the norm, (Carr & Springer, 2010; Sutherland, 2010).

Despite some exceptions, e.g. (Gawulayo et al., 2021); most research into parenting after acute health events has taken place in the northern hemisphere, (Pituch et al., 2020). In their literature review on parenting after stroke, Harris & Bettger, (2018) note that they were unable find research from Africa, South America and Asia pacific regions to include in their review and therefore cultural and geographical differences in parenting after stroke remain absent from the research literature, (Harris & Bettger, 2018).

Furthermore, parenting experiences are likely to be gendered both pre- and post-stroke, (Harris & Bettger, 2018; Kuluski et al., 2014b; Röding et al., 2003); yet a significant majority of literature concerns only mothers, and so more literature is needed to illuminate the impact of gender on parenting experiences after stroke, (Harris & Bettger, 2018; Pituch et al., 2020).

1.7. Impact on Children Following Parental Stroke

Stroke has the potential to alter the roles and responsibilities of different family members, disrupting the overall functioning of family life, (Coppock et al., 2018; Gawulayo et al., 2021). Children may need to adapt to role changes of their parents, (Butler, 2018; Kuluski et al., 2014a), and the experience of exposure to different parenting styles of temporary carers, (Harris Walker et al., 2021a). Children may experience day to day changes to their lifestyle, and may take on more of the household responsibilities, (Cameron et al., 2022; van de Port et al., 2007; Yilmaz et al., 2015), including contributing directly to the care of their parent; for instance, supporting with personal care, (Harris Walker et al., 2021a; van de Port et al., 2007; Yilmaz et al., 2015).

1.7.1. Impact on Psycho-social Wellbeing

Accordingly, the impact of parental stroke can threaten the psychosocial wellbeing of children, (Coppock et al., 2018). Children have described feelings of anxiety, loss, and stress, (Coppock et al., 2018). A young person who participated in a study by Coppock et al. (2018, p. 480) described their sense of loss as:

> *"..he's still a Dad like he cares for me and all that, but most of him now, he's like a friend now… it feels like you've lost something and it just feels like I've lost a bit of my Dad," (Mark - pseudonym).*

In a study by Visser-Meily et al., (2005), 54% of children exhibited mood or behavioural problems immediately following parental stroke, with 29% continuing to display these a year after. In a study by Kieffer-Kristensen et al., (2011), 46% of children with a parent with an ABI, displayed elevated symptoms associated with Post Traumatic Stress Disorder (PTSD) including avoidance and intrusive thoughts. A longitudinal study by Sieh et al., (2010), found that stress in children three years post-parental stroke, was positively correlated to the young stroke survivors' depressive symptoms, martial difficulties and female gender of the child.

Difficult feelings experienced by children of stroke survivors may be compounded by a sense of needing to keep their experiences to themselves to avoid upsetting their parent as a means of protecting them, (Cameron et al., 2022; Coppock et al., 2018; Kieffer-Kristensen et al., 2011; Kitzmuller et al., 2012). Consequently, Kieffer-Kristensen et al., (2011) stressed the importance of Health Care Providers (HCPs) assessing the needs of children of young stroke survivors even in the absence of overt difficulties.

1.7.1.1. Positive changes for children following parental stroke: Research has indicated that there may be some positive changes for children following parental stroke. Participants in the study by Gawulayo et al., (2021) described spending more time together as a family. Similarly, participants in the study by Kitzmuller et al., (2012) and Harris Walker, et al., (2021a) described a closer parent-child relationship. Although research examining the perspectives of children is limited, (Cameron et al., 2022); children in the research conducted by Van de Port et al., (2007) described feeling more needed and mature, and being able to take on more responsibility as positive changes. Similarly, children in the study by Cameron et al. (2022) reported that the skills and experience they gained supporting their parent was helpful life experience; along with becoming more compassionate of others, (Cameron et al., 2022).

1.8. Theoretical Framework: Using a Family Systems Framework to Consider the Impact of Parental Stroke on the Family

A Family Systems Framework (FSF) emphasises the need to consider the impact of the illness of one family member on the balance of the family system as whole, (Bornstein, 2007). An acute medical event such as a stroke inflicts rapid change to a family system, inducing stress and requiring swift action and adaptation in a short period of time, (Rolland, 1999; Sieh et al., 2012). A FSF suggests that future functioning of a family system requires the family grieve for their lost pre-stroke identity and reach acceptance of their new situation by achieving a sense of meaning and mastery over the experience, (Rolland, 1999).

Rolland, (1999) draws from the family life cycle model developed by Carter & McGoldrick, (1988), in which the family life cycle consists of different 'phases,' whereby significant events such as the birth of a first child, signify transition from one phase to the next. Rolland, (1999) highlights that managing an acute medical event such as a stroke when it is out of sync with the typically expected tasks of that life phase, is likely to be particularly developmentally challenging for a family, (Rolland, 1999). Specifically, the 'pull inwards' or added cohesiveness within the family that may be necessary to manage dependency when a family member has a stroke, may interact problematically with the life stages of a 'younger family,' which also require a 'focus inwards.' Thus, this may intensify the demands of the phase, leading to enmeshment and delayed transition from the phase, (Rolland, 1999). Furthermore, a stroke occurring when families are beginning to adopt a more outward focus, such as during the adolescent stage, may force a return to a 'pull inwards,' causing disruption and conflict during the phase, (Rolland, 1987).

1.9. Supporting Younger Stroke Survivors

Adult stroke rehabilitation aims to support stroke survivors to regain or adapt to the physiological and psychological changes following stroke, (NICE, 2013). More broadly, the goal of rehabilitation is to support stroke survivors to return to functional activities and participation in social and occupational roles, ultimately enhancing quality of life, (NICE, 2013; Toglia et al., 2019).

1.9.1. The Support and Rehabilitation Needs of Young Stroke Survivors

Given the likely differences in the priorities, and social and occupational roles of younger and older stroke survivors; rehabilitation needs to be sensitive and responsive to the differences between older stroke survivors and younger stroke survivors to be beneficial for young stroke survivors , (Lawrence, 2010; Toglia et al., 2019). Some of the specific needs and goals of young stroke survivors include parenting, returning to work and social activities, (Harris & Bettger, 2018; Morris, 2011; Toglia et al., 2019).

Research examining the support needs of young stroke survivors has highlighted that supporting young stroke survivors to regain age normative and meaningful social and occupational roles aids young stroke survivors in rebuilding self-identity and readjustment following stroke, (Hutton & Ownsworth, 2019; Shipley et al., 2018). The emotional and psychological support provided as part of rehabilitation may support young stroke survivors to make sense of their experience of having a stroke and integrate it into their life narrative, (Hutton & Ownsworth, 2019; Morris, 2011; Shipley et al., 2018).

1.9.2. The Unmet Needs of Young Stroke Survivors

Unfortunately research indicates that some needs of young stroke survivors remain unmet following rehabilitation by services which have traditionally been configured to meet the needs of older stroke survivors, (Lawrence, 2010; Low et al., 2003; Morris, 2011). Sufficient emotional support and psychoeducation about the cause and prognosis of stroke appear to be particular areas of unmet need for young stroke survivors, (Coppock et al., 2018; Low et al., 2003; Shipley et al., 2018). Alongside a desire for a flexible, holistic approach to goal setting rather than a restricted focus on rehabilitation of physical function, (Shipley et al., 2018).

A recent study by Walters et al. (2020), found that across the UK and Australasia, a quarter of young stroke survivors in the 18-45 age range were not offered any rehabilitation following their stroke, despite less than optimum outcomes for this group at 12 months post-stroke. Walters et al. (2020), hypothesise that this could be due to a belief held by professionals that young stroke survivors who have experienced a mild stroke, may recover without the need for support from services. However, they highlight that during acute care, some of the later presenting difficulties such as mood disturbance, may not be apparent, and therefore young stroke survivors may be vulnerable to being overlooked by services, (Walters et al., 2020).

1.9.3. Supporting Parenting After Stroke

Research has indicated that current clinical practice does not routinely include goals and activities directly related to parenting in rehabilitation plans for young stroke survivors who have dependent children, (Edwards et al., 2014; Harris & Bettger, 2018; Harris Walker et al., 2021b). However it suggests that for young stroke survivors who are parents, rehabilitation goals should consider and reflect the emotional and physical demands of parenting, (Edwards et al., 2014; Martinsen et al., 2012; Sieh et al., 2012; Harris & Bettger, 2018). Furthermore, HCPs should pay attention to the parent-child relationship, and the specific vulnerabilities of young stroke survivors who are parenting, such as being able to make time for rehabilitation, (Edwards et al., 2014; Martinsen et al., 2012; Sieh et al., 2012; Harris & Bettger, 2018). Ystaas, (2019) emphasised that rehabilitation offers the ideal opportunity for HCPs to support young stroke survivors to collaboratively problem solve and learn how to adapt to successfully complete tasks related to caring for their children.

Edwards et al. (2014) hypothesised that a barrier to including parenting related goals in treatment plans might be an avoidance caused by the anxiety of talking about parenting for both young stroke survivors and HCPs. Specifically, the possibility that young stroke survivors may withhold difficulties and concerns for fear of judgement or referral to social care, (Edwards et al., 2014; Harris Walker et al., 2021a). Conversely, HCPs might feel challenged by holding both safeguarding and rehabilitation needs in mind simultaneously, compounded by a lack of clinical training in how to consider and discuss parenting needs as part of routine practice, (Edwards et al., 2014; Holloway & Tyrrell, 2016). Edwards et al. (2014) stress that asking HCPs about their views on asking about and supporting parenting is necessary to understand worries and reservations that interfere with best practice.

1.9.4. Supporting Parenting After Stroke: Perspectives of Young Stroke Survivors with Dependent Children

Qualitative research exploring the perspectives of young stroke survivors around parenting support following stroke is limited. However, a study by Toglia et al., (2019) found that almost half of young stroke survivors reported that they were not providing as much care to dependent children or loved ones as they hoped to be doing post-stroke. In the study by Edwards et al., (2014) participants included in the study were parents who had experienced an ABI and were receiving inpatient treatment in a rehabilitation unit. Participants expressed their desire to feel like a parent again and some reported being able to use strategies learnt during rehabilitation to engage in parenting tasks. Participants described feeling empowered by the support provided to reengage with parenting. Edwards et al., (2014) suggested that facilitating a return to parenting during rehabilitation might address the multiple losses experienced by young survivors of an ABI.

In a scoping review of literature around the needs of parents with a physical and cognitive disability, Pituch et al., (2020) reported that parents expressed the view that clinical training related to the needs of disabled parents would be beneficial for HCPs to increase their clinical knowledge, enhancing the rehabilitation provided to them. Across the studies included in the review, parents described that the demands of rehabilitation could feel incompatible with their responsibilities as a parent, occasionally leading to disengagement. Accordingly, parents voiced the need for rehabilitation to take account of their parental role, (Pituch et al., 2020).

1.9.5. Adopting a Family Centred Approach

Harris Walker et al. (2021a) suggest that by creating family centred treatment plans, discussions about parenting will be prompted, and space created for thinking and learning about the impact of stroke on caring for dependent children. Furthermore, family centred care may support HCPs to think through the multiple demands placed on young stroke survivors and their likely engagement with treatment plans, (Harris & Bettger, 2018; Harris Walker et al., 2021a). A family centred approach in healthcare has been described as a strengths based, collaborative approach to healthcare that attends to and considers the whole family system in the planning and delivery of treatment, (Grawburg et al., 2019; Karpa et al., 2020). In stroke rehabilitation, family centred care includes supporting communication between stroke survivors, family, carers and professionals, and the prioritisation of highly valued goals around participation in treatment planning, (Grawburg et al., 2019).

A family centred approach to rehabilitation after stroke is particularly important because family and friends of young stroke survivors are often the primary source of practical and emotional support for young stroke survivors, including the in the provision of childcare during recovery, (Harris Walker et al., 2021a; van Heugten et al., 2006). A family centred model of care should therefore support professionals to consider the experience and wellbeing of family members and carers, and respond accordingly, potentially providing them with their own support, (Holloway et al., 2019).

According to a FSF, taking into account the developmental stage of a family should enable HCPs to achieve a broader view of family strengths, resources and vulnerabilities, vital for family centred care, (Rolland, 1999). Furthermore, they may be able to offer more attuned support with resolving difficult emotions that have arisen from the 'pull inwards' and attempt by family members to achieve a balance between offering care and pursing individual goals, (Rolland, 1987).

1.9.6. Supporting the Children of Young Stroke Survivors

Cameron et al., (2022) draw attention to the fact that the increasing prevalence of stroke in working age adults, means that HCPs are increasingly likely to support stroke survivors with dependent children living with them at home, and who therefore, need to be considered in family centred care planning, (Van De Port et al., 2007). However, they suggest that HCPs may feel ill equipped to do so given limited knowledge and experience, (Cameron et al., 2022). Including the children of young stroke survivors in stroke rehabilitation may include involving children in the rehabilitation of their parent, and/or providing support directly to the child or young person.

1.9.6.1. Including children in parental rehabilitation: Harris Walker et al., (2021a) suggest that including children in the rehabilitation sessions of their parent could benefit children by supporting them to feel included, and able to help and support their parent at home. According to Butler, (2018), this could be motivational for the parent and increase the meaningfulness of the rehabilitation plan. Furthermore, psychoeducation around the location of stroke in the brain and the link to specific deficits may help children to better understand the behaviours and emotional responses of their parents, improving familial relationships (Butler, 2018; Harris Walker et al., 2021a).

1.9.6.2. Providing psychosocial support for the dependent children of young stroke survivors: Family-centred stroke rehabilitation should assess and respond to the support needs of dependent children in addition to the parent, (Grawburg et al., 2019). Research that has assessed the impact of parental stoke on children has called for clinical assessment of children in the acute phase of stroke recovery, with the provision of psychological support for children and young people for persistent emotional and/or behavioural difficulties, (Kieffer-Kristensen et al., 2011; Sieh et al., 2010; Visser-Meily et al., 2005). Providing age appropriate information about stroke and local support services has been identified as a key area of support for children, in order to increase their understanding of stroke and their own emotional reaction, (Butler, 2018; Cameron et al., 2022; Coppock et al., 2018; Visser-Meily et al., 2005).

1.10. Summary of Literature of the Experiences of Young Stroke Survivors, Parenting After Stroke and the Support Needs of Young Stroke Survivors

The literature presented here has highlighted the sudden and disruptive nature of stroke for young stroke survivors and the additional challenge for young stroke survivors who are caring for dependent children. The need for services to meet the unique needs of young stroke survivors has been discussed alongside the suggestion that services should offer a family focused approach to rehabilitation, including parenting related goals in treatment plans and offering support for dependent children. However, Edwards et al. (2014), highlight that in order to develop a more holistic understanding of how rehabilitation services support young stroke survivors with dependent children, it is the important to explore the experiences of HCPs working in services.

1.11. Literature Review I: Stroke Professionals' Experiences of Working with Young Stroke Survivors with Dependent Children.

1.11.1. Objective

The aim of the scoping review was to explore current literature around stroke professionals' experiences of working with young stroke survivors with dependent children.

A systemic search and review for relevant literature was completed in four electronic databases, CINAHL, Complete Academic search complete, PsychINFO and Scopus. See Appendix A for the literature review process and exact search terms.

It was not possible to identify any studies that explored stroke professionals' experiences of working with young stroke survivors with dependent children. This was not unexpected given the lack of research attention afforded to young stroke survivors as noted previously. However, the review includes two studies, both of which focused on how rehabilitation staff support the child relatives of individuals receiving rehabilitation as part of family focused rehabilitation. The two included studies were published in 2007 and 2020. The study by Shrubsole et al., (2020) was based in Australia and the study by Webster & Daisley, (2007) was based in the UK. Both are quantitative studies using a survey design, although Shrubsole et al., (2020) collected qualitative data from open-ended questions regarding facilitators and barriers to their work with children.

1.11.1.1. Study 1: Webster & Daisley, 2007: The study aimed to explore the extent to which rehabilitation staff include children in family focused rehabilitation The study was interested in the personal, practical, and contextual factors that influence a staff members' decision to include child relatives in the rehabilitation. Ajzen's (1991) theory of planned behaviour was applied as a theoretical framework to assess the different factors.

A cross-sectional survey design was used, along with a secondary prospective survey design for a subsample of participants. Themes generated from semi-structured interviews with 11 participants formed the basis of the questionnaire.

Work with children was defined as work focused primarily on the child and their needs, including information giving, emotional support and support with family relationships and communication.

Multidisciplinary rehabilitation team members working in the NHS and in one independent sector organisation were recruited via a directory of rehabilitation services. A subsample of participants were sent a second questionnaire a month later. Most of the participants worked in post-acute services (51%). The majority of participants reported that they had not received any training that they considered relevant to working with child relatives (77%).

263 participants returned the main questionnaires, and 70 participants returned the second questionnaire. The study found that only 19% (n=50) of participants had worked with child relatives in the past month, despite the fact that most participants had positive beliefs around working with child relatives. The study compared those who had worked with children in the past month with those who had not. Participants who had worked with child relatives were more likely to perceive colleagues as holding favourable views about the work and had more positive intentions to work with child relatives in the upcoming month. They also believed they had more control over the decision and were less anxious about working with children. Furthermore, those who had worked with children were more likely to have received training that they considered to be relevant Based on responses to the follow up questionnaire, perceived behavioural control was a significant predictor of behaviour in the following month.

The authors concluded that children do not appear to be routinely included in the rehabilitation provided to people with an ABI, indicating that the needs of child relatives may be largely unmet. A perceived lack of control, and specifically of training, support and skills appeared to influence staff decisions, alongside personal and workplace beliefs. The authors suggest that for rehabilitation to become more family focused, training is required that emphasises the value of including children in the work and support staff to feel equipped to do so.

A strength of the study is the robust development of the questionnaire. Furthermore, the authors suggest that the findings are likely to be representative of UK rehabilitation services as participants were recruited from over half of the services contacted. However, they acknowledge the potential for bias as those who did not respond may have been less interested in the study or thought it less relevant to their work. Similarly, they highlight that the subsample of participants who volunteered for the second questionnaire may have had more interest with working with children. A further source of bias may have been introduced with inclusion of the independent service who were interested in the study. Thus, the authors suggest that actual rates of working with children may be lower than the study suggested.

The study represents an important attempt to explore the extent of family focused support offered by rehabilitation staff working with people who have experienced an ABI and specifically whether the family system, particularly children, are thought about and included in the work. Furthermore, the study highlights that the decision to include family members in rehabilitation is likely to be influenced by beliefs around the value of the work and perceived skills and abilities in being able to do so. This is applicable to this research when thinking about the support offered to young stroke survivors who are actively parenting and how staff members experience their work with this client group.

Further relevance for this research includes the UK context and recruitment of multi-disciplinary staff from mainly post-acute service settings. However, although the majority of people with an ABI have experienced a stroke, some have not which limits applicability.

1.11.1.2. Study 2: Shrubsole et al., 2020: The study aimed to explore the current practices of Speech-Language Pathologists (SLPs) working with the children of people with acquired communication disability. Acquired communication difficulty (ACD) such as aphasia can occur as a result of ABI or a traumatic brain injury (TBI). The authors were interested in the impact of ACD for the person and family system, and how SLPs addressed the needs of children in line with a biopsychosocial approach., The study aimed to investigate SLP working practices in providing information and counselling to children. They explored facilitators and barriers, hoping to identify the perceived needs of SLPs working in this area.

An online survey was completed by 98 SLPs working in Australia with adults with ACD. 76 surveys were included in the analysis. Participants were recruited through social media, an email based forum, newsletter and at a SLP conference. Additional participants were recruited through snowball sampling. Participants were aged between 20-39 years. The majority were female, had over 5 years' experience working with people with ACD and worked in inpatient rehabilitation with people with aphasia. Questions related to providing information and counselling to children, and facilitators and barriers to this, were asked in an open-ended format. This was followed by ratings of confidence and knowledge, and frequency of working in these areas on a five-point rating scale.

Demographic information and data from Likert scales were analysed using percentage calculations and frequency counts. Data from open-ended questions was analysed using qualitative conventional content analysis, (Hsieh & Shannon, 2005). The final step in the analysis included mapping data according to areas in the COM-B model (Michie et al., 2011), investigating Capability, Opportunity and Motivation.

The findings of the study indicated that despite the potential of working with children of people with ACD, most SLPs ‘never’ or ‘rarely’ did, (n=44; 75.86%). Of the minority who did, the work usually involved directly or indirectly providing information. Similarly, most SLPs ‘never’ or ‘rarely’ provided emotional support for children, (n=45; 83.33%). Of those who did, some provided support directly, (n=5), or alongside other HCPs, (n=4) or referred to another service (n=4). The majority of participants (n=57) reported that they believed services to children should be improved, including better access to children, improved resources for children and greater focus on their needs.

Responses to questions about barriers to providing education and counselling to children included: a lack of access to children meaning their needs were not always thought about; lack of resources; family priority; lack of self-confidence, knowledge, or experience in providing support to children; and concerns around professional boundaries and the remit of their work as a SLP. Responses to questions about facilitators to providing education and counselling to children included: family engagement; having appropriate resources; and a supportive MDT environment.

The authors concluded that the current service provided by SLPs is likely to underserve the children of people with ACD and therefore service improvements are necessary. They suggest this should include training for SLPs to provide support and information to children of people with ACD and an attempt to change working practice to encourage people with ACD to bring their children to sessions with SLPs. They highlight the need for further research to explore the perspectives and practice of SLPs, using study designs to achieve more in-depth, detailed data.

Although the study focused on supporting the children of people with ACD rather than the experience of working with people with ACD who are parenting, the study provides important insights that are relevant to this research. Notably, that SLPs are aware of the need to think about people with ACD within the context of their family system, acknowledging the potential impact on children and their need for support. It also draws attention to the barriers and facilitators of working with children of people with ACD including the training and support needs of SLPs.

As noted by the authors, a strength of the research is that it was the first known study to explore current practices of SLPs working with the children of people with ACD, therefore representing an important attempt to contribute knowledge to this area.

Limitations of the study included the survey design, meaning participants were unable to elaborate on responses in the same way they would have been able to do in a semi-structured interview. Furthermore, applicability of findings to this study is limited by the focus and setting of the research. The research focused on people with ACD and whilst some of those people will have experienced a stroke, others will not. SS may experience a broader range of impairment and therefore have more complex needs. The research also took place in Australia and so this limits its applicability to the current UK training and service context. Moreover, the SLPs who participated in this study primarily worked in inpatient settings. This differs from HCPs working in ESD teams who work within community and home settings, whose work is therefore centred within the family context.

Overall, both studies highlight the need for family focused rehabilitation that considers a person in the context of their family system. An important part of working with young stroke survivors with dependent children is to think about that person in the context of their family system, particularly in relation to their parenting role, responsibilities, and relationship to their children. The two studies included in the review focused specifically on what rehabilitation staff do in relation to supporting the child relatives of the individuals receiving support. This forms part of family focused rehabilitation as discussed earlier in the chapter, alongside considering the parenting needs of individuals. However, both studies discuss that including and supporting child relatives in rehabilitation appears to be a practice occurring only infrequently, and therefore the needs of child relatives might not be consistently met. Both studies urge for training and service development to support rehabilitation staff to appreciate the value and feel supported to include children in their work.

1.12. Literature Review II: The Experiences of Staff Supporting People with Acquired Neurological Disabilities/Health Conditions who have Parenting Responsibilities for Dependent Children.

1.12.1 Objective

In order to capture any relevant research that extends beyond that focused on stroke or ABI, a second literature review was conducted to examine research on staff experiences supporting people with a broader range of neurological disabilities such as multiple sclerosis (MS). The rationale for this was that there may be similarities in the experiences of staff supporting young stroke survivors and those supporting people with conditions such as MS. When considering MS specifically, most people receive a diagnosis of MS between the ages of 20-40 years, (Mutch, 2005). It is therefore a diagnosis commonly received at a time when people are considering having children or have existing parenting responsibilities. Furthermore, the tasks of parenting can be considerably affected by the difficulties associated with the condition, (van Capelle et al., 2016).

A systemic search and review for relevant literature was completed in four electronic databases**,** CINAHL, Complete Academic search complete, PsychINFO and Scopus. See Appendix B for the literature review process and exact search terms.

Once again, it was not possible to identify any studies that explored the experiences of staff supporting people with acquired neurological disabilities such as MS, with dependent children. The lack of research in this area has been highlighted by others, (e.g. Coles et al., 2007; Wheeler et al. 2022); however the studies outlined below highlight aspects of staff experiences and practice that are relevant to the review aims, providing further context for the current study.

1.12.1.1. Study 1: Harding et al., (2012): The research aimed to gain the perspectives of health care professionals on how they contribute to the quality of life (QoL) of people with Huntingdon's Disease, (HD). Eight health care professionals from a specialist HD unit in a hospital in the UK were recruited to take part in the study. The sample included nursing, OT, physiotherapy, SLT, psychology and dietetics. Each participant took part in one semi-structured interview and the data gained from interviews was analysed using grounded theory, (Strauss & Corbin, 1994). Eight themes were produced from the analysis including: Quality of Life; the unit; health-care workers; communication; hopes, fears and behaviour; family involvement; ongoing support; and future directions for enhancement of quality of life. Family involvement was described as beneficial when feasible and appropriate, aiding in understanding an individual and their needs and delivering a person-centred approach.

Harding et al., (2012) state that they hope their research will act as an initial starting point for understanding how to support QoL for those with HD. They note in their paper that four of the themes created from the analysis are described in detail and four themes are described only briefly, including family involvement. The rationale for this is unclear. The detail provided about the theme of family involvement is poor and so limits understanding of health care professionals' perspectives and approach in this area. It is unclear what family involvement looks like in practice, and whether this extends beyond gaining information from family members, to working directly with family members such as offering emotional support or providing information. It also mentions nothing about considering the parenting needs of people with HD or thinking about the needs of dependent children. Although this limits the applicability of the research to this study, it does highlight the desire of heath care professions to think holistically about a client, situating them within the context of their family system.

1.12.1.2. Study 2: Coles et al., (2007): The research aimed to evaluate an intervention for children of parents with MS, developed by Coles et al., (2007) and adapted from an intervention designed for the siblings of children with a learning disability. The intervention took place in Australia and consisted of a six-day residential camp offering group based educational and recreational activities, and the opportunity to build connections with other children with parents with MS. The groups were facilitated by two of the authors, a senior occupational therapist, and a trainee psychologist. The intervention aimed to improve knowledge of MS, increase adaptive coping strategies, and reduce caregiving stress. The authors also predicted that the intervention would indirectly target any adverse impacts of caregiving for parents, such as reducing worry. The study used a single-group, longitudinal design, participants were 20 children who attended the camp and their parent with MS. Questionnaires were completed by children pre- and post-intervention (n=20); and at follow-up, three months after the camp, (n =16). Parents also completed questionnaires pre-intervention and at follow-up.

Despite the relatively small sample, some significant pre-to post- treatment and follow-up effects were reported including reduced caregiver stress and increased knowledge about MS. The authors concluded that their results support the rationale for offering intervention to the children of people with MS. Applicability of the research to the current study is limited, most notably due to the fact that a six-day residential intervention does not reflect the general practice of rehabilitation services in the NHS. However, it is possible that aspects of the intervention are, or could be, incorporated into current practice such as providing information and emotional support for children. As noted previously, this suggests that rehabilitation staff are aware of the benefit of thinking about a client within the context of their family system, taking into account the support needs of children.

1.12.1.3. Study 3: Mutch, (2005): The report described the development of an intervention aimed at children, (9-14 years), who have a parent with MS. Similarly to Coles et al. (2007), the one day intervention aimed to provide information about MS, explore anxieties about having a parent with MS and facilitate social connection with other children with a parent with MS. The intervention was a one-day workshop, facilitated by a MS specialist nurse, a psychologist, and staff from a young carers group. The morning workshop aimed to provide interactive education about MS and how various difficulties associated with MS can impact on everyday functioning. The afternoon session explored the needs, worries and psychological consequences of MS for all members of the family.

Although formal outcome measures were not used, parent feedback indicated that the workshop had been helpful to open up conservations about MS in the family. Parents also perceived that their children displayed greater understanding and patience with their symptoms. Feedback from children who attended the intervention is absent which limits a fuller understanding of the potential benefits of the intervention. However, the author argues that the positive feedback from parents demonstrates the importance of family centred intervention including the provision of both information and emotional support. An important finding highlighted in the article is that parental beliefs acted as a barrier to gaining access to children in order to offer the intervention. These included beliefs that MS did not affect their children and that information about MS may cause worry rather than alleviate it. This has implications for clinical practice and highlights the role clinicians play in supporting clients who have parenting responsibilities to understand the benefits of family centred intervention.

1.12.1.4. Study 4: Wheeler et al., (2022): Wheeler et al., (2002) outlined a single case report of a family based intervention aimed at supporting communication and adjustment in a family where the mother has a diagnosis of MS. The intervention was carried out by a trainee clinical psychologist with a family in the UK under the care of a family support service. The report aimed to highlight the importance of including children in therapeutic interventions, and specifically the role psychologists and neuropsychologists can play in this by drawing on their existing skillsets. The intervention offered to the family aimed to support knowledge and communication about MS and enhance psychological flexibility with managing difficult thoughts and feelings. It was underpinned by strengths based narrative and Acceptance & Commitment Therapy approaches, with session outlines included in the report.

Formal outcome measures were not used to assess the helpfulness of the intervention. However, qualitative feedback collected from the family indicated greater knowledge about MS and more open conversations about MS and the emotional impact of living with the condition in the family. The authors suggest that wider potential benefits of such interventions include reducing the likelihood of ongoing family distress and service use, and better educational and social outcomes for children.

As noted, the family were offered the intervention as part of support offered by a dedicated family support service. The authors acknowledge the unique nature of the service context and state that at the time of writing the report, the service was the only NHS service in the UK focused on meeting the information and psychological support needs of children with a parent or family member diagnosed with a neurological condition. Although this limits applicability to some extent, both to MS services and stroke ESD teams, the report demonstrates the value of family based interventions. Specifically, interventions that incorporate education and emotional support for children and/or family members. This has implications for clinical practice both in rehabilitation teams generally and for staff supporting young stroke survivors in ESD teams. Furthermore, although the work in this report was carried out by a trainee clinical psychologist, providing health information and offering emotional support is likely to form part of the work of all members of a rehabilitation team.

1.13. Rationale and Clinical Relevance

This study attempts to address some of the recommendations made by the research presented throughout the introduction, namely, to explore the experiences of staff working with young stroke survivors with dependent children in order to contribute to the limited research base of family focused rehabilitation practices offered to this population. To the knowledge of the researcher, there has been no previous research that has explored the experiences of rehabilitation staff working with young stroke survivors with dependent children and therefore there exists a lack of understanding about their views and experiences and about how supported they feel in their work. The study aimed to explore staff experiences using a study design that will allow for collection of in-depth, rich data.

The study aims to contribute to knowledge and understanding of staff experiences in a contemporary UK service context. By recruiting through ESD teams the data should capture the experiences of staff working directly within the family context of young stroke survivors, where they are exposed to a 'live' sense of family dynamics and observe first-hand the impact of stroke on parenting and other family members. Staff from ESD teams support stroke survivors during their transition back from acute care and into their home environment which can often be a challenging time for stroke survivors where the demands of parenting are present regardless of any residual impairment from the stroke. This is a significant and interesting time for ESD staff to be supporting young stroke survivors with dependent children and thus an important area of research.

By contributing to the limited evidence base, it is hoped this exploratory study will enable a better understanding of the experiences of rehabilitation staff working with young stroke survivors with dependent children, and the impact their experience has on their practice. A better understanding of the experience of rehabilitation staff can inform recommendations and contribute to service development guidelines for offering effective family focused rehabilitation for this population.

1.14. Study Aim and Research Questions

The research aims to gain an understanding of how staff members of a stroke service experience working with young stroke survivors who have dependent children and how they describe their experience of support that facilitates their work.

To address this, the research questions are:

1. How do staff from an Early Supported Discharge team describe their experience of working with young stroke survivors who have dependent children?
2. How do staff from an Early Supported Discharge team describe their experience of support that facilitates their work with young stroke survivors who have dependent children?

2. METHOD

2.1. Overview

This chapter outlines the study's epistemological position, study design and ethical considerations. This is followed by the procedure and analysis, which includes consideration of reflexivity and research quality.

2.2 Focus of the Research

Due to the Covid-19 pandemic, the focus of the research was changed to reflect the restrictions on direct contact with participants, particularly those using NHS services or those deemed to be potentially vulnerable. Accordingly, the focus of this research was changed from how young stroke survivors experience parenting after stroke to staff experiences of working with young stroke survivors with dependent children. As noted previously, the voices of young stroke survivors are relatively neglected in stroke literature, particularly those with dependent children. The research had hoped to gain an understanding of how young stroke survivors experience parenting after stroke in order to contribute to the limited research literature. However, given the paucity of research on the experiences of rehabilitation staff working with young stroke survivors with dependent children, it was considered that focusing on staff experiences of supporting this population could add important insights into this area of stroke research, and contribute to service development.

2.3. Epistemology

Underpinning every research question is a set of ontological and epistemological assumptions that researchers should make explicit as part of the research process (Willig, 2013). Ontology is concerned with the nature of world, and specifically, what exists and therefore what can be known about (Willig, 2013). Epistemology refers to the theory of knowledge. Particularly, what constitutes knowledge, and the reliability and validity of claims of knowing (Willig, 2013). The epistemological position of a piece of research guides the focus of the research, what can be said of the data, and how meaning and experience is thought about, (Braun & Clarke, 2006).

The current study adopts a critical realist position (Bhaskar, 2008). Critical realism sits in the space between realism and relativism. The realist position assumes that scientific enquiry can uncover a singular and objective universal truth, (Taylor & Ussher, 2001). Conversely, relativism postulates that in the absence of ‘pure experience,’ the pursuit of research should be the exploration of how cultural and societal discourses operate to create different versions of reality and experience across contexts (Willig, 2013). Critical realism therefore, aims to understand phenomena with the acknowledgement that reality is mediated by social, political, and geographical context and therefore multiple perspectives and experiences of reality are possible, (Willig, 2013).

This research invited participants to explore their experience of working with young stroke survivors who have dependent children with the rationale that a better understanding of the experience of stroke professionals can inform service development. In line with realism, the research understood ‘stroke,’ ‘parenthood’ and ‘stroke professional’ as objective realities with material evidence of their existence in the form of a scan, the presence of children and accreditation respectively. However, in keeping with relativism, the research recognised the flexibility in how these realities are held and understood. A stroke diagnosis, parenting, what it means to be young and to provide rehabilitation to young stroke survivors is constructed in language and culture. Social and cultural ideas and values of both participants and the researcher influence descriptions and the meanings of experience and therefore the knowledge constructed, (Guba & Lincoln, 1994; Willig, 2013).

2.3.1. Justification for thematic analysis

A thematic analysis was considered to be well suited to achieve the aims of the analysis as it enabled a detailed story to be told of the data and reflection of both the shared and diverse experiences of participants, (Braun & Clarke, 2019; Terry et al., 2017). Given the limited evidence base regarding staff experiences and practices of working with young stroke survivors with dependent children, the study was exploratory. The aim was not to contribute to the development of a theoretical framework or model, but rather to use a broad lens to offer an overview of patterns in the data reflecting the views and experiences of stroke staff. Providing a broad overview of views and experiences sought to illuminate the needs of staff and services and highlight further avenues for research.

Thematic analysis is not tied to any particular epistemological position, it is theoretically flexible, (Braun & Clarke, 2006; Terry et al., 2017). This was compatible with the critical realist epistemology of the study. A critical realist thematic analysis offered one possible account of the data. It produced an analysis of how individuals create meaning from their experiences, while situating that meaning within the wider social context, (Braun & Clarke, 2006).

A predominantly inductive approach to analysis was adopted. This is a ‘bottom up’ approach, ensuring that interpretation is tightly bound to the data, with the data itself providing the foundation of the analysis and not a pre-existing theoretical framework (Braun

& Clarke, 2006; Terry et al., 2017). This was considered appropriate given the exploratory nature of the research. However, themes do not exist in the data waiting to be retrieved, but rather they are created, and made sense of, through an interaction of the data and a researcher's positioning, experiences and assumptions, (Braun & Clarke, 2019; Willig, 2013; Patton, 2015). Thus, some degree of deductive analysis was used when coding and assessing the relevance of codes to the research questions, (Byrne, 2022).

2.4. Design

2.4.1 Qualitative Approach

Qualitative approaches aim to provide in-depth, rich, and detailed descriptions of experience (Yates, 2004). In health research, qualitative approaches can offer something different but complimentary to the knowledge obtained through quantitative approaches, offering insight in the experiences and real worlds of both patients and health care professionals, (Braun & Clarke, 2014). Semi-structured interviews provide the opportunity to elicit detailed accounts of participants knowledge, understanding and feelings, to develop a shared understanding of the research topic, (Yates, 2004). A qualitative approach using semi-structured interviews was therefore compatible with the study aim. Only through gaining adequate knowledge of the meaning stroke professionals make of their experiences, can they be adequately supported to fulfil their roles, thereby providing optimal support for young stroke survivors with dependence children.

2.4.2. Interview Schedule

The interview schedule was developed in collaboration between the researcher and research supervisor, (see Appendix C). The interview schedule was used flexibly throughout interviews allowing participants to 'open up' about ideas, thoughts, and feelings, whilst also steering the interview, to ensure data gathered was relevant to the research questions, (Yates, 2004; Willig, 2013b). The reflexive journal was helpful to note prompts that appeared particularly useful during interviews.

2.4.3. Inclusion/Exclusion Criteria

Clinical staff from two ESD teams, working directly with young stroke survivors, were offered the chance to take part in the research. Clinical professions working in the ESD teams include Speech and Language Therapists (SLTs); Occupational Therapists (OTs); Physiotherapists; and Clinical or Counselling Psychologists.

Staff members without any experience of working with young stroke survivors with dependent children were excluded from taking part in the research.

2.4.4. Resources

The research required a dictaphone, the cost of which was covered by the researcher. No costs to participants were incurred other than their time.

2.4.5. Sample

Purposive sampling was used to recruit participants across two ESD teams.

2.5. Ethical Considerations

The ethics of this research were considered in line with the following guidance: British Psychological Society's Code of Ethics and Conduct (2018); British Psychological Society's Code of Human Research Ethics (2021); British Psychological Society's Ethics Best Practice Guidance on Conducting Research with Human Participants during Covid-19 (2020); UEL Code of Practice for Research Ethics (2015-16); and NHS Health Research Authority (HRA) guidelines.

2.5.1. Ethical Approval

Ethical approval was obtained from the University of East London, School of Psychology, (see Appendix D). Ethical approval was sought and obtained from the NHS HRA via IRAS, in order to obtain NHS R&D approval to work in NHS Trusts, (see Appendix E/F). Once ethical approval had been obtained, the Research and Development Teams for two provider organisations were contacted in order to gain R&D approval.

2.5.2. Informed Consent

Potential participants received information about the study verbally from the researcher during a ESD Multi-Disciplinary Team (MDT) meeting conducted via Microsoft Teams. The Participant Information Sheet (PIS) was distributed to the team during the meeting by email, (see Appendix G). The information outlined the purpose of the research and what participation would involve. Before the interview, participants emailed a signed consent form to the researcher, (see Appendix H). This was reviewed together at the beginning of the interview using the share screen function on Microsoft Teams, and participants were asked if they had any questions. Participants were reminded of their right to withdraw up until three weeks after the interview. Confidentiality and data management was also discussed.

2.5.3. Potential Distress

Issues of power are important to consider within the context of research interviews. Interviews require a delicate negotiation of rapport between researcher and participant, (Willig, 2013), and as researcher, I aimed to remain mindful of how comfortable participants appeared throughout the interviews and with disclosing certain information (Willig, 2013).

Given the nature of the research was to explore participant's experiences of an aspect of professional practice, the risk of the interviews becoming 'quasi therapeutic' (Willig, 2013), or of participants becoming distressed, was considered to be low. However, participants were advised they could take a break at any point during the interview. Additionally, they were provided with a debrief sheet following the interview (see Appendix I). As researcher, I had the options of using my reflexive journal and speaking to the researcher supervisor if I was to become distressed by what I heard during the interviews.

2.5.4. Anonymity

Given the hybrid model of working adopted by the ESD teams since the COVID-19 pandemic, the interviews took place over MS Teams, where the participant was in their own home or at the ESD team base. Participants were advised to find a quiet, confidential space to join the interview.

As described in the PIS, the information provided by participants during the interview was kept confidential. Confidentiality would only have been breached if the researcher became concerned about the safety of the interviewee or the safety of others. In which case, the researcher would have consulted the research supervisor and followed safeguarding procedures according to trust policy.

Participants were given participant numbers which were used to save their data and for direct quotations in the final report and subsequent disseminations. Potentially identifying information was removed from the transcripts. Only the researcher, research supervisor and examiners could have access to the anonymised transcripts.

2.5.5. Data management

A data management plan for the research was created in line with The Data Protection Act 1998, General Data Protection Regulation (GDPR) and UEL Research Data Management Policy. Data was stored on university cloud storage and backed up on the university server in separate encrypted folders. Files were saved using participant numbers. Once the thesis has been examined and accepted, audio recordings, consent forms and demographic data will be deleted. Anonymised transcripts will be kept for two years and then deleted.

2.6. Procedure

2.6.1. Recruitment Process

Once ethical and R&D approval was obtained, the researcher contacted a clinical/counselling psychologist from each ESD team. The psychologist was aware of the study and had agreed to assist in introducing the researcher to the ESD team. The psychologist introduced the researcher to the team leads, and a convenient time to attend a MDT meeting was arranged.

During the MDT meetings the researcher distributed the PIS and gave a brief verbal presentation about the study, inviting and answered questions. The team were made aware of how to contact the researcher. The psychologists and team leads assisted recruitment by reminding the team about the study in subsequent MDT meetings. Potential participants contacted the researcher directly, or via team leads. Team leads provided the researcher with the names and contact details of team members who were interested in order to make contact.

During the initial contact, the researcher and participant discussed the study information and inclusion criteria. A date for the research interview was agreed, and the researcher sent an invitation via Microsoft Teams. The researcher attached the consent form to be signed and sent back to the researcher via email before the interview.

2.6.2. Data collection

The interviews lasted up to an hour. Before the interview began, participants were invited to ask questions and reminded that they could pause the interview at any time should they wish to or decline to answer particular questions. The interview began with collecting demographic data, before moving on to questions related to working practice and experiences of working with young stroke survivors with dependent children.

At the end of the interviews, participants were thanked for their participation and asked if they had any questions. They were informed that they would receive a summary of the research if they had indicated that they wanted to on the consent form. Participants were reminded of their right to withdraw their data up until three weeks after the interview date. Participants were informed that they would receive a debrief sheet and this was sent via email when the interview was finished.

2.6.3. Participant demographics

Ten participants took part in the research. See Table 1 for demographics of participants.

Table 1 Participant Demographics

Age range	Number of participants
18-34	2
35 -44	4
45-54	4
Gender identity	
Female	10
Ethnicity	
Black British	1
White British	7
White other	2
Professional role	
Clinical or Counselling Psychologist	2
Speech & Language Therapist (SLT)	2
Occupational Therapist (OT)	2
Physiotherapist	4
Number of years working for ESD service as [professional role]	
1-3 years	1
3-5 years	3
5-10 years	6
10+ years	0
Number of years working for stroke services as [professional role]	
1-3 years	1
3-5 years	1
5-10 years	6
10+ years	2

2.7. Data Analysis

2.7.1 Transcription

All interviews were transcribed by the researcher as part of the analytic process to facilitate familiarisation with the data, (Braun & Clarke, 2006). Thematic analysis does not require a specific system of transcription, (Braun & Clarke, 2006), so a simple transcription including verbal exchanges and some non-verbal utterances was used.

2.7.2. Thematic Analysis

The interview transcripts were analysed using thematic analysis using guidance provided by Braun and Clarke (2006).

2.7.2.1. Aim of thematic analysis: The aim of the analysis was to develop a rich and detailed account of participants experiences, attempting to achieve an empathic understanding of experiences 'from within,' (Willig, 2013). The analysis aimed to notice patterns and connections across the transcripts to draw together a sense of the meaning contained within the data (Willig, 2013).

2.7.2.2. *Analytic process:* The six phases of analysis detailed in Braun & Clarke, (2006) are listed below. Although presented as linear, the process of analysis is an iterative process with frequent moving back and forth between phases.

1. Familiarisation with the data: Recordings of interviews were watched completely before transcription. Once interviews had been manually transcribed, transcripts were read and re-read to facilitate familiarisation with the data. Initial reflections and areas of interest were noted down.
2. Generating initial codes: Holding in mind the research questions, aspects of the data that appeared relevant were given initial codes. Data was coded at both semantic and latent levels of analysis in keeping with the theoretical assumptions of analysis and to capture the meaning communicated by the participant and my interpretation of the meaning, (Byrne, 2022). Accordingly, some data were double coded. Some codes were refined or discarded with further readings of the transcripts. See Appendix J for a brief coded excerpt of a transcript.
3. Searching for themes: This phase involved a review of coded data to notice and group patterns of shared meaning into potential themes and sub-themes.
4. Reviewing themes: In this phase the themes were reviewed for coherence and distinctiveness. The themes were reviewed for consistency with codes and the data. Holding the research questions in mind, some themes were deconstructed with sub-themes forming part of a different theme and some discarded. This aimed to produce the richest and most meaningful account of the data. See Appendix K for a table of initial and finalised themes and sub-themes.
5. Defining and naming themes: In this phase the themes were described in relation to the research questions and the data set. Themes were named with the aim of being explanatory and memorable, (Byrne, 2022).
6. Producing the report: This aimed to create a rich narrative that attended to the research questions and data set. It hoped to draw out relationships across aspects within the sub-themes whilst also paying attention to idiosyncrasies in the data. Data extracts were chosen to provide illustrative examples of the meaning of each sub-theme.

2.8. Quality of Research

Evaluation of qualitative research forms part of ensuring ethical and reflective practice, where participant time and effort is valued in the process of meaningful knowledge production, (Willig, 2021). The guidance provided by Willig, (2021), was used to consider the quality and value of this research:

2.8.1. Owning one's perspective

As noted, and in line with the epistemological assumptions of the study, the interpretation of data is acknowledged as one possible interpretation of the data. Qualitative analysis of data acknowledges the inherent connection between a researcher and the data they produce.

2.8.1.1. Reflexivity: Researcher's position: Reflexivity refers to the process of critically reflecting on the research process and in doing so, recognising the role of the researcher as an active participant in the research and in the production of knowledge, (Braun & Clarke, 2006; Willig, 2013). Personal reflexivity requires that a researcher reflect upon how their beliefs, social identities values, and experiences shape the research process; and how the process shapes the researcher, (Willig, 2013).

As a researcher, keeping a reflective journal offered the space for reflection about my relationship to the research topic and my interaction with participants. The reflexive journal enabled me to hold in mind particular experiences and aspects of my identity that were relevant to this research. This included being a parent myself and also a trainee clinical psychologist. Training in clinical psychology is intense and demanding. Completing training whilst parenting required a constant juggling of competing demands. When focusing my attention and energy on training, I was often left with a feeling of not being able to give as much of myself to parenting as I wanted, and vice versa.

This has inevitably influenced why I thought the research topic was both interesting and important. Although I have not experienced a stroke or have a disability that would impact on my parenting, I understand the demands of parenting and managing multiple roles. I can empathise and relate to the struggle that exists when feeling pulled in multiple directions. I believe parenting is undervalued and under supported in contemporary society. For many parents, juggling parenting and work is extremely challenging, particularly with the exceptionally high costs of childcare. I therefore approach this research topic with the belief that parenting should be better supported and those who parent with disability and disadvantage are particularly vulnerable and deserving of attention and support.

As a trainee clinical psychologist another influential factor for choosing this research topic is thinking about the role of clinical psychologists within MDTs, particularly teams that sit outside of typical mental health services, i.e. in physical health services. This is an area of interest of mine and one I may pursue following training.

2.8.2. Situating the Sample

Personal and professional details of participants were collected to allow the reader to consider the relevance of the findings to other settings or similar populations.

2.8.3. Grounding in Examples

Pertinent examples from the analysis were chosen to provide illustrative examples of the meaning of each sub-theme, allowing the reader to consider the link between data and my interpretations.

2.8.4. Providing Credibility Checks

Credibility was assessed by peer review of the research proposal and prolonged engagement and persistent observation with the data. Ten participants were interviewed for up to 60 mins each including time taken to build rapport. The interviews were recorded and transcribed in detail by the researcher. Analysis of the data was finalised through reflective discussion with the research supervisor. This helped me to hold assumptions and alternative interpretations in mind and facilitated a broader view of the data, supporting a richness in the final analysis.

2.8.5. Coherence

Reflective discussions with the research supervisor supported the developing narrative of the write-up, ensuring that the themes and sub-themes were presented in a coherent order, beginning with ‘broader’ ideas, and ending with more specific aspects of the data.

2.8.6. Accomplishing General Versus Specific

Due to the lack of previous research on the research topic, the goal was to provide a broad and exploratory account of the data. Limitations of the sample and applicability of findings are addressed in the discussion.

2.8.7. Resonating with Readers

The presentation of the research aimed to provide a clear rationale and aim of the study. The research aimed to provide readers with an understanding of the staff experience when working with young stroke survivors with dependent children, to be considered alongside research that has explored the experience of young stroke survivors. Adding to the research base by contributing the staff experience aimed to expand knowledge of family focused rehabilitation and areas of service development to meet the needs of this population.

3.0 ANALYSIS

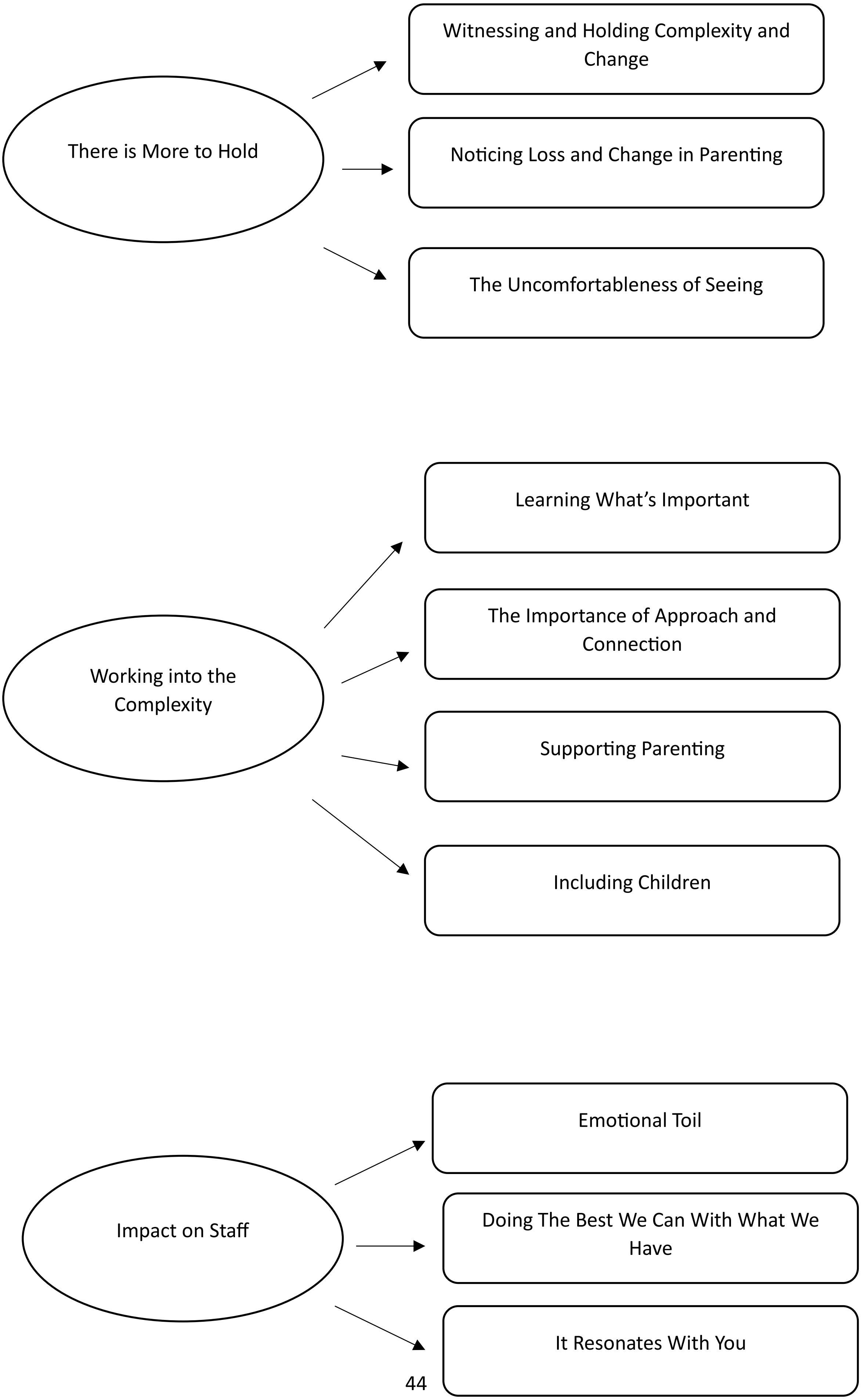
This chapter outlines the findings of the analysis following interviews with staff members from an ESD stroke team concerning their experiences of working with young stroke survivors with dependent children. Thematic analysis was used to analyse the data following the stages described in the methodology.

An introduction to the themes and sub-themes is provided. Sub-themes are then discussed in greater detail. Pertinent examples from the analysis have been reproduced for illustrative purposes of each theme. Italicised words belong to the researcher.

3.1. Introduction To Themes

The analysis generated three higher-order themes including ‘There is More to Hold’, ‘Working into the Complexity’ and ‘Impact on staff’ with a further ten sub-themes (see figure 1).

Figure 1


There is More to Hold
Witnessing and Holding Complexity and Change
Noticing Loss and Change in Parenting
The Uncomfortableness of Seeing
Working into the Complexity
Learning What’s Important
The Importance of Approach and Connection
Supporting Parenting
Including Children
Impact on Staff
Emotional Toil
Doing The Best We Can With What We Have
It Resonates With You

3.2 Summary of Higher-Order Themes

Thie first higher-order theme, ‘There is more to hold’ describes the feeling of complexity when working with young stroke survivors with dependent children including the need to think more broadly about the work given the broadness of change for young stroke survivors noticed by staff. This includes thinking about loss and change in parenting; with recognition of how parenting can feel an uncomfortable topic to ask about.

The second higher-order theme, ‘Working into the complexity’ describes how participants manage the experience of complexity when working with young stroke survivors with dependent children by working collaboratively to create person-centred goals focusing on regaining a sense of self and parenthood. Participants acknowledge the importance of building a trusting working relationship. They support young stroke survivors to regain parenting skills. This may involve including the children of young stroke survivors into therapy sessions.

The third higher-order theme, ‘Impact on staff’ recognises the emotional experience of the work for staff, heightened by the presence of children and a pressure to ensure support is ‘good enough’. The emotional experience is exacerbated by a resonance staff feel due to identification with young stroke survivors with dependent children. Connection and support from others in the team offers containment and support with thinking about the work.

3.3. Higher-Order Theme 1: There is More to Hold

3.3.1. Sub-theme 1: Witnessing and Holding Complexity and Change

Participants spoke about complexity when working with young stroke survivors with dependent children, attributing this to the life roles and demands that young stroke survivors often return to following stroke, such as raising children and employment.

> P2:...they're always complex scenarios. I don't think I've ever come across a younger family where there isn't psychological, or, you know, that I think the big thing is the pressure to work.
>
> P4:…yeah, like a very difficult situation, and one that I'd never sort of dealt with before, like very, very, complex.
>
> P5:…they are naturally just more complex in the, you know, returning to a high demanding job or looking after multiple children. Things like that do become more complex.

Complexity is also accounted for by the unexpectedness of stroke and suddenness of change for young stroke survivors with dependent children observed by participants.

> P1: Two situations really stick out in my memory and one is quite recent of a young woman in her 30s who had a massive, massive stroke and she had a child of five and just literally in the blink of an eye, life changed for her and she needed all disciplines and she needed a full care package.
>
> P3:…many of our younger survivors may not fit that typical picture. They look completely OK and that's the conundrum. They look fine, but they're not fine. And how do you explain that? How do you quantify struggles?
>
> P9: There is something about you know, being of working age where actually it's a, it's a sense of you know, what are our expectations of when someone has a stroke, I'm young, you know, I didn't think strokes could happen this young, or is it, umm, this isn't what I expected from my life being the age that I am.. and you know, that sense of, you know, living with the disability, for example, compared with their peers and I think all of those things, I think it makes, it makes the work feel quite complex.

Participants witness and hold in mind the loss and change felt by young stroke survivors with dependent children, and for some young stroke survivors, the wish for things to be as they were pre-stroke. One participant talked about the loss leading to the young stroke survivor believing they are a burden or not a good enough parent.

> P2:…that was really difficult because for the patient he very much wanted it to be like it was before and we had to work a lot with that, about yes, he was grieving for that.
>
> P9: I think for, for, some parents it can be a real sense of umm, I think it's the loss. It's the loss of, umm, the loss of the relationship of how it was, if that makes sense. So before, before, the stroke happened, and I think that real acknowledgement sometimes of actually this relationship may not ever be the same because physically, the person's different , umm, and I suppose that sometimes that real struggle with, umm, supporting parents, who've been able to, umm, show that they are still the child's parent.
>
> P3: Certainly a lot of families we meet, from the stroke survivors' point of view, the themes that arise include feeling a burden or feeling I'm not a good enough mum, or a good enough dad anymore. I'm too different. I can't be the person I ought to be or should be.

The complexity of working with young stroke survivors with dependent children requires broader thinking. Participants formulate the needs of the young stroke survivor within the context of their family, thinking about the needs of members of the family, both separately and as a whole family system.

> P9:…to think about what are the ongoing needs for the client, but also for the client's family … umm, and, I think generally… I don't know, I think generally with the people who have strokes younger we're more likely to work with the system that's around them as well as them.
>
> P8:…you are kind of slightly broader because you're thinking about multiple pieces of people's needs and how you can meet those needs and how you can support, kind of two very different sets of emotions but with one focus.
>
> P1: I mean, we've seen it, that, that the younger case there the husband was doing everything. I mean he was, there was nothing he wasn't capable of. But first meeting I could see that he's going to break, and he did. And you know, because you can't, as a parent you know you can't keep up day and night, 24 hours, working, providing full care, arranging somebody to sit and support your loved one. You know, the emotional turmoil that you've gone through..

Participants talked about getting to know the family system, noticing the gatekeeping role that family members may adopt. Thinking with the family and hearing their perspectives is considered to be a valuable source of information.

> P1:…for me, there is a barrier.. so who's supporting the patient? And I often find whoever that is, you need to also build a relationship with because you need them as key to enter into this unit, you know. And so if you don't build up a therapeutic relationship with the support network, then you've had it too.
>
> P5: I think then not necessarily just talking to the patient but actually getting a good grasp from other members of the family and whether that's the spouse, you know, the patients' parents, or if it's appropriate, sometimes the children themselves can actually be really valuable, and it helps you get a better insight because sometimes patients will paint you the picture that maybe you want to see rather than what's actually happening, or vice versa.

Participants observe the relationships between family members or close others. They recognise relationships can be a valuable source of support, whilst simultaneously looking out for evidence of potential conflict; understanding that any tension in the relationships might fed into the therapeutic relationship and engagement in rehabilitation.

> P5:…in their own homes, they know their environment, they've got the people around them to love and support them, I think, that helps with motivation and engagement with therapists.
>
> P10: The families were supportive as well. Umm, I remember with that gentleman he, he had a really, really supportive wife, and umm, she supported him with doing all the exercises and from like a physiotherapy point of view, speech as well, she's up with him so she's been really involved and really supportive and you know, looking after the kids..
>
> P2:…you could see and obviously pick up on the tension you know, and you know her frustration with that he wasn't better. And so those relationships and, and, kind of trying to work through those relationship dynamics that kind of come in through this.. very difficult as well.

3.3.2.Sub-theme 2: Noticing Loss and Change in Parenting

Participants notice and hold in mind the difficulties faced by young stroke survivors with dependent children to fulfil specific parenting tasks following their stroke, and how this may challenge their sense of place within their family and identity as a parent.

> P8:…being able to, like, reprimand your children. So, you know, if they can't tell their child not to do something, from doing something dangerous like running out into the road, to going to bed on time, they feel like they lose that, that authority… that kind of.. that position.
>
> P9: I think quite a lot of, it kind of, comes down to where parents are physically different as well and have been very physically active with their children and actually that real sense of they're missing out, but also the children are missing out. And sometimes that's a sense of helplessness that could kind of come about from that.

Furthermore participants pick up on the sensitivities that exist when others take on some of the parenting role when a young stroke survivor is unable to; perhaps feeling a sense of relief when those taking on the role are attuned to the potential difficulties surrounding this e.g. participant1.

> P1: I think it was a family member came round, it might have been her mother in law, I'm not sure; and she had obviously provided all care whilst she was in hospital for seven months, the patient. So and, and she was a lovely lady because she had acknowledged that the patient was now back but incapable of caring for the child, but, but she also didn't want to step on those toes, so as a professional on the perimeters you can think, ah, you've got some dynamics here.

> P4:…all those responsibilities that are very everyday, walk your child to school, like, and then all of a sudden it's like that responsibility is taken away from them, and they're not allowed to do that. You know, family members, I don't know, the nan's taking the child to school.

However, some participants also describe noticing positive changes for young stroke survivors with dependent children including a slowing down and spending more time together as a family and feeling closer as a consequence of supporting each other through adversity.

> P5:…he was then able to spend more time with his children. He was able to take them to school and be there when they came in from school and things like that, which he didn't, he couldn't do previously because he would be up and down the country and [*working job role*] and things like that. Umm, so I think he, he, likes that he could do this different sort of role for this time being.

> P3: They talked a lot about how this experience had brought them closer and how they sat with that uncertainty of wanting the hospital to call, but also not wanting the hospital to call because what could be said in that phone call would be so upsetting you know and how they held each other in those uncertain moments.

3.3.3.Sub-theme 3: The Uncomfortableness of Seeing

For some participants, it can feel uncomfortable asking young stroke survivors with dependent children about parenting or ruptures in familial relationships. Due to the discomfort, they may avoid asking directly or maintain safety by sticky to the 'manual.' Others may worry about it being too intrusive to ask about or concerned that it will open up a conversation in which they may receive information that feels too difficult to work with, or not part of their remit in their professional role.

> P4: I think as far as it goes with like parenting, I think, I would feel, I don't know what the word is, apprehensive, I guess to bring it up if the patient didn't bring it up first because it's so personal**.** Yeah, I think yeah, I think maybe like generic questions I could like feel comfortable asking, but I wouldn't feel comfortable asking like very specific questions.

> P7: I was almost scared to say too much because I wasn't going to.. I didn't feel I was equipped to be able to fix it. So if she really broke down, I was like, actually, I'm not sure how I'm going to help her through that. So I spoke with umm, the stroke psychology team at the time.

> P2: I think a lot of particularly junior [*professional role*] will go in and think right, I know that this is an impairment, a problem, we need to focus on this today

> and may kind of go in there with that blinkered look of ‘okay, I don't know how to really deal with this argument that's happening with the, the, the husband and wife at the moment… ‘Oh I'm here to work on your.. let's do some balance exercises,’ you know. And that's.. I, I feel that's quite normal, quite typical actually, because when you haven't got that clinical experience kind of work off script. That's what all professionals default too.

Nevertheless some participants are aware that it might also feel difficult for young stroke survivors with dependent children to bring up the topic of parenting, specifically sharing any difficulties they might be experiencing.

> P7:...because I think there are lots of sensitivities umm, and, people do, do, things very differently and I think that there is concern about being judged for parenting choices.
>
> P10: They might not say, they might just, you know, keep it for themselves and think, ‘okay, I will probably figure it out somehow,’ or, but as a professional is, is a key thing right to check and make sure that everything is okay.
>
> P8: I mean the child, she was quite withdrawn to begin with, and I think quite scared of the whole situation, and I think mum was masking quite a lot because of that, like pretending that everything was okay.

Some participants talked about how working with young stroke survivors with dependent children elicits thoughts about safety and potential safeguarding considerations.

> P4:…the first thing that we need to look at I suppose is safety. So like can like.. often we will be involved in discussions around, and this is true for everybody, but like, can the person who's had the stroke raise the alarm in an emergency and, and, and, all those kinds of things, and it's kind of they, obviously, they’d need to be able to do that on behalf of a dependent child as well. And I suppose our job really is to feed back to the wider team in that case.
>
> P3:…they pick up on safeguarding queries or they pick up on a vulnerability in the client and then what steps do I need to take, you know, or they they're being very careful in ensuring children are safe, family is safe.
>
> P10: But at the end of the day it’s, it's about, you know, making sure that our patients are safe. And we do our best to support them in their homes and try to get them better than they are. And I always say, ‘safety comes first.. whatever, safety comes first okay so try to not do something that will put you in danger.

3.4.Higher-order Theme 2: Working into the Complexity

3.4.1.Sub-theme 1: Learning what's Important.

Participants described goal setting with young stroke survivors with dependent children as person-centred; achieving this by thinking holistically and attempting to understand the 'personhood' of the young stroke survivor and their valued life roles. Some participants described acknowledging the parenthood of young stroke survivors and their familial roles and bringing that into goal setting.

> P5:…because you know a parent has so many different roles, not just as a parent, but also, you know, whether they're, they're someone who works, and other responsibilities and that way. I think in that sense the training makes you look at the multiple different elements that make up somebody and, and, and working with that to, you know, to identify goals and what are sort of positives to motivate somebody or what might hinder them in their recovery.
>
> P8: I think the most important thing to do when you meet a new patient is to get to know them, to get to know what makes them tick, what's important, kind of, what the family dynamics are, what, what they spend their day doing.. know what gets them out of bed essentially.
>
> P2: What was your previous role? What would make you feel like Dad or husband? … just something to help them feel a bit more like them.

Some participants therefore spoke about rehabilitation goals directly linked to aspects of parenting. They noted that goals related to parenting tasks were likely to feel more relevant and motivating for young stroke survivors.

> P2: I kind of thought right, we need to come away from very specific getting her to do these exercises that actually maybe she can't see the relevance of, and actually we need her to be mum. She needs to be mum. She needs to practice walking the child to school.
>
> P6: My work has been around them being able to physically look after their children, so it's been completely integral to their goals.
>
> P4: The younger people that I've worked with, it does, a lot of their goals do tend to be… obviously if they've got children, they do centre around like their children, like being able to read them a story or like I don't know, maybe not for speech therapy, but like walking their child to school, or like there's, I suppose there's a different motivator there.

At times, even if goals are not related to specific parenting tasks, recovery is thought about in the context of returning to care for children.

> P5:…he was the chap that wanted to work on his dexterity skills, umm, and that came up in a number of things, so you know, for example, buttons, zips, things like that. Which I would largely assume for him, may also be to support his kids.
>
> P10:…at some point, umm, it's been discussed about, uh, mum to kind of, I don't know, go and stay somewhere else just to try first on, on therapy and, you know, try and get her better just to be able to call her child.

3.4.2.Sub-theme 2: The Importance of Approach and Connection.

Participants take care when entering the homes and lives of young stroke survivors and their families. They approach slowly and mindfully, respecting and navigating personal and familial boundaries. They hold in mind that the intensive nature of support provided by the ESD team might feel intrusive to young stroke survivors and their families.

> P1: The young parents especially, are the most challenging because you also have to take that step back and, and appreciate that's their unit and they do things their way so you have to learn the dynamics of their family quite quickly, and their expectations.
>
> P4:…you've got to be very mindful as well when, when, there are children I guess, to I suppose it's like knowing how to word things in the right way so that they're not like frightened, or cos it must be a really weird experience, like people coming into their house and like they've never.. and like as we said, our team is it's big and there's you know, it's intensive so, umm yeah, I suppose you just have to be mindful.

Participants talked about the importance of actively listening to young stroke survivors, acknowledging the reality of their experience and the impact of stroke.

> P9: I think it's that openness and transparency, umm, and I think also, there's also, I suppose, being able to be umm, to be real, actually, with clients about how devastating this has been potentially for their family and for them, umm, but also to provide them with some hope in terms of things can be different.
>
> P3:But there's a sense of being with someone and acknowledging their experience for what it is. I often find myself saying in the MDT meeting that an assessment is an intervention, and the most important thing is that that person feels listened to.

> P8: Umm, and generally, it's the little things, isn't it? That's what are the most important, and it's listening. If you listen, they'll give you those, those really important things. And then you can work from there.

The importance of connection and taking time to build a trusting therapeutic relationship between participants and the young stroke survivor and members of their family was also discussed.

> P1: …we're having to build up the trust very, very, quickly, and therapeutic relationship, especially when you consider personal care…for like a young mum .. it's huge.
>
> P3: We could do all these strategies and, and, very, you know you can do all sorts of big and wonderful things, but I believe strongly there needs to be a, a sense of connection.

Flexibility was spoken about as important for participants in their work with young stroke survivors with dependent children. Flexibility was described in relation to scheduling appointments and in how participants approach the work with young stroke survivors and their children.

> P6: I think we are very flexible, because one, we go to them, and we try and uh work within their routines and at times that it's going to suit them. So recently we had a patient who, she had five children, umm and she uh asked us if she could have a break from therapy whilst the kids were on school holidays, and we, we gave her a pause and then continued afterwards.
>
> P7: I was always really careful in terms of timings of appointments, particularly for, for, the client who had the younger children. Just making sure that actually someone else was going to be, like the nanny was present, or someone was going around, so that because otherwise it was just like too many calls on her time.
>
> P8:… so it's, your protocols always there.. the evidence based is always there. Yeah. But it's how you apply. It's all in application, isn't it? So, you have to be able to manipulate that, that way of working to fit the situation that you're seeing.
>
> P1: I would think people that have not had experience of young nephews, nieces or whoever, yeah must really struggle with how to say, they keep a very professional boundary, but actually children need you to just sit on the floor and they'll come to you if they want to. And the same way if they don't.

3.4.3. Sub-theme 3: Supporting Parenting.

During rehabilitation participants support young stroke survivors with dependent children to regain physical aspects of parenting such as playing, carrying children, and walking to school.

> P1: So you can imagine for somebody with a massive balance issue and a one sided weakness, you had to support her to bend to pick the toys up and then put them somewhere.
>
> P2: I can remember particularly working with a younger mum, you know. She had a 5 year old and you know, the five year old was playing tea parties, so you know we worked on getting onto the floor and playing tea parties (88)
>
> … we helped her with her affected arm, hold the teacup and then did the like [action drinking tea] because she was aphasic she then actually came out with, "Umm," you know, like oh lovely tea
>
> … and obviously you know the daughter was ecstatic. you know that Mommy was playing.
>
> P10: ..we did the exercises to go out and walk. As I remember her saying that, you know, I would just like to walk to the shop and back, to the local shop and back. So yeah, umm, towards the, the end of our input, she actually managed to walk to the shop with one of her kids and then walk back.

Participants also hold in mind the relationship and communication between parent and child and rebuilding the parent-child connection that may be disrupted following stroke.

> P1:… if that's what she wants to do, then you can work on the upper limb, but if she is not aware of neglecting the baby, then that that's your barrier. You know, because you can see the importance of the bonding and necessity of getting that arm working as otherwise what's going to happen to that child.
>
> P2: …the child was, you know it was, she was very much, you know, trying to get mummy's attention, you know, and, and, I suppose, you know I could, cause I remember this case as I was going to help a more junior colleague and, and I, ,I just remember looking at this whole scenario. Everyone's kind of just sitting there and the child was eager to play and just you know, like.. Mummy.
>
> P8: So it's like actually, just applying a stock answer is, is, never going to get to like the centre of who somebody is or the centre of that relationship. Umm, like it has to be more than that , and so we like we, we, ditched the stock phrases,

> we went for a more kind of gentle approach and, and he did really well. And that relationship got much better.

Participants describe the work as requiring them to think creatively to deliver rehabilitation focused on specific parenting tasks, adapting certain tasks or activities so they were manageable for the young stroke survivor whilst still meeting the need for the parent and child.

> P6: I even bought a massive bag of rice, so a patient could practice lift.. lifting and carrying an object that, something that's going to be like movable to try and like mimic and mock up what it's like to carry a child, umm, and then we've problem solved around carrying children safely using slings.
>
> P1:…we had, in the end, the speech therapist and I, we made flashcards, so she could, she could say, 'It's okay, I'm me, I just can't speak to you.
>
> P8:…and she always used to read the bedtime stories. So, those were her goals, umm, and, we were able to identify certain books that she could read, it was repetitive books and it was only certain books, but actually that was really special, because then they were, they became like the special books that look mum read. So yeah, yeah, it worked and games, kind of instead of playing Uno, they would play Snap, which was fine. You know, we just had to adapt things, so it wasn't quite so, so complicated.

Whilst working on parenting tasks, some participants described a mindful process of rebuilding parental confidence by moving from a position of offering a lot of support and guidance to gradually retreating back to let the parent take over.

> P1:… it was very much giving her the skills to get back in the kitchen to start doing it, to back off and, and let her try, get her engaged and, and, and that's how we did it.
>
> P8: So very, very supported to begin with, and then I gradually kind of took a, more of a step back until she could do it on her own.

3.4.4.Sub-theme 4: Including Children.

Participants hold in mind the children of young stroke survivors even if they are not physically seen. They are curious about what the children may have witnessed, the usefulness of the information they may have been provided with about stroke, and the impact the stroke has had on them.

> P4: I think she was 15. And, but unfortunately both of her parents ended up, had had strokes, yeah, so in that situation, even though you know, actually she was independent with a lot of things, you know, herself, we still, you know, straight away when we went in we were still very vigilant in thinking like how do we make sure that this like girl is supported, like off the bat, rather than like waiting for her to like, you know, reach a point of not managing.
>
> P8: …they're just told, no no, shush shush, mummy will be okay … and actually they just need their questions answering, but if the adults around them aren't equipped to answer those questions. Then it can have a huge impact.
>
> P9:…the team might notice, umm, changes in children within the family.. umm, and thinking about, you know, is it that the parents need some support, or actually, is it that the children need some individual support.

Participants take into account the age of the child, and whether they have adopted any of the domestic or caring roles following the stroke of their parent. They are cautious about children assuming too much responsibility and mindful of the disruption this may have created.

> P1: I even contacted safeguarding to see what support we could get that person, that young person, because she was almost having to come in and adult, and do and make adult decisions, and to care for two parents where she was at least very difficult developmental age. Yeah she had to put, to put college on hold.
>
> P3: We often see that children take on some of those responsibilities. Umm, but then it is revised sometimes that after a while the family realises it's not sustainable, that they have taken on a lot as a gesture of wanting to be available and helping but realising that they can't, they can't offer it. Or they feel they're isolated themselves. They've lost contact with their social world.
>
> P10: So the thing was, umm, her children were, umm, quite big so not where, a small age, and umm, I know we've asked for carers to come and uh support her just purely to, not to, not put pressure on their kids. Although they said no, we happy. I mean, they helped their mum because it's mum, right? But the thing is, it's not, is not fair though, I mean, they're still kids, so, uh, I had, as I said, to organise a care package for her.

Some participants described their experiences of including the children of young stroke survivors into therapy sessions. The responses indicated that when children were included in sessions, this was usually due to the perceived benefit to the child and to the parent-child relationship. One participant, (participant4) described a challenge they faced when including children in the work.

> P2:He used to do a lot of play fighting with the boys on the floor, like rolling around on the floor and so again we were, we were actually exploring how to get onto the floor and, and actually we did a little bit with his son .. about him trying to, rather than.. it was a little bit like he had to understand that Daddy had one arm and that he had if he was going to be picked up, you know that he reached up and held Daddy's neck and or he climbed on his back and just exploring ways that they could still bond and have that relationship.
>
> P4: So I've had people who are learning to, I don't know like read out loud, and then their children have, have, been there and we tried to like include them in their sessions where we can. But then it's really difficult if, I've had it before when one of the children said, 'oh mum, that's, don't be silly, that's not how you say that word,' and so it's kind of, how do you manage that? Because it's not, you know, obviously, that's a, a normal thing for a child to, to say and, and to get involved.
>
> P8:...and so we did lots of therapy work together, and supporting game playing, so that they became confident with how to play with her, and she became confident with her abilities as well. And then we did the same with reading.

Despite the perceived benefits of including children in the rehabilitation, responses indicated that the decision to include children in the work was often unplanned, with children becoming involved as a result of their own curiosity or request, or because they happened to be in the room when the therapy was taking place.

> P1:…[*child of young stroke survivor]* she pulled me away and we went into the hall and her bedroom and she said 'I can't do it anymore, I'm struggling.' And it was very quick, so she must have seen, she, I don't know she, I won't say that it's me personally, perhaps she saw uniform, perhaps it's the authority. I don't know. I don't know what she saw, but she had enough confidence to ask for help and I was able to access it for her.
>
> P8: I think I'd done about maybe three or four sessions, and the daughter would then sidle up beside me, umm, and just kind of looking and what.. it was another mum that I was working with.. 'what are you doing with Mum?' What, what, has mummy got any homework this week? And it was like, yes, I am giving mummy homework this week. Would you like to help Mummy with her homework? And she's like, yes, I would.
>
> P4:…it depends on the family I guess, so I'll will be led by whatever.. like, for example, some families I've worked with have always liked, like the child has always just been present, and so it feels, it would just feel weird not to include,

> you know, and often the things that we do are probably quite nice for children to join in.

Two participants identified that a lack of access to children can act as a barrier to including children in therapy sessions.

> P10: No, no, umm, because I remember anyway when umm, when I used to have the sessions, the children were in school.
>
> P8:…not really being able to access or support them, that's really remote, but that's for the older kids who, you know, are kind of, in the house, but they're up in their room, they're harder to, they're harder to get to. So that's a barrier, age.

3.5.Higher-Order Theme 3: Impact on Staff

3.5.1.Sub-theme 1: Emotional Toil

Participants described feeling a pressure when working with young stroke survivors with dependent children. This included feeling a sense of pressure to offer the right support and the pressure associated with being at the centre of the support for a young stroke survivor given the nature and intensity of ESD.

> P9: It feels a bit of a sense of how.. we need to get it right. We need to be able to really support this person and persons, if it's, you know, a young family as well.. to be able to function, to help to support with being able to care for children.
>
> P4: I suppose the thing is that we're the ones, because we're such an intensive service, we will be the people that are seeing what's going on in the day to day, a little bit more than maybe like social workers, maybe don't get out to see people as often, so I guess that's important, like as part of our role is like passing on information.
>
> P7: I suppose I'm feeling the pressure to just make sure that I've presented her with all the options that I think will be beneficial, but I'm just needing to leave it in her court as to what she actually wants to pick up on.

Some participants noted how the pressure they experienced was exacerbated by having to work ‘off script,’ due to the differing support needs of young stroke survivors with dependent children compared to older stroke survivors.

> P4: …there's been situations working with younger families which have been stressful like partly because it's like a new situation for me that I've never had to like, I've never sort of come across and there's not a, there's not like a, you know, do this, it's not like a checkbox like flow diagram type situation..
>
> P8: Oh yeah, by the seat of your pants, winging it a bit, you know, right, rolling with it.. and just going OK, what works here.

This brings with it an emotional toil for participants. They notice their own difficult emotional response to the work and experience of 'taking the work home.'

> P1:…to see the implications that her life might have to change in order to provide care and support and supervision for them where she had all this ambition. Yeah, yeah, I, I have to say I struggled with it.
>
> P4: There's normally always an, an, emotional element to working with younger families. I think that's, I think that's all. I don't think I've ever worked with a young family, where that hasn't been part of it, kind of an emotional… I mean, and I suppose that's true for a lot of stroke survivors. But yeah, I think anything centered around children is obviously particularly emotive.
>
> P9:…if we see them at the end of the day, we're gonna go home with them effectively…[*laughs*] it's like, you know, how do I process this?

Participants shared different methods of managing the demands and emotional toil of the work.

> P8:…the way that I manage that personally is understanding that that's not my emotion. That's not my story, it's.. I don't, I don't own that. That's, that's, theirs and their emotion, that's what they're feeling, umm, and, and I'm the, I'm the supporter in that that role.
>
> P5: I know that having the stroke psychology team as something to offer them, so that you're not giving them this devastating news and then saying, right, you've got to get on with it now.
>
> P2:…you know, then we have six weeks. We have six, you know, they'd been away at specialist for six months. We have six weeks and, and, I'm always telling my team, you know, we've got to think really realistically about what we're achieving in six weeks.

However, responses indicated a shared experience of seeking connection with others in the team when things feel complex, both to provide emotional support and ensure the work is being held by the team rather than by individual practitioners.

> P3:…we listen out, and you hear, oh, there's something brewing, and we might then sort of tentatively set up something just so that they, they don't feel they're the only person holding a lot of information. Or holding expectations because sometimes our colleagues do.
>
> P4: I would also say, yeah, to make sure that, I suppose, make sure you're talking to the rest of the team and make sure that you're like sharing all of your like, because I suppose sometimes when you walk into these situations you feel like it's all on you.
>
> P8: …I would happily phone any of them. Umm, but it's normally a) who you can get hold of umm, and b) maybe somebody who's also involved who would really be able to kind of identify with, well, twofold, identify with what you're, you've just gone through. And also you're handing over information, so it's the shared sharing of information as well. So as well as a bit of a debrief, and maybe an emotional kind of like , ‘oh my goodness, that was really difficult. I just need to sob for a minute.. listen to me while I do that.

Despite the emotional toil associated with supporting young stroke survivors with dependent children, participants identified satisfaction and interest in their work. They derived pleasure from observing positive change for families and the impact of the work for the children of young stroke survivors.

> P1:…it was a really, really interesting piece of work.
>
> P2: I think the smiles from the patient was evidence of feedback, I think you know I could see a little tear in the husband's eye, and you know, and obviously, you know, the daughter was ecstatic, you know, that Mummy was playing.
>
> P6: …I enjoyed it because when they achieve their goals, umm, it gives me a lot of satisfaction.
>
> P8:…it was good. It was quite nice… so that they became confident with how to play with her, and she became confident with her abilities as well.

3.5.2.Sub-theme 2: Doing The Best With What We Have

Participants described a lack of training and resources to draw from when supporting young stroke survivors with dependent children.

> P4: It's, hard, basically, it's and we get, there have been some resources like the Different Strokes I think is one that we often try and, and look at, but, to be honest, I don't really feel like there's that many resources available for us for particularly young stroke survivors who have young children.
>
> P7: I don't think there was any form of module or anything that existed that looked at provision of therapy in the context of parenting. Umm.. no, I think it is something you just pick up in terms of goal setting and yeah, just as, once you're actually in practice.
>
> P8:…it would be really lovely to be able to go into a stroke survivor who's younger, who has or a stroke survivor who has got dependent children, yeah, to, like, go in with, like, a nice information pack and to go, look, this is gonna really support, like, I don't know, just be able to support the difficult conversations, or like things that the kids want to ask, you know, 'what's going on with mummy's hand?'

However, some participants were able to identify aspects of their professional training that they could apply in their work and reflect on how their general clinical experience enabled them to feel more confident.

> P1: It didn't, no, no, none at all [*training*], with [*profession*] we very, the whole ethos is holistic approach and those keys terms of thinking about what the person wants to do, needs to do, has to do, and what has to happen in order for that to change and then how do we support that rehabilitation for them to achieve it.
>
> P6: I'm an experienced uh, [*role*] and I've worked in the community for a long time and in the same service for a long time, so I felt, I feel confident going into these patients. Umm and I didn't have a patient, a young stroke survivor with children until I was quite far into my role as a [*role*] in the community. I think, I would have felt more nervous going into it in the community setting when I was newly qualified.
>
> P9:…doing that [*training*] has enabled me to kind of really think about people's roles, to think about society actually, and people's views of strokes, physical health at different ages, views of disability.. umm, you know, ideas around identity and how is that shaped or formed as we grow up in, in the context that we're living in. And, as much as that sometimes feels like a lot to hold in mind, that's what, that's what we're, that's what we're working with.

Participants also recognise the importance using the experience that exists within the MDT to support the work, including senior staff supporting their junior colleagues and using joint visits as opportunities to think together about the work.

> P1:…these bigger strokes, these complex ones, with, with dependent children, you would probably go and do a joint visit anyway, so that you've got multiple heads trying to problem solve and plan.
>
> P2:…it's being recognised nationally that we don't think we're doing enough for this patient group. Umm, but that's obviously not translated into the clinical knowledge, and I think we just have kind of have to use our experienced colleagues in the team to try and support our younger colleagues.
>
> P9: We would do some joint visits actually as well, so to go along with the physios and OTs and SLTs, umm and maybe try and do some problem solving in the moment if there are some real difficulties happening for the clients and/or their families.

3.5.3.Sub-theme 3: It Resonates With You

Participants talked about a resonance they experience when working with young stroke survivors with dependent children which heightens the emotional element to the work.

> P10: I mean it was different I, because, obviously when you when you see a patient that age, someone that age having the stroke is, you know, emotionally is quite difficult..
>
> P2:…it's very emotive and heavy for the clinicians as well, and I think particularly I found that as I've got older and I've got young children and I see families the same age, I think I felt it a lot more.
>
> P9: I think it's also being, being, mindful that, you know, I'm a parent myself and actually some of this is going to resonate with me, umm, and, you know, it's about being prepared for that as a clinician and being able to.. have time and space to process that .. and I think that's what, that's the other part of kind of working with younger people who experience strokes is to be able to really have some good enough thinking space as a clinician.

Responses indicate that participants draw on their personal experiences of parenting or experience with children to inform their work and support them to feel more comfortable.

P2:…I think that's, I don't know, in reflection, whether that was my mum skills and mum's hat on….. But yeah, I think that probably, that dynamic probably changed the way that that treatment plan went.

P6: Definitely parenting myself like I had no idea before. Umm like, my knowledge about pacing and fatigue and delegating. So I would use that, umm, but never really had like a true understanding of the demands of parenting until I've been a parent myself, if I'm honest.

P8:…so you kind of know how to approach children and I've got my own [*laughs*], so you kind of, you've got that, so that knowledge and experience I definitely pulled on.

P7:…but I do think it was helpful having the experience of.. so, I'd already had my, my oldest daughter by then. But I think… if I hadn't of had that experience, yeah, I, I, don't know, I think the understanding would have been maybe a little bit different, of pressures of parenting ..I think it just, yeah, it sort of made it feel comfortable.

4. DISCUSSION

4.1. Overview

In this chapter the findings of the research are considered in relation to the research questions and existing literature. This is followed by a critical review in which strengths and limitations of the research are discussed along with implications for practice, policy, and future research.

4.2. Summary of Results

4.2.1. Higher-order theme 1: There is More to Hold

This higher-order theme recognised the complexity and sense of uniqueness experienced by participants when working with young stroke survivors with dependent children. The broadness of change for young stroke survivors with dependent children was observed and held in mind by participants, requiring a broadening of thinking and formulation skills. This includes working with both the young stroke survivors and the system around them. Participants held in mind loss and change in the parenting role of young stroke survivors with dependent children. For some participants, talking about parenting was spoken about as being uncomfortable due to perceived intrusiveness and concern about how to work with the information given. Participants also spoke to their thinking about parenting as centred around safety and considering the safeguarding needs of a family.

4.2.2. Higher-order theme 2: Working into the Complexity

This higher-order theme described how participants worked into the complexity experienced when supporting young stroke survivors with dependent children. Participants recognised the benefit of thinking holistically and flexibly when goal planning, creating person-centred goals that aim to support the young stroke survivor to regain a sense of self, including their parenthood. This allowed the broadness and uniqueness of supporting young stroke survivors with dependent children to be understood and worked with. Participants spoke about how support might feel intrusive and so adopted a slow, mindful, and flexible approach, taking time to work on building a trusting therapeutic relationship with the young stroke survivor and their family.

Participants described therapeutic work that involved creatively adapting parenting tasks to suit the needs of the young stroke survivor, aiming to rebuild their confidence. Some participants described supporting the children of young stroke survivors by making onward referrals, organising care for the parent to alleviate some of the caring responsibilities adopted by the children, and supporting parents to talk to their children about stroke. Participants shared how they included children of young stroke survivors directly in therapy sessions, viewing a benefit of this to be an opportunity to provide information to children about stroke, and preventing them from feeling excluded. Including children in the work appeared to be mostly unplanned, based on their curiosity or presence at therapy sessions.

4.2.3. Higher-order theme 3: Impact on staff

The third higher-order theme described how participants experienced emotionally their work with young stroke survivors with dependent children. Participants described a sense of pressure to make sure their support is ‘good enough.’. The emotional toil of the work felt heightened by the presence of children and observing the impact on them. Participants found different strategies for managing their emotional response to the work but there appears to be a shared experience of seeking comfort from the team and observing the benefits of working collaboratively. Participants experience satisfaction when they observe positive change for families.

Participants identified that needing to work outside of familiar protocol adds to the pressure of supporting young stroke survivors with dependent children due to a lack of training and resources they can draw on. However, some participants were able to identify aspects of their training that were helpful, including thinking holistically about a person and about their valued roles and identities.

The emotional experience described by participants also appears heightened by a resonance they experience, identifying with participants based on age or life stage or having their own children, i.e. it “hits home” (participant9). However, participants could also draw on their personal experiences, and knowledge and skills they have gained from parenting to inform the work and feel more comfortable.

4.3. Research Questions And Existing Literature

4.3.1. How Do Staff From An ESD Team Describe Their Experience Of Working With Young Stroke Survivors Who Have Dependent Children?

4.3.1.1. Witnessing and holding complexity and change: The participants in this study noticed the broad and multifaceted change that young stroke survivors with dependent children may experience, contributing to a feeling of complexity when working with this population. Participants attributed this to the demands of the multiple life roles that young stroke survivors often occupy and consequently the expectation of a return to these, including parenting. This is consistent with previous research that has highlighted the disruption that results from the diversion from the anticipated life trajectory of working age adults, and therefore, the greater burden of disability and risk to wellbeing that may result from experiencing a stroke at a younger age, (Banks & Pearson, 2004; Harris & Bettger, 2018; Harris Walker et al., 2021b; Hutton & Ownsworth, 2019).

Participants also understood complexity as resulting from the unexpectedness of experiencing a stroke at a younger age and the suddenness of change that results. This is well documented in previous studies that have pointed to the shocking and traumatising nature of stroke and the resulting difficulties faced by young stroke survivors in making sense of and accepting their experience, (Banks & Pearson, 2004; Coppock et al., 2018; Harris Walker et al., 2021b; Kuluski et al., 2014b; Shipley et al., 2018). This is likely to be further compounded by the problem of invisibility, highlighted by a participant in this study. Specifically, that young stroke survivors may look fine to others, despite struggling with the consequences of ‘invisible’ impairment such as cognitive difficulty, (Stone, 2005). Although this is unlikely to be unique to young stroke survivors per se, they are likely to be uniquely affected due to societal norms and expectations of how non-disabled younger adults function and contribute within society; leading to feelings of frustration and being misunderstood, (Röding et al., 2003; Stone, 2005).

Responses from participants in this study indicated that they recognised that young stroke survivors are likely to experience difficult emotional responses to the experience of having a stroke. The feeling of loss and wanting things to be as they were pre-stroke, were specifically highlighted by participants in this study as something they hold in mind. This seems especially important given the time point at which ESD is offered during stroke recovery, with young stroke survivors likely to be in an early stage of accepting and making sense of their experience.

Participants discussed the feeling of uniqueness and complexity when working with young stroke survivors with dependent children as requiring broader thinking and working. Specifically, participants described the need to formulate the needs of young stroke survivors within the context of their family system, considering both the needs of the young stroke survivor and their family members. Previous research in the field of ABI, has indicated that adopting a systemic approach supports the development of a broader, more contextualised understanding of the injured person’s experience and difficulties, (Evans-Roberts et al., 2014).

This is in line with a family systems framework (FSF), which emphasises the systemic impact of a medical event such as a stroke, and the specific familial challenges of a younger stroke that is out of sync with the anticipated tasks of that life phase; for instance, taking care of young children, (Rolland, 1999). Specifically, this relates to the added demands on a family unit to support and care for a parent who has experienced a stroke whilst simultaneously caring for dependent children and striving towards the pursuit of individual goals, (Rolland, 1987).

The FSF highlights how managing these conflictual demands is likely to induce stress in the family unit, impacting on individuals within the family and their relationships, (Sieh et al., 2012). Furthermore, it stresses the need to consider the interplay between an illness or health condition and both the life phase of the family and the family context, including wider societal impacts such as ideas and about ability, wellness, privilege and inequality, (Rolland, 1999). Staff who are supported to use a FSF when formulating and thinking about the needs of a young stroke survivor may be more likely to notice and consider the specific disruption and stress experienced by a family and consider those who may be particularly disadvantaged in recovery. For instance, families with little social support or financial pressure, potentially exacerbated by having time away from work.

According to Rolland, (1999) adopting a FSF can offer a structure and common language for staff when thinking about the support they offer. One such example is thinking about the familial 'tasks' brought about by illness or disability. This includes supporting a family to shift from a pre-illness to post-illness identity, consisting of re-evaluation of previous life and family structure whilst maintaining some continuity and achieving a sense of mastery and acceptance, (Rolland, 1987). Furthermore, Rolland, (1999) argues that the FSF can support longitudinal thinking with a family in order to consider both current support needs whilst in the crisis phase of the illness, and potential future support needs. This involves recognising the changing priorities and demands faced by a family as they move into different life phases and parenting responsibilities shift.

Previous research has emphasised the importance of rehabilitation staff considering family members as 'patients' with their own support needs, (Grawburg et al., 2019); and therefore bolstering the wellbeing of family or others who provide vital sources of practical and emotional support for young stroke survivors, (Harris Walker et al., 2021b; Kuluski et al., 2014a; van Heugten et al., 2006). This approach allows maximal recovery opportunity for the young stroke survivor and family adjustment and acceptance to be facilitated, by drawing out the adaptive resources of a family and potentially strengthening familial relationships, (Karpa et al., 2020; Kuluski et al., 2014a).

This is a promising finding and may represent a shift in working practices to becoming more family centred. For instance, in a survey of rehabilitation staff including OTs, SLTs and physiotherapists, working with people post-stroke, only one-third reported that they typically offer family-related intervention; with desire to do this low across disciplines, (Rochette et al., 2007). The study took place in Canada and was not focused on young stroke survivors with dependent children, limiting generalisation to the current study. However the authors note that family focused rehabilitation goals were more likely to be identified when working with stroke survivors in their own homes and when family present. This is relevant to staff working in ESD teams and may have accounted for the findings in this study.

Participants in this study also highlighted the value of working alongside family members in order to support the young stroke survivor, viewing family as a source of valuable information to guide their understanding of the difficulties. They described both observation of the relationships between family members and directly eliciting the perspectives of family members. This appeared to help participants in this study to capture a broader understanding of difficulties and manage the complexity of working with young stroke survivors with dependent children. It is also in line with previous research that has emphasised the importance of observing family functioning throughout rehabilitation to assess likely engagement with rehabilitation and determine if referral to additional services is necessary, (Harris Walker et al., 2021a).

4.3.1.2. Noticing loss and change in parenting: Participants described being aware of changes in the parenting roles of young stroke survivors with dependent children, identifying specific tasks such as reprimanding children that may become difficult following a stroke and the resulting shift in identity as a parent. Some participants identified the difficult emotional consequences of the changes in parenting such a recognising a sense of helplessness in young stroke survivors. This is consistent with previous research exploring the experiences of young stroke survivors that has highlighted a shift in parental role and feelings of loss at being unable to complete certain parenting tasks, (Edwards et al., 2014; Harris Walker et al., 2021b; Kitzmuller et al., 2012; Kuluski et al., 2014a; Pituch et al., 2020).

The responses from participants in this study also indicated that ESD team staff are mindful of the sensitivities that may exist when family members pick up some of the parenting tasks when a young stroke survivor is unable to. Furthermore, one participant appeared to feel a sense of relief when the family member was also attuned to the potential impact of this for the young stroke survivor. This suggests that staff are aware of the need to consider how young stroke survivors with dependent children may experience a shift in their position within their family and the challenge associated with this. This is important given previous research that has indicated that although familial relationships provide a valued source of support, young stroke survivors may struggle with the loss of some of their parental role to others, potentially feeling a sense of overprotection or of becoming a burden, (Ford et al., 2021).

Some participants described noticing positive changes for young stroke survivors with dependent children, including enjoying a slower pace of life and being able to spend more time with children. This is in line with previous research that found that young stroke survivors and family members reported enjoying more time together as a consequence of a stroke, (Gawulayo et al., 2021). However, it could be hypothesised that focusing on the positive aspects of the post-stroke parenting experience serves a function for ESD staff to minimise any discomfort that may arise from confronting and sitting with the reality of stroke for young stroke survivors and the complexity of offering rehabilitation to this population.

4.3.1.3. *The uncomfortableness of seeing*: The uncomfortableness appeared to act as a barrier for some participants to discuss parenting with young stroke survivors, despite their noticing loss and change in the parenting role. The avoidance for some participants of having conversations about parenting was understood in terms of parenting feeling too intrusive to talk about, or not feeling equipped to work with the information received. Furthermore, for some participants the presence of dependent children seemed to centre safety and safeguarding concerns. This appeared to dominate the thinking space, making it difficult to shift to a position of thinking about the parenting needs of a young stroke survivor as rehabilitation needs that can be worked with by the team. Alongside this however, participants in this study also displayed awareness that parenting might be a difficult topic for young stroke survivors with dependent children to bring up themselves.

These finding are consistent with previous research that has suggested that talking about parenting is likely to be anxiety inducing for both HCPs and young stroke survivors and may therefore be avoided, leading to parenting support needs going unrecognised, (Edwards et al., 2014; Harris Walker et al., 2021a). Research has indicated that it may feel particularly challenging for HCPs to discuss parenting whilst simultaneously holding safeguarding concerns in mind and responding when ethically and legally appropriate, (Edwards et al., 2014; Holloway & Tyrrell, 2016).

The difficulty of talking about parenting and tendency to avoid asking as part of routine assessment is not limited to rehabilitation services for health conditions such as stroke. It has also been highlighted in mental health services, indicating it may be a wider, systemic issue within healthcare systems, both in the UK and globally, (Rampou et al., 2015). Previous research has highlighted the need for more clinical training for HCPs to feel able to talk about parenting in a comfortable and helpful way, (Edwards et al., 2014; Holloway & Tyrrell, 2016). Based on the young stroke survivor literature, it could be hypothesised that those who facilitated conversations about parenting may be more inclined to adopt a family centred approach and in doing so create a safe space to share parenting concerns, (Harris Walker et al., 2021a). The potential benefits of this in enabling more conversations about parenting to take place, are supported by the findings of the current study.

4.3.1.4. Learning what's important: Participants described collaboratively developing person-centred rehabilitation goals that aimed to support young stroke survivors to regain a sense of self and their valued life roles. This appeared to represent an important aspect of the experience of working with young stroke survivors with dependent children, allowing the broadness and uniqueness of the work to be understood and worked with. To some extent, the broadness and flexibility of goals could be understood as a result of the context of ESD, the less rigid nature of the home environment and the presence of family facilitating an individualised approach, (Holloway & Tyrrell, 2016; Van Der Veen et al., 2019). Nevertheless, the finding is positive given previous research that has highlighted the disappointment of young stroke survivors when support received by services has felt unaligned with the goals and expectations of younger adults, (Shipley et al., 2018).

Some participants described goals related to regaining aspects of parenthood, understanding the meaningful and motivating nature of parenting related goals. Although previous research has recommended the inclusion of parenting related rehabilitation goals in order to meet all support needs of young stroke survivors, this has not been part of routine clinical practice with young stroke survivors, (Edwards et al., 2014; Harris & Bettger, 2018; Harris Walker et al., 2021a). Even if goals were not specifically related to parenting, some participants discussed goals in the context of returning to parenting tasks. This is consistent with rehabilitation goals often being articulated using impairment based terms, despite linking recovery to the return to valued life roles, (Sansonetti et al., 2018).

4.3.1.5. The importance of approach and connection: Although there are likely to be many parallels in how participants approach their work with older stroke survivors and young stroke survivors with dependent children, there appear to be certain experiences that feel heightened when participants engage and build a therapeutic connection with young stroke survivors and their families. Although mindful of being intrusive, there is an essential intrusiveness necessary to get to know and understand the young stroke survivor and their family, and to provide adequate support to meet their needs.

In essence, the approach adopted by participants aligns with the principle of ‘Well begun is half done’ (Lang & McAdam, 1996), acknowledging the importance of beginning well and being mindful of how the family system understands the work. Providing emotional support for young stroke survivors by listening and acknowledging the reality of their experience is likely to support engagement in rehabilitation, (Harris Walker, et al., 2021a). It also adheres to national guidelines which state that responsibility for providing emotional support during rehabilitation sits with the entire MDT, (NHS England, 2021). The findings from this study differ from previous research that has indicated that that the emotional consequences of stroke at a younger age can be overlooked and poorly understood by services, (Holloway et al., 2019; Shipley et al., 2018).

Participants offer flexibility with the scheduling of appointments with young stroke survivors with dependent children. This indicates an awareness of the conflict that may exist for young stroke survivors between making time for recovery and taking care of their children; potentially leading to a real or felt sacrifice in one or both areas. This is consistent with recommendations from previous research that has highlighted the risk of further difficulties and disengagement for young stroke survivors with dependent children if rehabilitation becomes too demanding or unmanageable, (Edwards et al., 2014; Harris & Bettger, 2018; Martinsen et al., 2012; Sieh et al., 2010).

Flexibility was also discussed in relation to being able to apply manualised treatments in a flexible way and in adapting working practises when interacting with children of young stroke survivors. For one participant, this meant recognising when to be flexible with professional boundaries, such as offering a more relaxed, non-intimidating approach, such as, sitting on the floor. Interestingly, the study by Shrubsole et al. (2020) found that concern around maintaining professional boundaries acted a barrier to including children in rehabilitation sessions.

4.3.1.6. Supporting parenting: Despite barriers in asking young stroke survivors about parenting, some of the participants in this study described their experience of supporting young stroke survivors to relearn a broad range of parenting tasks during rehabilitation. The support offered was focused on enhancing the parenting capabilities and independence of young stroke survivors. Previous research has suggested that parenting-focused rehabilitation may alleviate the feeling of multiple losses experienced by younger parents with an ABI, (Edwards et al., 2014). Although the views of young stroke survivors were not obtained in this study, the rehabilitation described by participants appeared to provide young stroke survivors with the opportunity to regain a sense of their parenthood and enhance self-efficacy, thereby challenging critical beliefs they may hold around their capabilities or not feeling 'good enough' as a parent. This is significant, as perceived self-efficacy is considered to be an important buffer against parental stress, particularly during times that are especially challenging, (Bornstein, 2006).

Some of the participants also held in mind the impact of stroke contributing to ruptures in the parent-child relationship and discussed how they consider ways to support this in the work. Parents with an ABI have expressed their desire for support with both the practical tasks of parenting and in rebuilding and maintaining the bond with their children, including through the use of 'quality time' spent together, (Dawes et al., 2022). Results of this study indicate that ESD team staff have the opportunity to meet that need during the rehabilitation.

Participants described therapeutic work requiring creative thinking to adapt parenting tasks to suit the needs of the young stroke survivor. An example provided by a participant in this study included using a bag of rice to practice carrying a child. They also described a process of scaffolding, reducing support gradually over time to build parental confidence. A study exploring the perspectives of people parenting with a physical disability and/or cognitive impairment found that although many parents are able to modify parenting tasks based on their individual needs, they benefited from the support of professionals to enrich and expand on this to ensure they are not excluded from tasks due to their disability, (Pituch et al., 2020).

4.3.1.7. Including children: Consistent with a family centred approach, participants in this study thought about the needs of the children of young stroke survivors even if they were not physically seen. Participants considered a child's understanding of stroke and the adequacy of the information they have received from others, acknowledging the possibility that the adults around the child may not be fully equipped to provide enough information. Participants also considered the support needs of children and whether onward referrals for additional support were appropriate. This demonstrates awareness by ESD team staff of the potential disruption to overall family functioning when a parent has a stroke and the risk to the psychosocial wellbeing of children, (Coppock et al., 2018; Gawulayo et al., 2021; Visser-Meily et al., 2005). Previous research has highlighted the importance of HCP curiosity and assessment of child functioning given the potential to overlook difficulties due to a lack of overt 'symptoms,' potentially serving the function of protecting parents, (Kieffer-Kristensen et al., 2011).

Participants in this study spoke specifically about their experiences of supporting the children of young stroke survivors who had adopted additional domestic and caring responsibilities following the stroke of their parent. They appeared cautious about this and keen to ensure they explored additional support options. This aligns with conceptualisations of childhood as a 'precious' time to be protected and of adolescence as a time for achieving separation from parents through greater autonomy and independence, (Carter & McGoldrick, 1999; Jackson & Scott, 1999). Children of young stroke survivors adopting caring or domestic responsibilities is well documented in previous research, (Harris Walker, et al., 2021a; van de Port et al., 2007; Yilmaz et al., 2015), as are potential challenges and restrictions facing young carers, (Thomas et al., 2003). Interestingly, research exploring the perspectives of children following parental stroke has also highlighted some positive aspects to caring for parents including feeling more mature and learning valuable life skills, (Cameron et al., 2022; van de Port et al., 2007). This reinforces the need to base rehabilitation on the specific formulation of a young stroke survivor and their family.

Some participants in this study discussed rehabilitation sessions with young stroke survivors where children were included in the sessions. Often this was to support the parent-child relationship by helping the young stroke survivor to relearn ways of interacting with children following their stroke. At other times, children were included to prevent them from feeling excluded or in order to provide them with information about stroke. This could be challenging at times, as highlighted by one participant, who recalled an instance where a child corrected their parent when practising reading.

The potential benefits of including children in rehabilitation sessions have been well documented, alongside the compatibility of this with a family centred approach (Harris Walker, et al., 2021a; Shrubsole et al., 2020; Webster & Daisley, 2007). The benefits of providing children with a role in the rehabilitation includes providing children with a sense of meaning and purpose, enhancing family relationships, (Dawes et al., 2022). The benefits of providing children with information about stroke includes the opportunity to gain a better understanding of stroke and how it has affected their parent behaviourally and emotionally, as well as becoming more reflective about their own emotional responses, (Butler, 2018; Cameron et al., 2022; Coppock et al., 2018; Visser-Meily et al., 2005).

In inviting children into rehabilitation sessions, Rolland, (1999) highlighted the power that HCPs hold in conveying a message about who should be included in conservations about the impact of stroke, acknowledging the disruption it is likely to cause for the entire family. Furthermore research by Cameron et al., (2022), indicated that even if not formally invited to join rehabilitation sessions, children may nevertheless observe sessions and support their parents to practice exercises and work towards their goals.

However, despite potential benefits, previous research has indicated that including children in rehabilitation therapy occurs infrequently, identifying barriers that include a lack of training and support, and workplace beliefs regarding the remit of professional roles, (Shrubsole et al., 2020; Webster & Daisley, 2007). Although some of the participants in this study discussed including children in their therapy, it was often 'ad hoc' and child led; potentially the nature of ESD support facilitating children's access to therapy sessions. However, despite this, a specific barrier that has been documented previously and also highlighted by participants in this study, is a lack of access to children in order to include them in sessions, (Shrubsole et al., 2020). In this study the lack of access was attributed to children being at school or in their bedrooms at the time of sessions. Shrubsole et al., (2020) suggest a shift in working culture is needed for HCPs to encourage parents to include their children as routine practice. Overall, Dawes et al., (2022) highlight the general infrequency of including children in rehabilitation reflects the lack of research in the area to guide clinical practice.

4.3.1.8: Emotional Toil. Participants described feeling a sense of pressure when working with young stroke survivors with dependent children. They understood the pressure as coming from wanting to ensure the support provided met the needs of a younger family and feeling at the centre of the support. They also described a pressure resulting from having to work 'off script' due to the lack of a 'manual' or guidance to draw from to meet the specific needs of this population. Furthermore, participants described an emotional toil resulting from witnessing the loss and change experienced by young stroke survivors. This was further heightened due identification with participants, based on age, life stage or having similar aged children. The emotional experience that is elicited requires time and space to process, or else they may 'take the work home'. This underpins the need for adequate support/supervision for ESD staff.

4.3.2. How Do Staff From An ESD Team Describe Their Experience Of Support That Facilitates Their Work With Young Stroke Survivors Who Have Dependent Children?

4.3.2.1. Managing the emotional toil: Participants discussed different methods of managing their emotional experience of the work. These supported participants with gaining some distance from difficult emotions that were evoked. Methods included locating the emotions back into the family system, taking comfort from being able to refer young stroke survivors to the stroke psychology team and focusing on reasonable expectations about what can be achieved in the short ESD timeframe. In addition to individual coping strategies, responses indicated a shared experience of seeking emotional support via connection with others in the team. This served the purpose of offering space to debrief, offload, and ensure the work is held as a team rather than individually.

4.3.2.2. Doing the best with what we have: Participants described feeling ill-equipped when supporting young stroke survivors with dependent children due to a lack of training and resources to draw on in the work. This is consistent with previous research that has also noted the scarcity of training and resources relevant to family centred practice with this population and with those with an ABI. This includes training and support in asking about parenting during assessment and in offering information and support to children during rehabilitation, (Pituch et al., 2020; Shrubsole et al., 2020; Webster & Daisley, 2007).

Dawes et al., (2022) propose that rehabilitation staff should be trained to offer information to all members of a family without it needing to be requested. They suggest the development of digital tools to support information giving, particularly to children. This fits with the reflections of a participant in the current study, who stated that it would be helpful to be able to provide children with an information pack about parental stroke, particularly when access to provide information verbally is limited.

The lack of training and resources has been attributed to the perception of stroke as a health event of older age leading to a lack of research and service development based on the needs of young stroke survivors, (Banks & Pearson, 2004; Different Stroke, n.d.; Harris & Bettger, 2018). As noted previously, others have highlighted the need for more research, staff training, clinical guidelines and service development to better meet the needs of young stroke survivors who are parenting and to assess the efficacy of rehabilitation aimed at supporting parenting, (Edwards et al., 2014; Harris & Bettger, 2018; Morris, 2011; Smajlović, 2015).

Despite the lack specific training, some participants in this study were able to draw from aspects of their professional training that supported them in their work. This included thinking holistically about a person's needs and drawing from theories around identity and becoming disabled. More experienced therapists also reflected on how their general clinical experience enabled them to feel more confident. It could be hypothesised that the confidence encouraged a more flexible approach to the work, allowing greater diversion from the 'manual' in response to the needs of young stroke survivors. The study by Shrubsole et al., (2020) is consistent these findings, highlighting a lack of experience and self-confidence as barriers to working with children. Likewise, Rochette et al., (2007) found that more experienced therapists were more likely to offer family-centred rehabilitation compared with novice therapists. They suggested that this may result in part from experienced based knowledge encouraging a broader view of stroke consequences for a family, potentially alongside greater personal experience of the impact of family illness.

Participants in this study expressed their recognition of the value of experience based knowledge, discussing the benefits of joint visits and MDT thinking in order to meet the complexity of supporting young stroke survivors with dependent children. The importance of utilising the skills, experience and knowledge of the MDT in the context of stroke and ABI rehabilitation is well documented, (Holloway & Tyrrell, 2016; Wohlin Wottrich et al., 2007). Evans-Roberts et al., (2014) state that working systemically with the complexity of ABI can result in rehabilitation staff feeling de-skilled and overwhelmed and therefore supervision and consultation from others in the team is vital for managing the demands of the work. A supportive and knowledgeable MDT may also facilitate more family centred practice, including working directly with children, (Shrubsole et al., 2020).

Participants also discussed using knowledge gained from their personal life experiences to guide their work. Specifically, they described using knowledge they gained from their own parenting or experience with children to understand the demands of parenting, to think together with the young stroke survivor about treatment goals, and to interact with the children of young stroke survivors. This appears to support participants to feel more comfortable in their work and develop a positive working relationship with young stroke survivors and their family. This may have felt participially pertinent for participants when working with young stroke survivors due to the lack of professional training to guide working with this population, coupled with the resonance of supporting young stroke survivors who are of a similar age and with similar life experiences. This may feel like a marked contrast for participants who cannot yet draw from lived experience of older age to inform their work with older stroke survivors who form the majority of their caseload. It could be hypothesised therefore that participants experience a sense of greater freedom to think more broadly and creatively with this client group.

Furthermore, although it is unclear how much participants in this study shared about their own experiences of parenting with young stroke survivors, they may have consciously or unconsciously shared their experiences as part of forming a therapeutic alliance with young stroke survivors and their family. Previous research by Lawton et al., (2018) indicated that rehabilitation staff use varying degrees of self-disclosure to offer openness and trust as part of building and maintaining the therapeutic alliance with stroke survivors, a core ingredient of successful rehabilitation, (Lawton et al., 2018). The importance of effective supervision is reinforced here, supporting staff to use personal experience and knowledge in a safe and client-centred way. Psychologists working within stroke teams are likely to be particularly adept at doing this, due to their training in working with transference and counter transference.

4.4. Critical Review

4.4.1. Quality

As outlined in the method, guidance provided by Willig, (2021) was used to assess the quality of the research. This includes acknowledging that interpretation of the data and application to theory and research offers just one possible understanding of the data. This accords with the critical realist epistemology of the study. There are many possible contextual factors that situate the research process. Some of the relevant social and political context is the impact of austerity on the resources of NHS services and the high cost and low availability of childcare.

4.4.1.1. Reflexivity: Keeping a reflective journal helped me to remain aware of my relationship to the research process, including thinking about what influenced my choice of research topic. Conducting the research has reinforced to me the importance of this topic and the reality that parenting has not been given sufficient attention in healthcare training and policy and therefore also in practice, across both mental and physical health settings. Furthermore as a trainee clinical psychologist it has been insightful to think about the role of clinical psychology in different settings and about the transferable skills that contribute to MDT contexts. Specifically, I have been thinking about how as a psychologist I can bring systemic perspectives into team thinking and reinforce the importance and value of 'connection' between members of staff and staff and people who use the services.

The reflective journal also provided space for me to think about my interactions with participants and the positions in which I may have been situated. Like myself, a significant proportion of the participants were parents. I noted in the journal times when I felt that assumptions were made or communicative gestures that appeared to communicate a shared understanding of what it is like to be a parent. The parallels of participants who are parenting, sharing about their work with young stroke survivors who are parenting to a researcher also parenting, inevitably influenced the interactions, research process and production of knowledge.

Similarly, for participants who were not parents, many like me were around the age of the young stroke survivors they were thinking about when describing their experiences. As above, this also inevitably created a perceived shared experience that influenced the research process. Overall, keeping a reflective journal helped me to remain mindful of potential bias whilst also supporting the latent part of the analysis.

Methods of maintaining quality in this research include a detailed description of the sample of participants enabling readers to consider the relevance of the research to other contexts. The credibility of the final analysis was supported by reflective discussions of the analysis with the research supervisor and keeping a reflective journal. The research process and rationale has been described and the process of theme development documented (see Appendix J/K). Pertinent examples from the analysis and thick descriptions of the themes are included in the write-up. The findings were also considered in respect to previous literature. Overall, the research aimed to provide a broad and exploratory account of the experience of ESD team staff working with young stroke survivors with dependent children. This should be considered alongside research that has documented the experience of young stroke survivors. To support the usefulness of the research recommendations for practice, policy and research have been provided, (see 4.5).

4.4.2. Strengths

To the best of the researcher's knowledge the current study represented the first attempt to explore how staff members of an ESD stroke service experience working with young stroke survivors who have dependent children and the impact their experience has on their practice. A qualitative approach allowed for the collection of detailed and in-depth data that provided an understanding of aspects of the experience of staff and their working practices. This included how complex it feels when working young stroke survivors; their experiences of providing support for parenting; and including the children of young stroke survivors into therapy sessions. The study makes suggestions for how to expand on the findings and include the voice of young stroke survivors. It also makes recommendations for practice and policy.

Based on reflections from some of the participants in this study, participants appeared to perceive taking part in the research as a positive experience. They commented about the value of having time to reflect on their work. One participant mentioned that participating in the interview resulted in a new perspective of the work. Another participant stated that the discussion in the interview led to an idea for service improvement. They reflected that working in busy services, that they do not regularly get the space to think about service improvement ideas and how to take them forward into action.

4.4.3. Ethical And Methodological Considerations

4.4.3.1. Thematic analysis: Given the limited evidence base and therefore exploratory nature of the study, thematic analysis was considered well suited to achieve the research aims. Thematic analysis allows a broad overview of data, noticing patterns and similarities and differences across the data. However, thematic analysis does not offer in-depth accounts of individual experiences and therefore it is possible that valuable aspects of individual participant's experiences were not attended to. However as this research was focused on the breadth and not depth this was considered acceptable and offers avenues for future research.

4.4.3.2. *Online data collection:* Due to the Covid-19 pandemic, university guidance stipulated that all data collection was to be conducted online. Thus, interviews with participants were conducted via Microsoft Teams. Although research interviews would have traditionally been conducted face to face, at the time of data collection, hybrid working was standard clinical practice for ESD team staff and therefore they were familiar with communicating via Microsoft Teams. They were also used to finding appropriate and confidential spaces in which to hold meetings. Therefore, considering this alongside the nature of the research, i.e., that it related to working practises and not personal experience, it seems unlikely that the virtual method of data collection would have significantly influenced the responses provided during interviews.

4.4.3.3. Social desirability bias: The face-to-face nature of research interviews increased the likelihood of socially desirable responding and therefore, this is a consideration for this study. Socially desirable responding may have protected participants from perceived judgement of their working practices or discomfort at disclosing certain beliefs that they may have perceived to be discordant with the assumptions of the researcher. For instance, beliefs around whether their role should support parenting related rehabilitation goals. Socially desirable responding may therefore have prevented participants from disclosing their true anxieties around the work. However, specific factors that should have reduced the likelihood of socially desirable responding include participants participating in the interview in a private location, taking time to build rapport and assuring confidentiality of what was spoken about during interviews, (Tourangeau & Yan, 2007).

4.4.3.4. *Sample:* The sample contained participants from a diverse range of professional backgrounds, representing those who work within ESD teams. The rationale to collect data across professional groups was so the data was representative of the experiences of staff who form part ESD teams. However, to extend and add nuance to the findings, future research could compare and contrast the experiences of different professional groups. This may lead more directly into recommendations for training improvements.

The sample was less diverse in other respects, however. Particularly in regard to the ethnicity of staff, and gender. All participants in this study were female. It is difficult to ascertain how representative this is of ESD teams throughout the UK, although it is possible that female staff are generally overrepresented within stroke teams. This is comparable to other research into staff rehabilitation practices, where female participants have represented a large majority of respondents (e.g. Shrubsole et al., 2020; Webster & Daisley, 2007). In line with a critical realist perspective, participant responses are situated by context and the intersection of their identities. As a white, female researcher interviewing predominantly white and female participants, this invariably influences the responses given and data generated.

A further consideration of the sample is sample size. Ten participants took part in the study, which is generally considered adequate for qualitative research, (Guest et al., 2006). However, it is acknowledged that decisions around the 'adequacy' of sample size are limited if based solely on the number of participants, rather than also accounting for quality and impact of data generated, (Vasileiou et al., 2018). In the current study recruitment was constrained by the impact of Covid-19, service pressures and time constraints of the university.

A final consideration of the sample concerns the potential for selection bias. Participants volunteered to take part in the research which therefore introduces the possibility of bias. It is possible that those who volunteered were more interested or experienced in working with young stroke survivors with dependent children. However, the diversity of responses and work experience reported by participants reduces the likelihood of significant selection bias in this sample.

4.4.3.5. Timing of transcription and analysis: In later interviews, the schedule of interviews meant that transcription and analysis could not take place before each subsequent interview. This may have limited data collection in the sense that earlier analysis may have drawn attention to patterns or meaning within the data that could have then been explored in more detail in subsequent interviews. Equally however, this would have risked leading the interviews and loosing other important aspects of participant experience.

4.4.3.6. Generalisability: Due to the contextual nature of qualitative research, the aim of this study was not to generalise the findings to the broader stroke staff population. However, the study aimed to provide an initial understanding of the experience of ESD team staff working with young stroke survivors with dependent children and the description of participant demographics allowed readers to determine potential transferability to other services.

4.5. Implications and Recommendations

4.5.1. Practice And Policy

4.5.1.1. Training: The findings from the current study support previous recommendations for greater access to training for staff from ESD teams. This should be based in assessing the parenting support needs of young stroke survivors and incorporating parenting related goals into family centred rehabilitation plans. The training should address both clinical skills and beliefs about the worthwhileness of supporting parenting that may impact on the utilisation of clinical skills. Training to discuss and assess parenting both sensitively and comprehensively might go some way in overcoming the anxiety about holding such discussions. The learning should then be reinforced in appropriate supervision spaces to continue to develop clinical practice in the area. Training to guide clinical practice with the children of young stroke survivors is also necessary and should include how to include children in rehabilitation sessions as well as how to offer direct support to children including the provision of information.

However, although training needs are highlighted, it is also important to acknowledge the necessity of further research to inform training and ensure that training addresses the specific support needs of young stroke survivors with dependent children. This includes utilising co-production with young stroke survivors with dependent children for both research and training to incorporate theory with lived experiences. Clinical psychologists are trained to use systemic models to support thinking about family systems alongside the emotional content of the work. As clinical psychologists are often part of MDTs in stroke services, they would be well suited to develop and deliver this training.

4.5.1.2. Clinical practice: When working with young stroke survivors with dependent children, staff from ESD teams should formally assess the parenting support needs of young stroke survivors as part of initial assessment. Methods of assessment should be standardised across the team with flexibility to adapt the assessment to suit the needs of the individual. Standardised assessment should provide particular assistance for those with less clinical experience or those who feel less equipped to discuss parenting support needs . The outcome of the assessment should be formally recorded and incorporated into rehabilitation plans, client notes and any ongoing referrals to other services.

Similarly to previous research, this study highlighted barriers to providing information to family members of young stroke survivors, specifically children. A shift in working practice to view information giving to family members as a standard offer included in rehabilitation provided by ESD teams may encourage conversations about this from the initial assessment, creating a clear expectation of what can be provided and allowing young stroke survivors and/or family to consider their role in enabling access to children. Alternatively, if direct information giving to children is not desired, family members or parents can be supported to do this themselves, with support provided by staff. The use of appropriate digital tools to provide information to children should also be explored as a method of overcoming barriers in access, as described in previous research (e.g. Dawes et al., 2022).

An important part of clinical practice and something highlighted as an important source of support by participants in this study is the opportunity for peer support and consultation. Therefore, as part of maintaining good clinical practice and utilising training received, ESD team staff should have access to and be encouraged to make use of different supervision spaces including peer supervision and consultation with senior colleagues. This should foster the sharing of experienced based knowledge, thereby encouraging family-centred practice and enabling broader and more contextualised understandings of the support needs of young stroke survivors with dependent children. This may encourage junior therapists to feel more confident about working flexibly and ‘off script’ where appropriate. Group supervision spaces may also allow the shaping of workplace beliefs to becoming more facilitative of working on parenting goals or directly with the children of young stroke survivors, removing some of the previous barriers.

Supervision spaces can also provide ESD team staff with a space to share and make sense of the complexity and pressure they experience when working with young stroke survivors with dependent children. Emotional responses to the work could be explored and supported. In addition, identification with young stroke survivors could be discussed, both for how it can safely inform the work, and how it can exacerbate the emotional response to it. Psychologists working within teams would be well placed to facilitate these spaces using a systemic framework.

4.5.1.3. Policy and clinical guidelines: Current NICE guidelines for Stroke Rehabilitation in Adults, (2013), state return to work as a priority area to be assessed as early as possible during rehabilitation. However, a return to parenting is not currently considered within the guidelines, despite the likelihood that young stroke survivors are likely to experience a return to parenting after discharge from acute care despite residual impairment, (Harris & Bettger, 2018). Based on the increasing rates of stroke in those under 65, policy and clinical guidelines informing clinical practice with stroke survivors should reflect the broad range of needs of young stroke survivors including parenting. Clinical Psychologists who are trained in psychological and neuropsychological theory and practice would be able to support policy and clinical guidance focused on the neuropsychological rehabilitation in the context of the family system.

Based on the recommendations outlined above, current policy for working with stroke survivors should be reviewed based on its applicability to young stroke survivors who have dependent children. Policy should reflect and support the role of ESD team staff in working from a family centred perspective. It should support and guide staff with incorporating parenting related goals into rehabilitation and with including children of young stroke survivors into rehabilitation sessions where appropriate. It should guide clinicians to attend to the psychological needs of the whole family, and when to refer on when appropriate. Based on the findings of this research, policy should also highlight and protect the function of the MDT as a supportive space for staff and the role of consultation and supervision in enhancing clinical practice and supporting the wellbeing of ESD team staff.

4.5.2. Research

This study represented a first attempt to explore the experiences of staff from an ESD team working with young stroke survivors with dependent children. The focus was therefore broad, and attempts were made to avoid preconceptions about the views and experiences of ESD team staff. For instance, the focus of the research could have been how staff from ESD teams support young stroke survivors to resume parenting after a stroke. However, implicit in this is the assumption that staff from ESD teams view this as part of their role within rehabilitation. Given the findings of this study, there are a number of avenues for future research that could enable a richer and more in-depth understanding about certain aspects of the work with young stroke survivors with dependent children. This includes research that aims to provide greater understanding of how ESD team staff support parenting and the specific facilitators and barriers of working directly with children in the context of ESD support.

The voice of young stroke survivors was also absent from the current study and given the lack of previous research exploring the perspectives of young stroke survivors, this represents an important avenue for future research. Specifically, research exploring the perspectives and experiences of young stroke survivors with dependent children who have received support from ESD teams could be insightful. The research could explore how young stroke survivors experience talking about parenting with staff from ESD teams; and how they experience receiving support for parenting or support for their children where appropriate. Furthermore the voice of the children of young stroke survivors is also absent and lacking in the evidence base. Therefore, research that explores their experiences of being included in rehabilitation sessions and their ideas of facilitators and barriers would add to the knowledge gained from research in this area and could contribute to service development.

Future research could also examine aspects of identity and socio-environmental factors that may influence the experience and recovery of young stroke survivors and conceptualisations of and resources available for parenting. For instance, given that women are more likely to take on the primary role of caring for children even when working full time, (Doucet et al., 2010), it would be interesting to investigate whether the gender of young stroke survivors influences the likelihood that parenting related goals are included into rehabilitation plans. Furthermore, other factors such as age of children, lone parenting, race and socio-economic stressors may influence the interactions between young stroke survivors and services and young stroke survivors' experiences of support and could therefore benefit from further investigation. Furthermore, as mentioned in the critical review, although responses were gained from a range of professionals in this study, comparisons were not made due to the small number of participants from each profession. Future research may wish to explore differences between professional groups in how they engage with young stroke survivors with dependent children.

4.5.3. The Role of Clinical Psychology in Supporting Young Stroke Survivors with Parental Responsibility.

4.5.3.1. Direct support. Clinical psychologists working within stroke teams work collaboratively alongside others in the MDT to identify and provide support for a range of psychological difficulties that may impact on the wellbeing of young stroke survivors and their engagement in rehabilitation, (Perna & Harik, 2020). This includes support for difficulties such as low mood, managing loss associated with stroke and cognitive rehabilitation, (Perna & Harik, 2020). Clinical psychologists can also provide important brain injury education for the person and their family, supporting short term understanding of difficulties, expectations for recovery and planning for ongoing support needs, (Perna & Harik, 2020).

4.5.3.2. Indirect support. Clinical psychologists working within stroke rehabilitation teams are ideally placed to develop and enhance the psychological skillset of members of the MDT by offering training and facilitating regular consultation and supervision spaces. This can ensure that psychologically informed formulations form a core part of clinical practice that is underpinned by a biopsychosocial model, (Ebrahim, 2022). Using systemic frameworks clinical psychologists can encourage a workplace culture that considers the person within their family context and by doing so, considers parenting responsibilities and how these can both be supported and how they impact on time for recovery. Furthermore, by supporting the development of family-centred formulations attention is drawn to the experiences and support needs of all family members, including dependent children. This provides a broader lens in which to consider potential intervention options, and what could be a helpful focus of the work.

Clinical psychologists can also shape and support team ideas about the value of family-centred practice, addressing hesitancy and beliefs that may act as a barrier to working in this way, such as beliefs about the remit of professional roles or perceived skills and abilities. Clinical psychologist can support reflection and sharing of practice based knowledge, enhancing competency and confidence within the team. Clinical psychologists can use their skills in providing clinical supervision to facilitate a supportive space to reflect on and make sense of the complexity of the work with young stroke survivors. This includes the difficult feelings that may be elicited by the work and understanding and working through identification with clients, and transference and countertransference processes.

Importantly, clinical psychologist can use their existing clinical skills to support the direct and indirect work with people with neurological conditions and therefore further extensive training is not required, (Wheeler et al., 2022).

4.6. Conclusion

To the best of the researcher’s knowledge this is the first study to provide an understanding of the views and experiences of staff members from an ESD stroke service working with young stroke survivors with dependent children. The study found that working with young stroke survivors with dependent children is experienced as complex and requires a broadening of thinking and working. Loss and change in parenting felt by young stroke survivors is noticed and held in mind by staff. Some staff assess the impact of stroke on parenting and include parenting related treatment goals into rehabilitation. Some also include the children of young stroke survivors into rehabilitation sessions.

Recommendations from the study include greater access to training for staff in assessing the parenting support needs of young stroke survivors and including the children of young stroke survivors into sessions when appropriate. Clinical practice recommendations include standardised assessment of parenting across the team; ensuring information giving to young stroke survivors and their family members is viewed as part of standard clinical practice; and creating and encouraging the utilisation of different supervision spaces to enable sharing of experience based knowledge and reflection of the emotional experience of the work. Finally, it is recommended that policy and clinical guidelines are reviewed to reflect and support family-centred rehabilitation and the importance of attending to the psychological wellbeing of the whole family.

Clinical psychologists working within stroke MDTs can play a pivotal role in providing training, contributing to policy, and facilitating supervisory spaces using a systemic framework. Potential avenues for future research were outlined, including the need to explore the perspectives of young stroke survivors with dependent children who are receiving ESD support.

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6. APPENDICES

Appendix A

Literature Review Process I

Date of literature search: August – September 2022

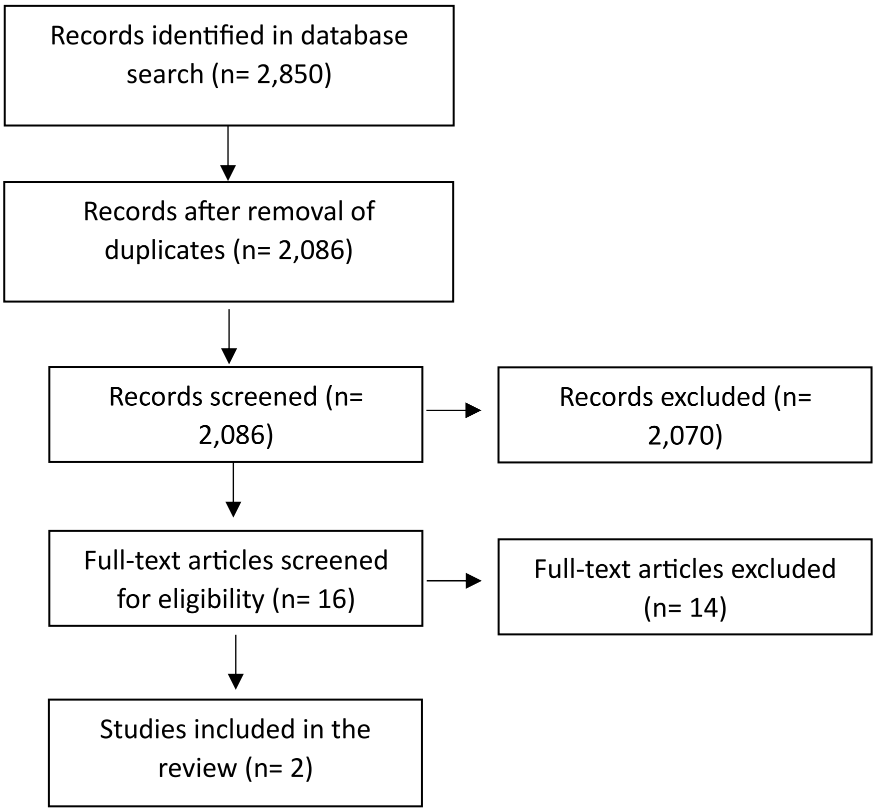
Databases searched: Academic search complete, CINAHL, PsychINFO, Scopus

Search Terms: AB (stroke or cerebrovascular accident or cva or acquired brain injury or ABI) AND AB (staff* or professionals or speech and language or SLT or physio* or nurses or occupational therapists or OT or psych* or early supported discharge or ESD) AND AB (parent* or father* or mother* or parenting roles or family

Exclusion criteria:

- Did not relate to stroke or related difficulties e.g. aphasia.
- Did not focus on rehabilitation staff working practices/views/experiences.
- Did not focus on an aspect of family focused rehabilitation e.g. parenting, working with children.

Literature review flow diagram



Appendix B

Literature Review Process II

Date of literature search: November – December 2023

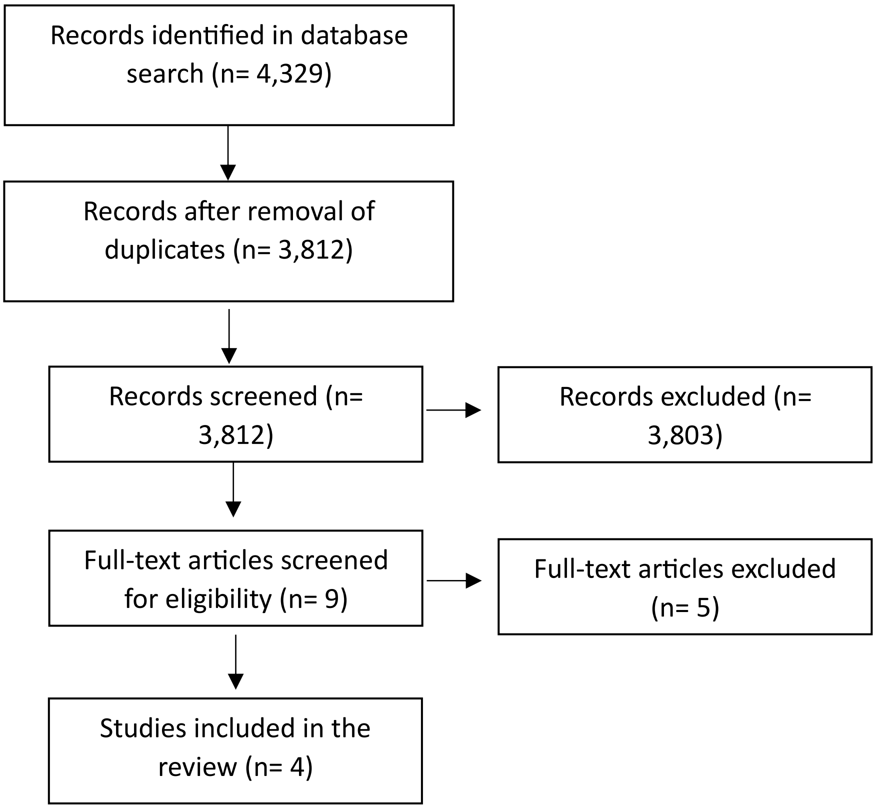
Databases searched: Academic search complete, CINAHL, PsychINFO, Scopus

Search Terms: (Stroke or acquired brain injury or ABI or acquired neurological disability or acquired neurological condition or multiple sclerosis) AND (staff or nurses or healthcare professionals or professionals or healthcare worker or speech and language or SLT or physio* or occupational therapist* or OT or psych* or early supported discharge or ESD) AND (parent* father* or mother* or family or parenting roles or parenting responsibilities)

Exclusion criteria:

- Did not relate to acquired neurological disabilities/health conditions (multiple sclerosis & acquired brain injury)
- Did not focus on rehabilitation staff working practices/views/experiences.
- Did not focus on an aspect of family focused rehabilitation e.g. parenting, working with children.

Literature review flow diagram



Appendix C

Interview Schedule

Stroke professionals' views and experiences of supporting Young Stroke Survivors (YSS) who have dependent children

Interview Schedule

Preamble and Introduction

Thank you for agreeing to take part in this study. As we have discussed I will ask you some questions about your experience of working with YSS who have dependent children and your experience of support that facilitates your work. You do not have to answer any questions you do not feel comfortable answering. The interview will take about 45 minutes to an hour. Please let me know if you would like a break at any time.

Demographic Data

Age: 18 – 34; 35 – 44; 45 – 54; 55 and over

Gender identity: **Female**

Ethnicity:

Professional role:

Number of years working for ESD service as *[professional role]*: Less than 1 year; 1- 3 years; 3- 5 years; 5 -10 years and 10 years +.

Number of years working for stroke services as *[professional role]*: Less than 1 year; 1- 3 years; 3- 5 years; 5 -10 years and 10 years +.

Your post

We will start by talking about your professional role and how you support people who have experienced a stroke.

Can you tell me a little about how you support people who have experienced a stroke in the ESD service?

Possible prompts:

- When do you typically start working with Stroke Survivors (SS)?
- How long do you typically support SS**? (Differ from older)**
- What sorts of goals do you typically work towards?
- Can you briefly describe how the Covid-19 pandemic has influenced your working practice?

Experience of working with YSS with dependent children

I'm interested in hearing about your experience of working with YSS with dependent children. By dependent children I mean children who live with the stroke survivor and who are dependent on their parent(s) for care.

Possible prompts:

- Can you tell me about your experience of working with YSS with dependent children?
- How does it compare working with YSS with dependent children with other SS?
- How important do you think it is for you as a <*professional role*> to address the parenting needs of YSS?
    - Prompt: What other things might take priority?
- When working with YSS with dependent children can you tell me about things that have worked well and less well?
- How does it feel to talk about parenting with YSS with dependent children?
    - Prompt: Does it feel like a difficult topic to talk about for some YSS?
- Can you give me some examples of how you typically talk to YSS about parenting after stroke?
- **What advice would you give to other staff working with YSS who have dependent children?**
- From your perspective, what is it like for YSS who have dependent children to access the ESD service?
- Can you suggest any improvements that could be made to the service to help YSS with dependent children to access the service?

Perspective on your knowledge and how you are supported to work with YSS with dependent children

We have talked a little bit about your post and also your experience of working with YSS with dependent children; perhaps we can now talk about how supported you feel to work with YSS who have dependent children and what knowledge you draw on.

Possible prompts:

- How equipped do you feel as a <*professional role*> to work with YSS with dependent children?
- What guidance, knowledge, and experience do you draw on when working with YSS with dependent children?
    - Prompt: How effectively did your professional training equip you to address the needs of YSS who have dependent children?
- **How confident are you in supporting YSS who have dependent children? Why do you think that is?**
- What are the things that have helped you in your work with YSS with dependent children?
- **What barriers do you experience as a <*professional role*> when addressing the support needs of YSS with dependent children?**

- What knowledge, guidance or training do you think would be important to have to support you and the team when working with YSS with dependent children?

Ending

Thank you for your time and agreeing to meet with me today and talk to me about your experiences.

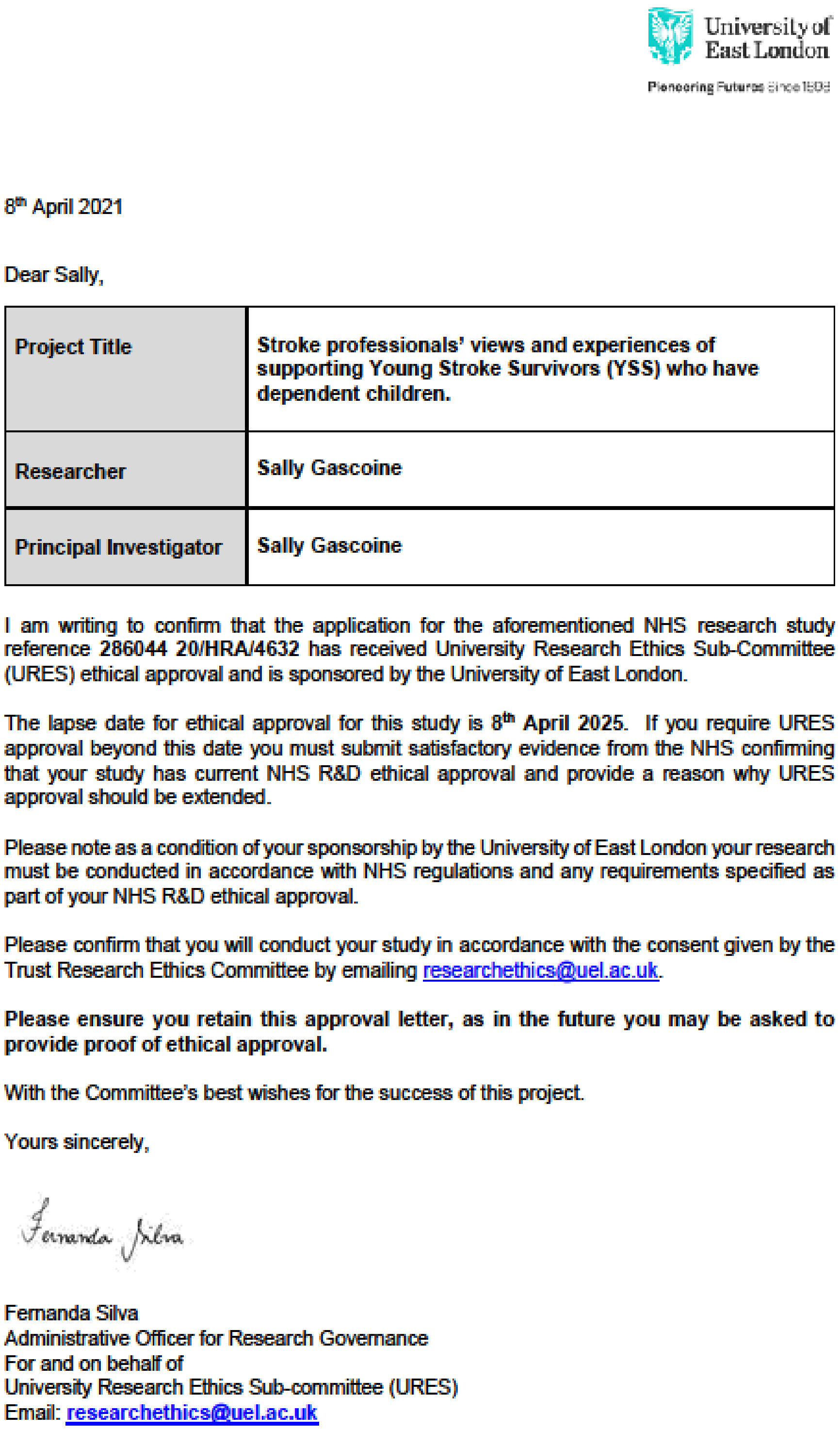
1. We are almost at the end, but I wanted to know if there is anything that I haven't asked today that you think is important?

2. Would you like to ask me anything?

- Debrief sheet and confirmation of consent (and three week cut-off for withdrawal of data).

APPENDIX D

UEL Ethical Approval Letter (first page)



University of
East London
Pioneering Futures Since 1898

8th April 2021

Dear Sally,

Project Title	**Stroke professionals' views and experiences of supporting Young Stroke Survivors (YSS) who have dependent children.**
Researcher	**Sally Gascoine**
Principal Investigator	**Sally Gascoine**

I am writing to confirm that the application for the aforementioned NHS research study reference **286044 20/HRA/4632** has received University Research Ethics Sub-Committee (URES) ethical approval and is sponsored by the University of East London.

The lapse date for ethical approval for this study is **8th April 2025**. If you require URES approval beyond this date you must submit satisfactory evidence from the NHS confirming that your study has current NHS R&D ethical approval and provide a reason why URES approval should be extended.

Please note as a condition of your sponsorship by the University of East London your research must be conducted in accordance with NHS regulations and any requirements specified as part of your NHS R&D ethical approval.

Please confirm that you will conduct your study in accordance with the consent given by the Trust Research Ethics Committee by emailing researchethics@uel.ac.uk.

Please ensure you retain this approval letter, as in the future you may be asked to provide proof of ethical approval.

With the Committee's best wishes for the success of this project.

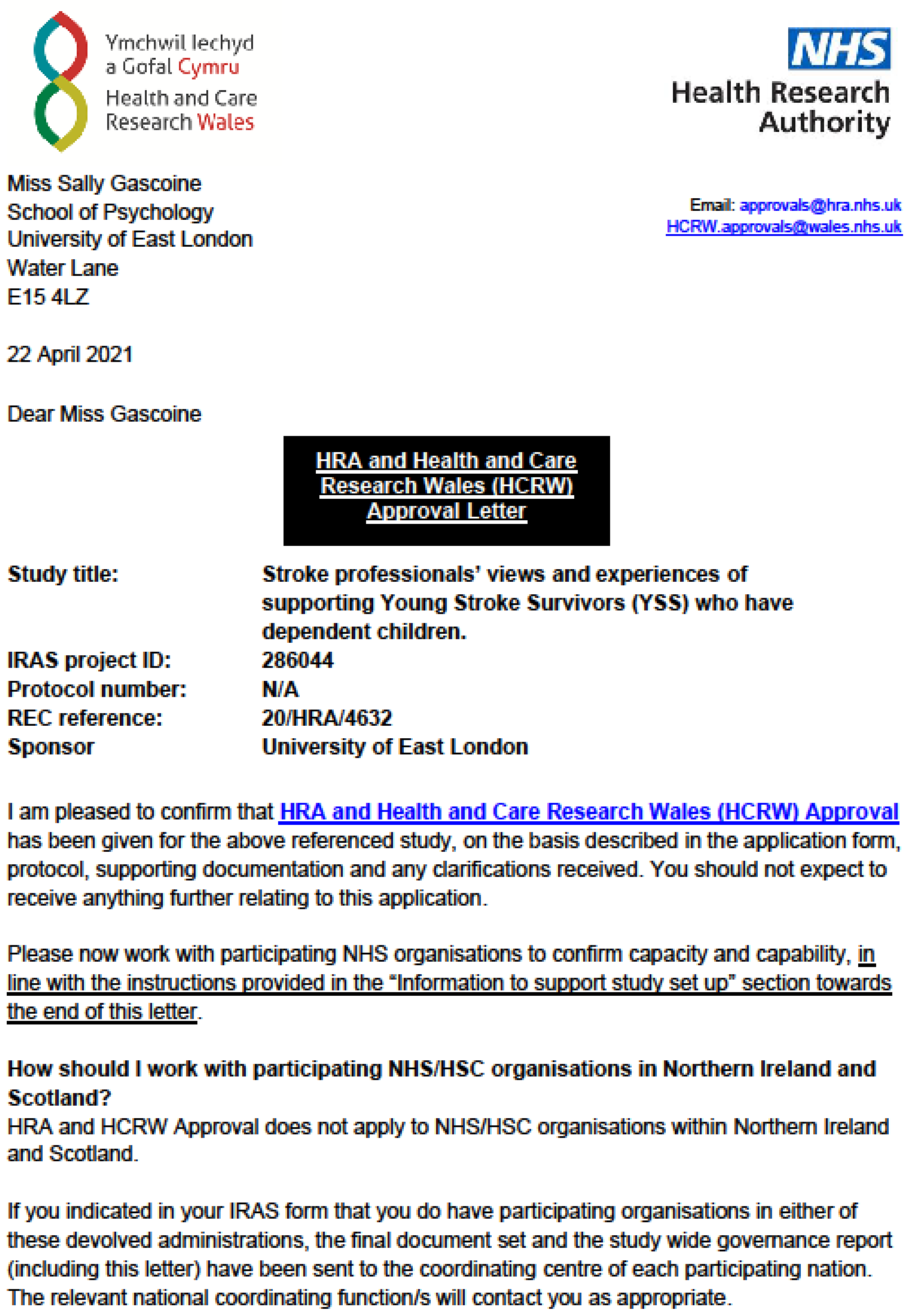
Yours sincerely,

Fernanda Silva

Fernanda Silva
Administrative Officer for Research Governance
For and on behalf of
University Research Ethics Sub-committee (URES)
Email: researchethics@uel.ac.uk

APPENDIX E

Letter of HRA Approval (first page)



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

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

Miss Sally Gascoine
School of Psychology
University of East London
Water Lane
E15 4LZ

22 April 2021

Dear Miss Gascoine

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

Study title:	**Stroke professionals' views and experiences of supporting Young Stroke Survivors (YSS) who have dependent children.**
IRAS project ID:	**286044**
Protocol number:	**N/A**
REC reference:	**20/HRA/4632**
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.

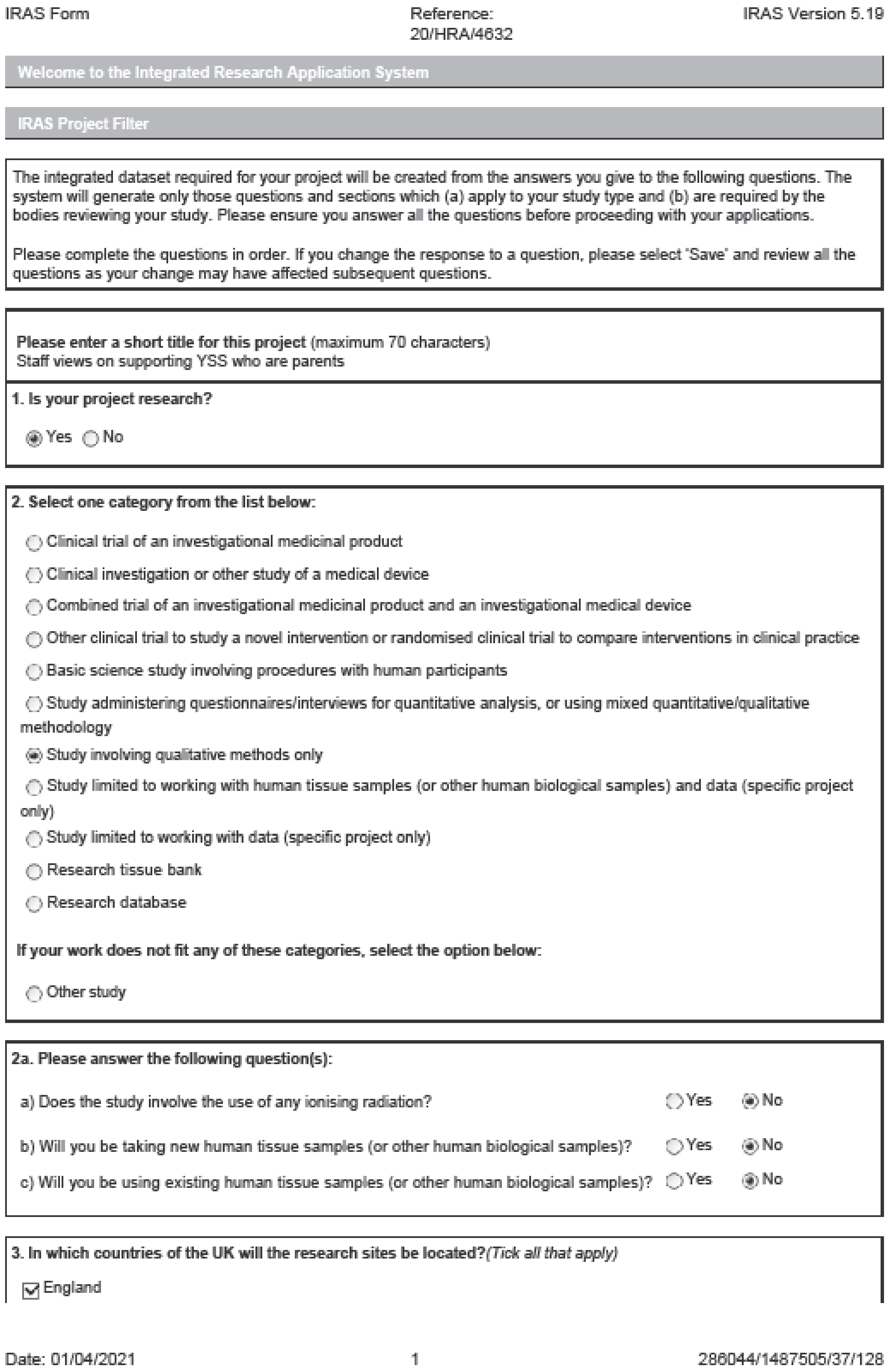
Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

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.

APPENDIX F

HRA Ethics Application Form (first page)



IRAS Form

Reference:
20/HRA/4632

IRAS Version 5.19

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Staff views on supporting YSS who are parents

1. Is your project research?

● Yes ○ No

2. Select one category from the list below:

○ Clinical trial of an investigational medicinal product

○ Clinical investigation or other study of a medical device

○ Combined trial of an investigational medicinal product and an investigational medical device

○ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice

○ Basic science study involving procedures with human participants

○ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

● Study involving qualitative methods only

○ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)

○ Study limited to working with data (specific project only)

○ Research tissue bank

○ Research database

If your work does not fit any of these categories, select the option below:

○ Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation? ○ Yes ● No

b) Will you be taking new human tissue samples (or other human biological samples)? ○ Yes ● No

c) Will you be using existing human tissue samples (or other human biological samples)? ○ Yes ● No

3. In which countries of the UK will the research sites be located?*(Tick all that apply)*

☑ England

Date: 01/04/2021 1 286044/1487505/37/128

APPENDIX G

Participant Information Sheet

PARTICIPANT INFORMATION SHEET

V 2.0 28/01/21

You are being invited to participate in a 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 and talk to others about the study if you wish.

Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Research Project Title

Stroke professionals' views and experiences of supporting Young Stroke Survivors (YSS) who have dependent children.

Who am I?

I am a Trainee Clinical Psychologist, studying at the University of East London. As part of my doctorate I am conducting the research that you are being invited to participate in.

What is the research?

I am conducting research into the experiences of Early Supported Discharge (ESD) team staff members working with or who have worked with Young Stroke Survivors (YSS) who have dependent children. The research aims to gain an understanding of how ESD staff members experience working with Young Stroke Survivors (YSS) who have dependent children and how staff members describe their experience of support that facilitates their work.

The research has been reviewed and has approval/management permission for the NHS (ethics and R&D). It has also been approved by the School of Psychology Research Ethics Committee. This is to protect your safety, rights, wellbeing, and dignity and means that the research follows the standard of research ethics set by the British Psychological Society.

Why have you been asked to participate?

You have been invited to participate in my research as a member of staff in an ESD service who I feel could help me explore my research topic. I am looking to involve clinical staff including psychologists, speech and language therapists, occupational therapists, support workers, physiotherapists, and nurses.

You are quite free to decide whether or not to participate and should not feel coerced.

What will your participation involve?

If you agree to participate, we will arrange to meet virtually via Microsoft Teams at a time convenient for you.

We will meet once for approximately 45-60 minutes.

I will ask you some questions about your experience of working with YSS who have dependent children and your experience of support that facilitates your work. You do not have to answer any questions you do not feel comfortable answering.

I will audio record the interview on a Dictaphone and using Microsoft Teams, so that I can listen to you fully without having to take notes. I will transcribe the recording of our interview and then delete the recording.

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 this area of stroke research and practice.

How will I use information about you?

I will need to use information from you for this research project.

This information will include:

- Your name
- Your contact details
- Your age, gender, and ethnic identity
- Your professional role

- Number of years working for the Early Supported Discharge Service (in time ranges)
- Number of years working for stroke services as *[professional role*] (in time ranges)

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. The anonymised transcript of your interview will only be seen by me and the research supervisor. Your anonymised data will be stored securely using UEL drive and cloud storage.

Once I have finished the study, I will keep some of the data so that I can check the results. I will write any reports in a way that no-one can work out that you took part in the study.

What are your choices about how information is used?

The information you provide during the interview will be kept confidential and will not be shared with any other members of the ESD team, including supervisors. However, in line with good clinical practice, if I was to become concerned about anything we discussed together, i.e. if I felt there was a risk to yourself or others, I may need to break confidentiality. I would do my best to speak to you about this first.

You can stop being a part of the study at any time, without giving a reason. 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 data being collected. After this time the data analysis will begin, and withdrawal will not be possible.

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 is used?

You can find out more about how I use your information by asking one of the research team or by sending an email to u1136024@uel.ac.uk.

Contact Details

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

Name: Sally Gascoine
Email: u1136024@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Dr Amy Bartlett. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: a.l.bartlett@uel.ac.uk

or

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

APPENDIX H

Consent Form

CONSENT FORM

V.2.0 28/01/21

Stroke professionals’ views and experiences of supporting Young Stroke Survivors (YSS) who have dependent children.

Please put your initials into the box

1. I confirm that I have **read and understood** the information sheet dated 28.1.21 (Version 2.0) for the above study. I have been able to think about the information. Any of my **questions have been answered** fully. I understand what is being proposed and the procedures in which I will be involved have been explained to me. ☐

2. I understand that taking part **is voluntary**. I am **free to leave the study at any time** without giving any reason and without my medical care or legal rights being affected. However, the researcher reserves the right to use my anonymous data after analysis of the data has begun (if it is three weeks or more after the interview). ☐

3. I understand that the data the researcher collects will be **stored anonymously** (during and after the study). This means that the data will not be able to be traced back to me. I agree that the information collected about me can be examined and stored for up to 2 years. ☐

4. I understand that in the event that the researcher was concerned about my welfare or the welfare of others they may need to break confidentiality. They would do their best to discuss this with me first. ☐

5. I agree that the researcher can contact me when the research has been written up to let me know the findings of the research. ☐

6. I agree to take part in this study. ☐

Participant’s Name (BLOCK CAPITALS)

…………………………………………………………………………………….

Participant’s Signature

……………………………………………………………………………………..

Researcher’s Name (BLOCK CAPITALS)

……………………………………………………………………………………..

Researcher’s Signature

………………………………………………………………………………………

Date: ……………………..…….

APPENDIX I

Participant Debrief Sheet

PARTICIPANT DEBRIEF SHEET

Thank you for participating in the research study on the experience of Early Supported Discharge (ESD) team members working with Young Stroke Survivors (YSS) with dependent children. By talking to me you have helped me to understand your experience of working with YSS who have dependent children.

If you feel upset or uncomfortable by anything that we discussed please speak to your supervisor who may be able to help you with this. Alternatively, please contact myself or the research supervisor on the contact details below.

If you continue to experience distress, please contact your GP or local Improving Access to Psychological Therapies (IAPT) service. In addition, you could contact the Samaritans on 116 123 or MIND on 0300 123 3393.

If you decide you do not want your information included in the study write up, please contact me by three weeks' time.

Once I have written up the study, I will get back in touch with you to let you know the findings of the project if you have given me consent to do so.

Contact Details

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

Sally Gascoine: u1136024@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor: Dr Amy Bartlett, School of Psychology, University of East London, Water Lane, London E15 4LZ, Email: A.L.Bartlett@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee:
Dr Tim Lomas
School of Psychology, University of East London, Water Lane, London E15 4LZ.
Email: t.lomas@uel.ac.uk

APPENDIX J

Coded Excerpt of a Transcript

Participant 1 Coded Transcript (from line 224)	**Code**
I: Umm, yes, so thinking about young mums as you said, or dads, this research is thinking about people with dependent children. So people who have had a stroke and have children at home. Can you tell me about your experiences of working with younger stroke patients with children	
P: So it doesn't? It doesn't, in my experience, it hasn't happened that often in the sort of four and a half years I've worked in this team. Surprisingly. But two, two situations really stick out in my memory	Young families stick out in my memory
and one is quite recent of a young woman in her 30s who had a massive, massive stroke and she had a child of five and just literally in the blink of an eye, life changed for her, and she needed all disciplines, and she needed a full care package, and she'd been away in a rehab centre for a long time, maybe, maybe, about seven months, because she's so young. So, so you can imagine there was, not only did she need to be physically rehabilitated, cognitively, speech.	Suddenness - blink of an eye life changed
She also had a relationship change with husband who was propping up this family	Changes to family relationships after stay in rehab
a little 5 year old who mummy is not talking, and Mummy doesn't look the same.	Mummy has changed - what the children notice
Plus you've got relatives supporting hubby and child.	System - thinking about family as a whole
I mean, everything was just, it was just, really sad.	Emotional impact for staff - it was really sad
Umm, and another one, there's an older child, so the child was 16. So this 16 year old, four years before, had been the person to call the ambulance for one parent who'd had a massive stroke, who'd rehabilitated one parent and seen massive changes, and then the same thing happened to the other parent, and she had to call the ambulance again for second parent.	Thinking about the child's experience and the impact on them - they've seen massive changes
Massive stroke, massive changes	Stroke causes massive changes
and that was really sad	Emotional impact for staff - it was really sad
She, she was 16 and embarking on college and it was me she confided in to say she couldn't do it anymore.	The child confided in me Holding a lot for the family Thinking about life stages of child
I: Oh really..	
P: So, I don't know where you want me to talk about how we supported them because umm with the older person,	Role of supporting parents to support child

with the older child, it was about supporting the parents to support her	
and getting psychology involved and, and I mean I, I even contacted safeguarding to see what support we could get that person	Liaising with safeguarding to ensure wellbeing of child
because she was almost having to come in and adult and do and make adult decisions and to care for two parents where she was at least very difficult developmental age. Yeah she had to put, to put collage on hold.	Thinking about role changes/developmental stage of child - child becomes the adult. What informs how we think about childhood - what children should and shouldn't do.
The other little one, umm, we did a lot of work. Actually, the husband and the family were absolutely brilliant	Impact on therapy when supported by the family system
but out of everything, the one thing that really upset me was that the patient needed to tell the child off because she was banging her computer and, but she was aphasic and she had to use nonverbal	Not being able to perform key aspects of parenting due to difficulties
and, and I as a parent myself I, I thought that's really hard, how do you, you know you can love somebody and you can snuggle in bed and you read them stories and they can read you stories and you can play with the child of five but how do you chastise, when you're nonverbal and you've got difficulty walking and you've got all these people that are alienating you	Understanding gained from being a parent myself - understand what is hard
I really found that bit hard.	Emotional impact of work - upsetting - I found that bit hard
I: Yeah, and I think that's, that's a really interesting point, actually, because it's like what is parenting, and you know, you've mentioned there are so many different roles..	
P: yeah, exactly many aspects to being a parent, and that's what you think of initially as a parent, the cuddles, the love, but the younger child that I talked about, she, the patient, her goal initially was to make that child it's lunch box, okay, for school, but actually as we, as we worked with her, she, she, she eventually we got her to the school gates to pick the child up,	Goals around parenting/looking after children
but that caused all sorts of problems because, because it alienated her from the mums, and they didn't know how to talk to her and she didn't know how to talk to them.	Secondary difficulties - alienation - unique to YSS
And it was like, it was a really big piece of work.	It was a really big piece of work
But I got that because I used to stand at the school gates, and it was me.	Understanding as parent and using that to be flexible with goals, build on, anticipate further challenges, or focus to the work
the speech therapist I worked with didn't have children and she went, "Oh my goodness, I hadn't even thought	Awareness and support of colleagues who may not

about those implications ” and I said that’s because that’s where all your social activities are made, all your invitations and that’s where you encourage those social skills for your child as a parent	understand aspects of parenting
I: So you used your experience as a parent to think past and around some of the goals and what some of the implications might be?	
P: Yeah, yeah, and we had, in the end, the speech therapist and I, we made flashcards, so she could, she could say, ‘It’s okay, I’m me, I just can’t speak to you,’ and then, and so people..	Being creative and flexible with goals - building a parent’s relationships with other parents.
it was a really, really, interesting piece of work.	An interesting piece of work
I: And it sounds like a lot of the goals, thinking about that person centred approach, it sounds like a lot of her goals were about getting her parenting back [*unclear*]	
P: Yes, yes, absolutely, absolutely it was and umm, I’m sure you’re going to talk later about how to interact children into your therapy. I mean, that’s hard, in itself, especially if you’re not used to young children.	Including children in the therapy - hard, especially if not used to young children
So, I, I would think people that have not had experience of young nephews, nieces or whoever, yeah must really struggle with how to say.. they keep a very professional boundary, but actually children need you to just sit on the floor and they'll come to you if they want to. And the same way if they don't..	Professional boundaries - being flexible when working with children - sitting on the floor and letting them come to you
I: Yeah	
P: I mean I've had experience of paediatric OT as well so , I had learnt you know, or just as a mum, you learn that don't you, you don’t go to a child, you let it come to you,	Drawing on different professional knowledge - experience with children as an OT and as a mum combined
yeah, but it works, it works time and time again so	Doing what has worked previously when working with children
I: yeah, it's interesting like you say about sitting on the floor, because it's almost that sort of forcing of a bit of a flexible approach I guess. You said about the professional boundary, and children can kind of create a different situation and kind of encourage you to work in different ways..	
P: Yeah, yeah, you have to be. I think, as an [*professional role*] I tend not to.. I try to have.. I try to be friendly. I try to access that particular person. It depends who I'm working with	Person centred - I try to access that particular person
The older child, the other one in the other family needed, needed you to be the professional because you, you almost held it together as you walked in you created calm and organization for her in this array of disruption. So that was using a very different communication method.	Being flexible -offering calm and containing in the disruption
I: And when did you become aware that, that's what you were offering, the going in and offering that kind of calm and containing of emotions?	

P: I think, I mean, the first time I, I walked in, I thought wowser, umm, my goodness.	Walking into chaos, thinking wow
I: Hmm	
P: It was chaos, and, and I think I must have, I must have, I don't know Sally. I'll be honest I, I must have instilled some confidence in them for that young girl to say, “Please could you come and talk to me privately,” and she did, she pulled me away and we went into the hall and her bedroom and she said ‘I can't do it anymore, I’m struggling.’ And it was very quick, so she must have seen, she, I don't know she, I won't say that it's me personally, perhaps she saw uniform, perhaps it’s the authority. I don't know. I don't know what she saw, but she had enough confidence to ask for help and I was able to access it for her. And of course, once you access it then that's helpful or not.	Being a trusted figure for the child, helping them to ask for help Being able to access help for child
I: Umm, and how was it for you to have her ask you, to say that to you, “I can't do it anymore.”	
P: Oh it, it, it really does.. I think as a mum, it does.. you can't help but think I'm quite, I'm quite, the compassion. It's never left me in all the years I've worked in the NHS	Emotional impact - and as a mum- hard to see. Providing compassionate care
and you just, I just kept thinking this, this, this young person has seen one parent and now she's seen it again,	Holding child in mind - their experience of the stroke
exactly the same she's had to call an ambulance, and if you ever even had to do that for anybody, that is traumatic, but to have to do it for your parents …. and she, I mean, what must she have been going..	Holding child in mind - their experience of the stroke
and then to see the implications that her life might have to change in order to provide care and support and supervision for them where she had all this ambition .	Thinking about the changes/disruptions to the child's life
Yeah yeah, I, I have to say I struggled with it.	Emotional toil, I struggled with it
I: Umm	
P: And hence I, I approached my, I came out of there and, and I talked it through with the with the matron and I I went to children’s safeguarding . I talked to the family hub	Seeking support/talking it through with team and safeguarding
I mean I went [*gesture – hands in air*], it went, because I just needed help and I wanted it quickly for her as well.	Seeking support - as I wanted help for me and for the child
I: So it's like you, sounds like you needed a bit of support with it because it was hard, and it was..	
P: It was big, it was too much for one person to handle.	Too much to handle alone - needing the team to support/hold the work

APPENDIX K

Initial and Finalised Themes and Sub-themes

Tables Showing the Review and Development of Themes:

<u>Initial themes generated (*without* final naming)</u>

Higher Order theme	Sub theme
Stroke at a younger age	What staff notice
	Emotional Toil
	Nature of ESD
Support provided by the ESD team	Setting goals
	Common themes for YSS
	Supporting Parenting
	Family Processes
	Working with children
What helps/facilitates the work	Connections
	Learning and knowledge
	Approach
Barriers	Service factors

	Availability
	Impact of stroke

After review and discussion with the research supervisor, the following themes and sub-themes were defined. Final themes and sub-themes were then named. Some key changes include:

- Sub-theme 'Emotional Toil' moved from the first theme 'There is more to hold' and into the last theme 'Impact on staff'.
- Nature of ESD discarded but some codes related to this moved into 'The importance of Approach and Connection'.
- 'Common themes for YSS' deconstructed into other sub themes such as: 'Noticing loss and change in parenting'; 'Witnessing and holding complexity and change'.
- The sub-theme 'family processes' merged into the sub-theme 'Witnessing and holding complexity and change'.
- The higher-order theme of 'What helps/facilitates the work' deconstructed into the sub-themes of 'The importance of approach and connection' and 'Doing the best with what we have'.
- Sub-themes of 'service factors' and 'impact of stroke' removed from final analysis.
- 'It resonates with you' created as a separate sub-theme to 'Emotional toil'
- The sub-theme of 'Availability' was deconstructed and partially included into 'Including children'.

Final themes generated *with* final naming

Higher Order theme	**Sub theme**
There is more to hold	What staff notice **= Witnessing and holding complexity and change (renamed)**
	Noticing loss and change in parenting
	The uncomfortableness of seeing

Support provided by the ESD team **= Working into the complexity**	Setting goals **= Learning what's important**
	The importance of approach and connection
	Supporting Parenting
	Including Children
Impact on staff	Emotional Toil
	Doing the best with what we have
	It resonates with you