School of Psychological Sciences and Health

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Post-Stroke Dysarthria: The psychosocial effects on primary communication partners

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Contents

Abstract

Introduction: Dysarthria is a common speech impairment following stroke. It is probable that the impact of the communication difficulty will be transmitted to the patient's primary communication partners (PCPs). This research investigates the possible impact of dysarthria focusing on the psychosocial effects on the relatives.

Method: Six participants with a relative with chronic post-stroke dysarthria (PwD) participated in an interview and completed two rating scales, which included a rating of their quality of life since the stroke, taking into consideration the effects of the dysarthria and one for their general well-being.

Analysis and Results: Interview data was thematically analysed and rating scales were analysed using quantitative analysis. The varied forms of feedback provided complementary information. Thematic analysis of the interview data were configured around the relatives' understanding of stroke, in particular the dysarthria, and how this has impacted their lives. It also looked at how the relative is responding to the effects and their feelings on the dysarthria management. Three main themes identified were: 'Feelings', 'Relationships' and 'Stroke and Speech'. From this small sample there is some indication that PCPs are impacted by dysarthria post-stroke and indications that the severity of the dysarthria will determine the significance of this impact alongside the type of relationship which the relative has with the PwD.

Conclusions: With the current focus on the impact on PCP in stroke rehabilitation it seems relevant to be collecting information about how PCPs view the impact of post-stroke dysarthria on their own well-being. With evidence from other areas of stroke research indicating the impact of the psychological impact on the PCP, SLTs need to be aware of how this particular speech impairment may be impacting on the PCPs of their patients so as to indicate what intervention they may provide.

Chapter 1: Introduction

According to the Stroke Association (2012) 150,000 people a year have a stroke in the United Kingdom. One third of these will die as a result, one third will recover and one third will live with a disability resulting from the stroke. This leaves 250,000 people in the UK with a long-term disability due to stroke. Stroke is a traumatic event for the patient and for the family and will probably bring about unwanted changes to the patient that will require major adjustments for all the family (Tanner, 2008). A communication disorder is a common disability post-stroke and can leave the patient and family with a lack of ability to communicate effectively. This can lead to feelings of isolation for everyone. It is not only the patient who suffers from the impairment, the whole family is impacted (Tanner, 2008). According to Parr, Byng and Gilpin (1997) the stroke can affect the family in four main ways: communication, physical changes, emotional changes and role changes. As such, this research project endeavours to investigate the impact on relatives of a family member with post-stroke dysarthria.

In Scotland specifically, stroke is the biggest cause of acquired disability (Stroke Association Scotland, 2010) affecting between twelve and fifteen thousand people a year, thirteen thousand of those will be a first stroke. Around four to five thousand of those people will have one or more impairment caused by their stroke. A communication impairment can be one of the major consequences of a stroke (Long, Hesketh and Bowen, 2009).

Dysarthria is a motor speech impairment caused by neurological disturbances. Dysarthria is a common type of speech impairment following non-progressive brain damage such as a stroke (Mackenzie, 2011; Sellars, Hughes and Langhorne, 2005). According to Duffy (2012), who conducted an audit on dysarthria literature, 22% of dysarthria cases seen by speech and language therapists were caused by stroke. The disorder is ‘characterised by slow, weak, imprecise, and/or uncoordinated movements of the speech musculature’ (Yorkston, Beukleman, Strand and Hakel, 2010). Even though there is evidence of around 20% of individuals who have had strokes being affected with dysarthria (Warlow, Dennis, Van Gijn, Hankey, Sandercock, Bamford, and Wardlaw, 2000), the effects of this disorder are not well documented and there has been very little research involving caregivers. Not only does the disorder affect speech, but it can also cause the patient psychological distress (Brady, Clark, Dickson, Paton and Barbour, 2011). The person with dysarthria post-stroke (PwD) may struggle to express their needs and feelings properly (Brumfitt, 1999).

Dickson, Barbour, Brady, Clark and Paton (2008), researched patients' experiences of post-stroke dysarthria by interviewing them via a semi-structured interview approach. Through this research the impact of dysarthria was shown to extend further than just the speech impairment. The interviewees highlighted the psychosocial effect of the dysarthria. This included disruption to how they viewed themselves (self-identity), their relationships, fears of stigmatisation and social and emotional disturbances.

As the people who are most likely to be interacting with the person with dysarthria (PwD), the patient's primary communication partner (PCP) (their family and/or caregiver) is most likely to be aware of and affected by the communication difficulty. The isolation felt by the patient can be transferred to their PCP (Long *et al*., 2009). The effect of a relative's stroke on a PCP has been well documented. It is common for the PCP to suffer under the pressure of the high level of burden (Visser-Meily, van Heugten, Post, Schepers and Lindeman, 2005), leading to deterioration of their own health and well-being. Research in this area has focused on the effect of the stroke as a whole and where communication has been considered this has been in relation to aphasia (a language problem), rather than dysarthria.

Dickson *et al.* (2008) interviewed three carers whose spouses had post-stroke dysarthria. The results of these interviews suggested that the carers were uncomfortable sharing the effects of dysarthria on themselves and consequently diverted the focus to the impact on their relative. The necessity for a more in depth project, focusing solely on the PCPs, was recommended in order to develop better understanding of their needs and experiences.

Yorkston *et al.* (2010) state that *'spoken communication is fundamentally a social act in which ideas, feelings and information are exchanged'* (Pg. 307). The Oxford dictionary (2011) uses the following definition of communication:

- **the imparting or exchanging of information by speaking**, writing, or using some other medium
- **the successful conveying or sharing of ideas and feelings**
- **social contact**

As can be observed from this definition there are three tenets that are central to communication. The extent to which humans use communication within everyday circumstances cannot be overestimated. Therefore, existing successfully within our society relies on our ability to be effective communicators. In fact, it has been said that relationships are built on interaction (Wahrborg, 1991). Wahrborg states that *'socialisation is an integral element in the nature of humanity'* (Wahrborg 1991 pg.42.)

Without communication interaction is not possible, and without interaction then relationships are unable to be sustained. *'In this sense relationships are communication'* (Wahrborg 1991 pg.45.) Therefore, Wahrborg's view matches that of Yorkston e*t al.* (2010) that communication is integral to developing and sustaining relationships. There has also been some indication that there is a causal relationship between communication problems and social difficulties (Duchan, 2000).

The impact of stroke on a person's communication ability varies very much from patient to patient. The dysarthria may not be the biggest impairment for the patient (e.g. as compared to any physical impairment they may have), but this does not infer that it is any less debilitating. Previous research into communication in stroke has demonstrated how people with aphasia (PwA) are socially isolated (Parr, 2004) and through Dickson *et al's* (2008)*,* research it has become clear that this is the case for PwD as well. Some examples of the change in their social situations include having to give up work or not being able to interact with friends and family as before. The effects of dysarthria on speech can reduce intelligibility, therefore causing family, friends and strangers to have difficulty understanding them. The ability to offer their thoughts and feelings freely through speech is therefore inhibited (Brady *et al.,* 2011).

Brady *et al.* (2011) describe how changes in behaviour of the participant and their communication partner can further exacerbate the impact of the speech impairment. A change in behaviour, from the person who has the dysarthria, can augment the feeling of isolation, i.e. by not socialising with family or friends in an external environment. In fact they may actively avoid certain situations, for example, accepting an 'inferior' product when selecting items in a supermarket rather than asking for assistance, or by limiting the words they use when speaking to single word answers. However, a change in behaviour from other people will promote a greater intensity of isolation. For example, when someone is enquiring after the PwD, they may communicate with the PCP rather than with the PwD directly. Friends or family may communicate differently with the PwD post stroke by avoiding conversation or restricting the conversation to only a few topics (Dickson *et al.* 2008). Stroke, as with any other illness, can leave the patient feeling easily tired (Yorkston *et al*., 2010). This in turn will affect their speech as the effort they will need to use to make their speech clearer can be exhausting for them.

The National Clinical Guidelines for Stroke, UK (2012) establishes the importance of encompassing the needs of the family within stroke care. For speech and language therapists to meet the needs of PCPs within post-stroke dysarthria intervention they need a better understanding of the effects of the communication disorder on the PCPs well-being.

The current study will investigate the impact of post-stroke dysarthria on the PCPs. The PCPs will be interviewed and will complete questionnaires in order to find out how they about the communication disorder and the impact it has had on their lives.

Chapter 2: Literature Review

Introduction

As this research project is concerned with the effects of post-stroke dysarthria on PCPs, this chapter will discuss relevant literature associated with this topic with a particular focus on the PCPs. As there is limited literature on the subject as a whole, the literature being discussed in this review has predominantly focused on general or progressive dysarthria research and with other communication impairments, e.g. aphasia.

The main aspects included in this chapter are: the psychological response to stroke, psychosocial well-being and how this is impacted by stroke, the National Health Service current expectations and approach to supporting PCPs of PwD post-stroke, information provision for PCPs and the benefits of being a PCP.

The Psychological Response to Stroke and Post-Stroke Dysarthria

The effects of a stroke can be varying in number and significance. It is a sudden illness that can bring about drastic changes in a person's life. The person and their family will go through a series of changes in both their physical and psychological recovery (Alaszewski, Alaszewski, Potter, Penhale and Billings, 2003). These changes have been compared to the stages that people progress through when they are experiencing grief. An acquired communication disorder following stroke can change the person's and their family's perception of the person's identity (McGurk and Kneebone, 2013). The adjustment to these changes can be viewed as a grieving process for the life pre-stroke and acceptance of what life is like post-stroke (Green and King, 2009). How the PwD views himself impacts how the family sees him. Therefore, the effects of dysarthria on the person need to be discussed in order to understand possible changes in the family dynamics and relationships.

Self-identity is something that we use daily to describe ourselves. It is a complex concept that has many different levels. For instance, we may view ourselves as being a certain self, but striving to be another – an ‘ideal self’ (Brumfitt, 1999). Self-esteem affects how we view our self-identity, and this is influenced by evaluation of ourselves through our unique perspectives and through others, and is the overall value that one rates of oneself (Brumfitt, 2010). There is a possibility that there is a connection between low self-esteem and depression. However, whether it is a cause or a result of depression is still being debated. Brumfitt (1999) describes our self-esteem as being fairly constant, but with the possibility of being influenced over time, e.g. by positive or negative events in the person’s life. This researcher goes on to say that society will influence our self-identity as we are able to change by interactions with other people and our ability to understand perceptions of self. She makes a connection with the possible instability of our self-concept and disruptions in our psychological wellbeing. In order to have successful social interaction, having self-identity is necessary (Walshe and Miller, 2011). We are thought to measure our self-identity against other people, especially those who are important in our lives. It stands to reason that the most important people in our lives are our partners or relatives (PCPs). Changes in relationships or the nature of the relationship can change self-identity (Lubinski, 2001). These changes will be felt by both the PwD and the PCP.

The role of communication in evaluation and development of self-identity is important. Therefore it can be implied that a speech impairment can, or will, affect it. As our self-identity is linked to the roles that we play in everyday life, e.g. in our work or within the family, if we are unable to fulfil these roles post-stroke then our self-identity and self-esteem are likely to undergo change. Dowswell, Lawler, Sowswell, Young, Forster and Hearn (2000) state that patients post-stroke and their relatives are constantly comparing their current situation with their pre-stroke life. They are measuring the progress of their recovery to their pre-stroke ‘roles’. Whilst Dowswell and colleagues have considered the stroke as a whole, the current research is interested in how the PCP of a PwD will be comparing the current situation with pre-stroke. Could this lead to a feeling of loss for both of them and, furthermore, a process of grieving? Alaszewski and colleagues (2003) indicate that professionals working within the field of stroke rehabilitation describe the process of recovery, to both the patients and the relatives, using the psychological model of grief.

The grief response has different levels which a person may experience over a period of time. Tanner and Gerstenberger (1988) discuss the grief response of having a communication impairment (aphasia, apraxia and dysarthria) following stroke. Their paper is not based on any statistical analysis of data, but on what they have *"typically observed in patients with neuropathologies of speech and language"* pg 80. According to them there are three dimensions involved – loss of person, self and object. The loss of person encompasses the psychological separation that the individual and the family experience due to a loss of 'normal' verbal communication. This could be further compounded by any physical impairments that the individual may have. The loss of psychological integrity impacts on the individual's self-identity. Loss of object could encompass a change in living circumstances, e.g. within their house, or their job, and the consequent loss of personal objects that they are attached to.

The process of grief is not a simple reaction but *'a complex progression of emotional and intellectual adjustments to separation from something or someone valued'* (Tanner and Gerstenberger, 1988, pg 80). An important aspect of the grief response that individuals with post-stroke dysarthria may encounter is that it is not just something they, but also their loved ones, may be affected by. The PCPs may be grieving for the loss of the relationship that they had with the individual, for the person that they once were and for the person that they might have been (Brumfitt, 1999). They too have to adjust and accept this change in their relatives' communication ability and any subsequent consequences. They also have to accept their change in identity and self-concept as they may be now facing a new role – as a carer.

Antonak and Livneh (2005) have investigated the psychosocial response of a person who has a chronic illness or disability (CID). They describe the response that a person with a CID will go through as Shock, Anxiety, Denial, Depression, Anger/Hostility and Adjustment. Tanner and Gerstenberger (1988) describe specifically the grief response that a patient or a relative may suffer from following communication impairment as including one or more of the following four stages: Denial, Frustration, Depression and Acceptance.

The individual uses denial to prevent any psychological pain (Livneh and Antonak, 2005; Tanner and Gerstenberger, 1988). The PwD and their PCPs wish that the PwD was able to return to their previous selves, and they are unwilling to accept that this might not be possible. They are determined that they will be able to overcome their difficulties or that it is temporary and will go away spontaneously. Tanner and Gerstenberger (1988) state that an important factor here is that the individual has been given the correct information (by health professionals e.g. doctors or speech and language therapists) about their impairment and that they are building their denial based on this and not on misleading information. While is it hoped that correct information is provided at this point there is the possibility of someone who is supporting the PwD and the PCP, either medical or non-medical (i.e. a volunteer at a support charity or by the individual accessing the wrong information from the internet), providing incorrect information and, therefore, possibly false hope. The development of denial over misinformation would mean they would be unable to progress through recovery as they will never be able to accept something that is false (Tanner and Gerstenberger, 1988).

Frustration typically manifests itself as anger, which for someone who is unable to express this anger fluently, can be seen as difficult behaviour (Tanner and

Gerstenberger, 1988). Constant reminders of their inability to fulfil their previous roles, e.g. answering the telephone, will perpetuate their feelings of frustration for the PwD and for the PCPs as they all have to adjust to new roles with the family unit. With the realisation that they are suffering a significant loss to their communication ability comes depression (Tanner and Gerstenberger, 1988). Severity or length of depression will vary with each individual, some people will be able to move through this stage relatively quickly while others will languish in a depressive state. Depression is possibly a natural stage towards acceptance (Livneh and Antonak, 2005). Acceptance must be differentiated from resignation, with all patients and their PCPs striving towards this goal.

Bray (1987) explains in more detail the reactions that the PCPs may experience after their relative has had a stroke. Fear of the illness, in this case a sudden stroke which can develop into a chronic illness, is first. Their knowledge of stroke may be limited or misinformed and so they will not understand the possible impact of the illness, for example speech impairments such as dysarthria. They may not be able to accept responsibility for caring for the individual and as a consequence be unable to provide them with appropriate emotional support. As with the grief response described earlier, relatives may then experience denial, which will result in a negative effect on the recovery due to inappropriate care.

The next stage can be bargaining (Bray, 1987). This is when the PCP ‘bargains’ with the patient or the therapist to produce speech as it was prior to the stroke, as long as they themselves fulfil the role which is expected of them e.g. ‘if I support the PwD or complete therapy exercises with them, you (the SLT) will make sure they have speech comparable to pre-stroke’. The ability to recover fully to previous ability is not always possible and the PCPs may have unrealistic expectations of the patient and the therapist. Depression, as with patients, can develop next. This can lead to the cyclical behaviour of avoiding people because they are depressed or people avoiding them due to the depression, therefore limiting their social circle, which in turn will perpetuate feelings of depression. Mourning for the loss of the pre-stroke situation leads to the family beginning to accept the new one and with that the final stage, rapprochement. However, this development of the new family situation can lead to the loss of a role for the PwD within the family as they all define themselves with new roles and therefore filling all the previous roles of the PwD and not redefining their 'new' ones.

Post-Stroke Depression and the PCPs

The link between long-term health conditions, such as stroke, and depression is well documented (Naylor, Parsonage, McDaid, Knapp, Fossey, and Galea, 2012) for the person who has had the stroke. More recently the impact on the PCP has been investigated as well (Berg, Palomaki, Lonnqvist, Lehtihalmes and Kaste, 2005; Han and Haley 1999; Scholte op Reimer, de Haan, Rijinders, Limberg and van den Bos, 1998). With the move towards providing care at home, it is important for this to be acknowledged and dealt with by health professionals. Berg *et al* (2005) state that while depression in stroke patients has been examined extensively, research into the psychological effects on the PCP is still limited. Within the initial stages post-stroke the impact on PCP can be immense and Berg *et al* (2005) found that PCPs were more likely to show signs of depression earlier than the patient themselves. They suggested this may be due to the fact that PCPs will be more aware of the long term impact of the impairments in the acute stages than the patient. They found that stroke severity is also a significant determinant of PCP depression. If the PCP was affected by depression in the acute stages of stroke this would most likely be a determinant of depression long-term, for example, eight months post-stroke. Berg *et al* (2005) suggest that investigation of the PCP's medical, social and emotional needs to be completed within the general management plan of the patient.

Green and King (2009) interviewed 26 men who had had a minor stroke and their wives. Their research examined the experiences that the couples had in the first year following the stroke. The study focused on the impact of the stroke as a whole and did not look any specific area, for example, speech and/or language impairments caused by the stroke. Both the men and their wives discussed their feelings of loss and the change in their roles within their relationship. Particularly the wives indicated feelings of having to be vigilant to their husbands' health at all times. Looking at the information specifically from the wives they experienced a loss of independence and also a loss of social interactions as people stopped visiting and they were limited in their activities away from home. Even though the stroke was a minor, it is interesting to note that there had obviously been an impact on the both the carers and the patients. While this research is looking at the stroke as a whole it is relevant in indicating some of the feelings that carers may experience. They interviewed the participants several times over the year which shows the change in how the couples view the stroke through the recovery period. However, only wives were interviewed and so there is no male carer perspective to compare.

Recent publication of a Stroke Association document, Feeling Overwhelmed (2013), stressed the impact of stroke on the carer. The Stroke Association surveyed 2,700 people who had had strokes and their carers. Of the respondents 937 were carers. The carers filled out a survey either by using either an online or paper form. The questions asked required either yes/no answers or a rating on a scale (predominantly 'strongly disagree to strongly agree') in relation to a specific question, an example being, 'My relationship with the person who has had a stroke has suffered or changed'. The statistics taken from this research showed that 79% of carers had experienced feelings of anxiety and 56% had felt depressed. The figures also indicated that over time the pressure of being a carer had a negative impact on the carer's mental health with 48% of carers feeling stressed at three years post-stroke, increasing to more than 69% at seven years post-stroke. Both carers and the patient feel overwhelmed by the long-term emotional impact of stroke. They also feel unable to deal with the impact, with two thirds of carers stating that they had not received any support with depression from health professionals. They highlighted that the emotional impact of stroke was actually the most difficult area to cope with. As 50% of the carers have difficulty communicating with their partners due to a cognitive or speech and/or language impairment (i.e. aphasia, dysarthria or dyspraxia. It is possible, therefore, that the communication impairment could be having a negative impact on the emotional and psychological well-being of the carers. However, as the statistical data provided for the study is not split into groups of those caring for someone with a communication impairment and those without one, it is difficult to reach specific conclusions based on this research. Nonetheless, the findings of the study do point to the desirability of conducting further research into this area.

The Stroke Association (2013) have reached a significant number of participants. Therefore they have a wide range of views from carers. However, they are looking at stroke as a whole rather than focusing on a specific area. This has allowed different areas of the impact of stroke on carers to be highlighted. As they have used a survey they have been limited in the complexity of questions they can ask so the carers have answered generalised questions, but not more specific ones which a smaller scale study, using interviews or focus groups would be able to do.

It is clear that the family could feel the effects of the communication impairment in quite a drastic manner. It would therefore be remiss of speech and language therapists to not take their role within the rehabilitation process seriously (Yorkston *et al*., 2010). The family equilibrium relies on being seen holistically and the individual must be treated as part of a whole (the family) and not independently (Luterman, 2001). The family are the people who will most frequently provide the patient with an opportunity to interact and how they go about this will affect the patient's rehabilitation.

Psychosocial Well-Being

Psychosocial well-being refers to how the mind and body adjust in relation to the social environment (Oxford Dictionary, 2011). This adjustment can occur in a conscious or subconscious manner.

The effects of an acquired communication disorder will be different for each patient (Brumfitt, 2010) as will their response to the resulting impairments. Everybody is an individual and so how they react to different situations will also be individual. If each PwD reacts differently to the communication disorder, then this is likely to be true for the PCPs as well. However, in order to grasp a general understanding of how patients and their PCPs will react, certain parameters need to be outlined. This will allow the data to be viewed in a consistent manner.

Normally the most significant recovery after stroke occurs in the first three months, but with continued support and rehabilitation patients can continue to show improvement for up to a year (Tilling, Sterne, Rudd, Glass, Wityk and Wolfe, 2001). After this point most patients' recovery will plateau. However, it is possible that there could be some recovery post the twelve month period, although it is likely that these improvements will be quite small.

The development of the patient's presentation will therefore affect how the relatives cope over time. Anderson, Linto and Stewart-Wynne*,* (1995), state that *"caregiving is a dynamic process"* (Pg. 7). In the acute stage the relatives will be in a state of distress and very likely traumatised due to the suddenness of the patient's stroke. Once the patient starts the recovery process they will then have to cope with the consequences of the impairments that the patient may have and how they will live once they have returned home from the hospital environment (Brumfitt, 2010). The long-term effects of a chronic disability caused by stroke are likely to have an adverse impact on the patient's well-being. However, not only the patient will feel the effects, but the relative can also be left with feelings of uncertainty and despair as the continuing implications of the disabilities become apparent (Pound, Parr and Duchan, 2001). Under the current health care structure in Scotland, relatives can be left with a large proportion of care-giving that the patient requires. The sudden effects of stroke can leave both patient and relative unprepared for such a change to their daily living (Rombough, Howse and Bartfay, 2006).

The existing literature which discusses the effects upon carers of stroke patients acknowledges there are many different factors involved in causing difficulties for the carers. Intervention for carers, in their own right, has been highlighted (Lui, Ross and Thompson, 2005; Low, Payne and Roderick, 1999; Anderson *et al.*, 1995) as they can experience a significant burden in the caregiver role. If appropriate intervention is not provided then this could cause any family support mechanism that has been provided for the patient to breakdown (Mackenzie, Perry, Lockhart, Cottee, Cloud and Mann, 2007). Anderson *et al.* (1995) investigated the long-term burden and impact of caring for someone post-stroke. They assessed 84 carers using sections of the Social Behaviour Assessment Schedule (SBAS), the Hospital Anxiety and Depression Scale (HADS) and the General Health Questionnaire 28 (GHQ-28). Of the 84 carers assessed 49 were spouses, 27 children and 7 other relatives (including siblings, nieces, nephews and grandchildren) and one neighbour. 82% of the participants were female. The carers reported that there was an adverse effect on family relationships. 79% of the carers reported emotional ill health and disruption to their social activities due to the burden of caring for the patient post-stroke. The researchers found that the emotional stability of the patient could be affected by the ability and readiness of the carer. This in turn affected the patient’s recovery. From the literature patient-carer mood interacts with motivation and general psychological state impacting either positively or negatively on the patient’s and carer’s health and well-being. In Dickson *et al*’s (2008) interviews, patients particularly highlighted the psychosocial issues caused by the speech impairment as more of an issue to them than the physical difficulty itself. If patients displayed negative behaviours e.g. apathy and lack of motivation for going on outings, this would have a negative effect on the carers (Anderson *et al*, 1995). In fact, in one study, carers rated negative patient mood as being the most stressful aspect of caregiving (Haley, Allen, Grant, Clay, Perkins, and Roth, 2009).

Another area highlighted by Anderson *et al*, (1995), was that the age of the carer also affected their ability to provide care. As most of the carers in their study were middle-aged or elderly, they were more likely to have pre-existing health difficulties which would limit the type of support that they were able to provide.

The isolation felt by carers cannot be underestimated; with the pressure on them to provide care they may feel unwilling to share their difficulties or anxieties. More specifically, carers may feel a reluctance to express their concerns (given they are not the individual with dysarthria) or they are experiencing feelings of guilt because they are struggling to fulfil the expected carer role (Dickson *et al*, 2008; Anderson *et al*, 1995).

The World Health Organisation (1997) definition of quality of life is *"an individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". (Pg 1).* There are several different terms that are assigned to describe this area of research – well-being, psychosocial well-being, quality of life are just a few examples. It can be difficult to tease apart what each term encompasses as researchers tend to use them interchangeably.

The World Health Organisation extends this to cover the many different areas that they consider to affect a person's quality of life. Included within these are physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment. The complex interaction of these different areas means that it is difficult to disaggregate them. However, in terms of this research the psychological state, level of independence and, most importantly, social relationships will be the main focus.

Walshe (2003) investigated the effects of acquired dysarthria on the patient's self-concept. Any patients with aphasia or cognitive impairments were excluded from the study. Of the 31 patients taking part in the study 71% were suffering from progressive conditions, while 23% had post-stroke dysarthria. The participants rated their self-concept using the Head Injury Semantic Differential (HISD) Scale (Tyerman and Humphrey, 1984), which has been used in previous studies with head-injury and stroke patients to show changes in self-concept. The adjective pairs used in the HISD were thought, by the author, to be relevant to the dysarthria population. They rated themselves on their past self and their present self, with the results showing that there was a significant difference between their ratings for their past and present self scores. This would indicate that the PwD felt that there had been a negative impact of the dysarthria on self-concept. Within the twenty concepts on which the patients rated themselves Walshe highlights, amongst others, them rating themselves as less capable, dependent, less confident and less in control. The majority of the participants in this study had progressive conditions, therefore it is difficult to know to what extent these findings are relevant to the post-stroke dysarthria population. However, this is something that Walshe has acknowledged and suggested as an area for further investigation.

If a patient with post-stroke dysarthria was to experience these changes in self-concept that Walshe (2003) has described this would most probably have a knock on effect of their personal relationships. Taking into consideration the different aspects of quality of life, social relationships being one of them, having a negative view of your ability to contribute to these relationships must affect the other party, e.g. the PCP, as well.

More recent research, using a questionnaire looking at 'Living with Dysarthria', supports the view that negative self-image affects communication (Hartelius, Elmberg, Holm, Lovberg and Nikolaidis, 2008). 55 participants took part in the study, 53 of which had dysarthria due to a progressive condition (e.g. Parkinson's disease or multiple sclerosis), 1 due to a stroke and 1 due to a traumatic brain injury. As most of the patients taking part were diagnosed with progressive neurological disorders this must be taken into consideration when comparing the results with patients with stable dysarthria i.e. dysarthria post-stroke. The authors did not discuss the results in relation to stable dysarthria, but focused more on the impact on progressive conditions. However, there are many interesting factors that have been highlighted. Their findings are consistent with Dickson *et al*. (2008) in that effort and fatigue were a main cause of difficulty as was the familiarity and number of the communication partners. Severity of dysarthria did not appear to predict the effects on the individuals, i.e. the more severe the dysarthria the more difficulties they would have, which was also consistent with Dickson *et al*. (2008) who found that even individuals with difficulties that SLTs would consider mild, still felt the speech difficulties had a negative effect on their communication. Hartelius *et al.* (2008) found that it was the moderate group who had the most difficulties rather than the severe. Their reasoning for this was the possibility that people with moderate difficulties are more likely to be within social situations more frequently than people with severe difficulties, but this was only supposition as this was not investigated. However, they did state that, *'there seems to be no unequivocal relationship between severity of dysarthria and perceived communication difficulties'* (Hartelius *et al.* 2008 pg. 18.)

All these studies (Hartelius *et al.* 2008; Dickson *et al*. 2008; Walshe 2003) very much focus on the patients and their experience of dysarthria. The paucity of literature for the impact on the PCPs makes it difficult to discuss how caring and interacting with someone who has dysarthria post-stroke is affecting them. However, as discussed in chapter one, Dickson *et al*. (2008), did interview three relatives in their research. The feedback from these interviews indicated that the relatives were uncomfortable about talking about their experiences and wished to focus on their spouses' dysarthria rather than talk about the impact on themselves. Dickson *et al*.

(2008) interviewed 28 PwD, 20 of which had a spouse, partner or friend who was caring for them. They reported that they had hoped to gather information from these relatives via focus groups but only the three spouses agreed to take part so they were interviewed. The information provided in the paper was limited to one paragraph. Obviously this is not enough to indicate what the needs of the relatives were in this instance, but the authors felt that this was something that needed to be investigated further.

Dysarthria, Psychosocial Well-Being and the Impact on Relationships

A PCP's lack of knowledge about dysarthria could affect their ability to produce a happy and effective communication environment. The change in "rules" for communication can be difficult for PCPs to accept. For example, it is expected that in conversation two adults are to take equal roles within that conversation. A speech impairment can cause these roles to change and for the roles to become unequal with the PwD possibly taking a more passive role than previously (Comrie, Mackenzie and McCall, 2001). Comrie *et al.* (2001) analysed conversations of five people with post-stroke dysarthria and compared them conversations of 19 non-brain damaged individuals. They found that the PwD did not participate as much in conversations using more minimal turns and shorter major turns that the non-brain damaged participants. While the patient will have fears and anxiety about speaking brought about by the dysarthria, so will the PCP. There may be negative attitudes attached to the person with dysarthria as they are now stigmatised by a disability (Brady *et al.*, 2011). Not only are the difficulties based in the lack of knowledge of the condition, but they are also affected by fear of embarrassment, both their own and for the patient (Lubinski, 2001).

Strategies are ways that the patient and their communication partner may change their interaction to enable it to be more successful e.g. sitting closer together and facing each other, trying to be in a quiet environment, give the person time to complete what they are trying to say, stay on topic etc. Without these PCPs may start to avoid communicating with the patient (Lubinski, 2001). Friends and family may also start to distance themselves as they fear the uncomfortable and embarrassing situations that might occur. This behaviour is a two way street, with the patient avoiding situations where people are not able to understand them, but pretend that they do and relatives keeping away so that they do not have to go through the pretence of understanding what is being said or showing their lack of ability to support the patient in successful communication (Dickson *et al.,* 2008).

Society dictates that as adults we should be able and successful communicators. Having to live with the anxiety of not being able to fulfil this role can lead to stress for the PwD and their relatives. As the patient has what is classed as a disability there is every possibility that they will face stigma and stereotyping (Lubinski, 2001). Furthermore, as the individual has had a stroke they may have a form of physical disability as well. This could further impact their situation, as possible communication partners may feel certain anxiety about the visible difficulties (e.g. facial paresis or hemiparesis) as well as the speech impairment.

Relationships within families also do not hold the same boundaries that people have with friends, acquaintances and strangers. Social constraints dictate the way that we interact with people outside of families. While we may feel able to be more honest with our family members, when communicating with friends we are more likely to moderate our true opinions (Lubinski, 2001). Feelings can be expressed within families that may not be possible in other relationships. It is possible that frustration is more likely to be expressed within the family and the complex nature of families can lead to many different complications in the rehabilitation process (Lubinski, 2001). Having unrealistic expectations of the patient's recovery, fluctuating between being supportive and not providing opportunities to communicate effectively or by speaking for the patient and thereby taking away their independence, can all compromise the improvement of the PwD speech skills.

Educating and supporting the family is therefore a necessary element within successful rehabilitation.

National Health Service (NHS) and Caregiving

It is projected that within the next 25 years Scotland's population will consist of 1 in 4 people being an older person (over 65) and 1 in 12 being over 80 (Scottish Executive, 2006). With an ageing demographic it is conjectured there will be an increase in long-term conditions, for example, disability due to stroke. In 2005 the Scottish Government developed a policy called Delivering for Health (Scottish Executive, 2005). Changes have been implemented within the Scottish NHS system in order to pre-empt the impact that the change in population will cause on services within the NHS. Treating people faster and closer to home is one aspect. Management of long-term conditions and encouraging people to take control of their own health and their own care with support is another. All services within the NHS have to be able to fulfil their role within this policy.

Delivering Care, Enabling Health (Scottish Executive, 2006) is the policy for nursing, midwifery and allied health professionals (within which speech and language therapy (SLT) is included). From the SLT perspective, this policy builds on earlier work called Building on Success (Scottish Executive, 2002), which was focused on providing care that was of high quality and patient centred, and, therefore, specifically providing support where possible to prevent hospital admissions and helping patients to live as independently as possible.

Allied health professionals work within multi-disciplinary teams to ensure that the patient is able to access the best possible care available. Each allied health professional (AHP) brings a specialist skill to the rehabilitation of the patient. In order to provide an effective service, feedback from service users has highlighted that the AHP must be able to provide both emotional support and empathy

(Scottish Executive, 2006). This includes providing care which is based on people's rights. There are many aspects to this, but in relation to the current study the most important one being is *'the respect for families and carers and the contribution that they make to patient care'* (Scottish Executive, 2006, pg. 13).

While SLTs work within multi-disciplinary teams to provide the care needed to their patients, it has long been acknowledged that patients and their family/carers must be included as integral members of this team. They are to be considered partners and not passive recipients (Scottish Executive, 2006). They should be provided with the best possible information to allow them to reach informed decisions about their care. In addition, their social and emotional well-being also needs to be considered and supported.

Patients and their families/carers are therefore an integral part of the rehabilitation process and long-term outcomes of patients' care. Of course there will be an impact on the patient's situation as they deal with a long-term condition such as stroke. However, their relatives are also expected to play their role within the healthcare system. While many carers have highlighted that they find giving their relatives the best possible care rewarding, it cannot be denied that there is substantial pressure and challenge being presented to them on a daily basis when having to face the long-term impact of their relative's condition (Buckner and Yeandle, 2011). In fact it has been suggested that the economic value of informal caregivers within the UK is £119 billion per a year (Buckner and Yeandle, 2011). So while the NHS is moving towards a model of care within the community and at home how does this impact the long-term well-being of the families undertaking this burden? Research undertaken by the charity Carers UK (Buckner and Yeandle, 2011) indicates that carers do not feel this contribution has been recognised and their needs are not being met by the NHS. It is considered that the NHS has a substantial mountain to climb before it is able to realise the duty of care it has for carers. In fact, the carers surveyed in Feeling Overwhelmed (Stroke Association,

2013) indicated that less than a quarter of the carers felt supported when the patient leaves hospital. The Stroke Association goes on to say that patients and carers should be supported long term, no matter how long this takes. The carers in the survey indicate that their own health has deteriorated due to the lack of support required for long term post-stroke care. It can often be assumed that they will be the main carer and they expressed that this was sometimes taken for granted by healthcare professionals. While they are willing to provide a duty of care and love, sometimes their own health can suffer as a consequence. They feel that they are not provided with sufficient information or training and are left to learn as they go along.

The strain of long-term conditions, such as disability post stroke, on patients and their carers can seriously impact their physical, social, emotional and financial well-being (National Health Service in Scotland and Giles, 2007). It also puts a significant strain on NHS resources as patients with long-term conditions are more likely to visit their GPs or outpatient departments or to be admitted to hospital. Mental health difficulties, e.g. depression, resulting from long-term conditions could also impact the person’s ability to cope. The Scottish Executive’s framework for Adult Rehabilitation (National Health Service in Scotland and Giles, 2007) highlights the importance of acknowledging the patient’s and their relative’s expert view on their condition and how it impacts their lives.

The Scottish Government’s document, ‘Caring Together – The Carers Strategy for Scotland 2010 – 2015’ (Scottish Executive, 2010) outlines the key actions to be implemented within these five years to ensure that the needs of carers are met. Within this document they recognise carers as equal partners and by providing them with support early on, any negative impact on the carer’s life due to their caring role would be prevented. In total there are ten action points. Two points that are pertinent to the current study are: Firstly, carers’ feedback of the healthcare system and their experiences within it will be recorded and, secondly, clear instructions and information on treatment will be provided to ensure the patients and their carers are able to make informed decisions about their treatment.

Information for PCPs

There has been significant proliferation in the literature regarding the fact that carers/family require the correct information and at reasonable times within the care pathway (Greenwood *et al.,* 2009; Mackenzie *et al*.; 2007; IRISS, 2011). Frequently carers state that they have not been properly informed of the difficulties that the patient may present with or how they are going to cope with such problems (Stroke Association, 2013). However, this is something which is very much at the forefront of the National Health Service (NHS) today, with guidelines stating that all health care professionals are supposed to should include family and carers in the decision making process and keep them well informed of the difficulties that they may face (RCSLT, 1996).

The lack of knowledge about the patient's difficulties can cause long-term problems for the carers. As outlined in the grief response section (page 13), in order for the patients and their carers to accept their new situation they have to form their basis of understanding of the difficulties on the correct information. Any misunderstanding can cause them to have grave misconceptions about the recovery the patient will experience (Wahrborg, 1991). Without being able to accept their situation, carers could suffer long-term feelings of anxiety or depression. This in turn can lead to a negative effect on the patient's ability to communicate successfully.

While professionals have much relevant information to impart to patients and carers, the knowledge that the carer has of the patient should not be underestimated. In some aphasia research it has been suggested that the carer's opinion about the severity of the patient's difficulties differed from that of the clinician. It was common for the carers to feel the severity of the patient's impairment was less severe than that felt by the clinician (Muller and Code, 1989).

Patients report that carers are quicker to understand them than people less familiar when they are speaking, and thus found communicating with them less effortful (Brady *et al*, 2011). Reasons given for why the carer is more able to understand are a shared understanding of interests and situations or that they were able to sit in closer proximity. Carers can become *'surrogate communicators'* (Brady et al, 2011 pg. 11) in the initial stages post-stroke. This could be due to the patient's lack of confidence in their ability to communicate effectively and so the carers step in to support them. As time progresses this surrogacy may become unnecessary and cause frustration for the patient. However, if managed properly, with a gradual withdrawal or with mutually agreed terms (e.g. specific times decided upon by the patient and the relative as to when it is appropriate for the relative to speak for the patient) the patient can begin to find their communicative independence again.

If supported properly and armed with the correct information and strategies a carer should be able to support the patient better than anyone. Their inside knowledge of the person and their environment provide them with a better understanding of the subtleties present in everyday communication. A speech and language therapist (SLT) can provide the relevant information to both the patient and their PCPs, but they would need to do this in a supportive and holistic manner. In order to provide it the SLT must reach the PCPs. Mackenzie *et al.* (2007) surveyed 37 carers of someone who had had a stroke. The carers identified that they would have been interested in more information about the stroke and the treatment than the patients. However, fewer than half the carers, whose relative was being seen for speech and language therapy, were included by or met with the therapist. Specific numbers for this group were not provided by the authors, so it is not possible to know, in terms of these research participants, how many people this information relates to. It is also important that the therapist is able to fulfil this role i.e. have the appropriate training to support the carers through the rehabilitation (Brumfitt, 1999). If there is to be an information programme developed it may be sensible to provide this as a multi-disciplinary approach with specialists providing information at different times. This would allow the professionals to support each other as well as the patient and their carers.

Benefits of Being a PCP

So far the discussion of the literature has focused on the negative consequences of caring for someone who has had a stroke, and more specifically, a communication impairment resulting from their stroke. However, occasionally in the literature there has been mention of the positive aspects of being a carer. Although there is a substantial burden placed on carers there have been reports some carers actually find satisfaction in the role and that their relationships have improved (Han and Haley, 1999). Previously any benefits that were highlighted by carers were considered to be a stage of denial. However, it is now thought that carers are adopting it as a coping strategy (Haley et al, 2009), i.e. as a possible acceptance of their new role.

In Green and King's (2009) research, wives whose husbands had had a stroke described positive changes to their relationships with their husbands. They indicated that they focused more on their relationship, being more open and appreciating other more. These studies are both focused on caring for someone with a stroke generally. There is currently no research in this area that is specific to dysarthria post-stroke.

The benefit of knowing the patient well allows the carer to understand cues and non-verbal communication that an acquaintance would not be able to decipher is also noted by the patients (Brady *et* al. 2011). Although there can be difficulties associated with boundaries, carers can have the ability to support the patient in communication providing them with the necessary encouragement to persevere and be successful.

Summary

Although research pertaining to the PCPs of a PwD is very limited, other studies in the area of stroke, aphasia due to stroke and dysarthria due to other conditions have indicated that it is an area that requires further investigation. Relationships are built on the feelings that people within that relationship have about themselves and about others. The literature has shown that communication impairments can impact how the person with the impairment and their PCP view themselves and this therefore has a cyclical impact on their relationship. Supporting PCPs through giving information, advice and strategies should provide them with the means to communicate effectively with the PwD. In order to fulfil this role the speech and language therapist must be fully aware of the needs of the PCP. While they currently are conscious of the fact that they can support them using evidence from research in other areas e.g. aphasia, it would be beneficial to have evidence relating specifically to the area of post-stroke dysarthria.

Aims

This project aims to investigate the effects of post-stroke dysarthria on the PCP's psychosocial well-being. Particularly, insight will be gained on:

- their feelings about the dysarthria and how that impacts them
- how their own relationships have been impacted both with the PwD and independent of the PwD
- how the PCP understands and copes with supporting the PwD

Chapter 3: Methods and Analysis

Within this chapter the research design will be described including the methods and subsequent analysis and why it was chosen. Information about how the participants were chosen, including their background and the background of the difficulties of their PwD. The project includes both qualitative and quantitative methods, the following sections outline the reasons why each of the methods were chosen.

Qualitative Research

The interventions used in speech and language therapy practice should be evidence based (Brinton and Fujiki, 2003). The use of quantitative methods to research speech and language therapy phenomena and types of intervention used is the most common approach. However, there are advantages of using a qualitative approach which quantitative means cannot provide. One advantage of using a qualitative approach includes being able to gather evidence in a natural setting (Brinton and Fujiki, 2003). Damico and Simmons-Mackie (2003) state that *"the first criterion is obvious: qualitative research is oriented toward social phenomena. As speech-language pathology focuses on human communication and social interactions of various kinds, this criterion may appear too obvious to state"* pg. 132.

Using qualitative methods to observe and analyse people with communication disorders allows for naturalistic view of what is occurring. If the effects of the communication disorder are viewed naturalistically and then this information is analysed in a way that allows for use in practice it will hopefully provide the most realistic approach in therapy. As communication is a behaviour and behaviours are influenced by context, using qualitative research approaches allows for the phenomena to be researched with these variables in mind (Damico and Simmons-Mackie, 2003).

It would be difficult to measure the experiences of the primary communication partners (PCPs) using only quantitative means. As already discussed in chapters 1 and 2 the lack of research in this area means that there are very few materials that would enable the measure of specific impact of post-stroke dysarthria. The formal assessments that exist are predominantly for use with the patient only and do not encompass enough detail to investigate the full extent of the effects of post-stroke dysarthria.

With the paucity of literature currently available, suppositions into the experiences of relatives of PWD can only be drawn from research in aphasia and progressive disorders. A qualitative approach allows the investigation to reveal the impact on PCPs through the collection of the data and subsequent analysis, which would ultimately reveal or demonstrate the participant's view.   This is known as the 'emic' perspective (Holloway and Wheeler, 2010). As there are six views being gathered these views can then be compared for patterns and similarities/differences in experiences.

Speech and language therapists collect information from a variety of sources when planning intervention in order to develop a holistic view of the patient. Speaking with the patient and their relatives is one method. This leads to an understanding of the impact of their difficulties on their everyday life situations. Furthermore, using interviews for research is a relevant approach in order to develop a thorough understanding of the relative's experiences of living with and/or supporting someone with post stroke dysarthria (Holloway and Wheeler, 2010). As health professionals, SLTs focus particularly on communication and interaction, which is in line with the 'person-centred and holistic approach' adopted by qualitative researchers (Holloway and Wheeler, 2010).

There are several advantages of including a qualitative approach when researching this area. Many of the experiences that humans have are dictated by the social constraints that they live in. While experiences in certain areas, e.g. aphasia, have been explored there are still new perspectives on the impact of dysarthria post-stroke to be gathered and discussed. Holloway and Wheeler (2010) state that "The basis of qualitative research lies in the interpretive approach to social reality and in the description of the lived experience of human beings." (page 3). The approach of qualitative research provides the participants' perspective and their experiences, which fits within SLT information gathering and client-centred therapy.

Collection of rich and in-depth data through interview allows for new theories to be developed and for current ones to be strengthened or contradicted (Holloway and Wheeler, 2010). Using another form of data collection, for example focus groups, is also possible for this type of research. However, the use of interviews allows for the participants time to answer questions honestly and freely, to reflect on their comments and ideas and for researchers to immediately clarify points made (Holloway and Wheeler, 2010). While focus groups may allow participants to use social interaction to generate new ideas or remember things that they may have forgotten, they may also be guided or influenced by other members of the group. The complexities of setting up and running such a group would require more skills than that of a one to one interviewer (Holloway and Wheeler, 2010).

As the theories are not predetermined, analysis of the interview data should reveal what the experiences of relatives of people with post-stroke dysarthria are and whether there are similarities and/or differences to other post-stroke communication impairments (e.g. aphasia).

Qualitative analysis is required in order to analyse the interview data. By selecting a qualitative approach the researcher is able to use a person-centred perspective (Holloway and Wheeler, 2010) which helps health professionals, speech and language therapists in this case, understand the individual person's experiences. It can be difficult to quantify people's experiences and feelings, so the use of this type of approach provides a way to describe them in a systematic manner. Thematic analysis has been decided upon for this research project as it is not bound in a theoretical framework (Braun and Clarke, 2006) but it still allows for a thorough presentation of the data. Braun and Clarke state that this method should be undertaken by novice qualitative researchers as it provides core skills for further qualitative analysis. Although qualitative analysis is a relatively new skill for the researcher, it was deemed to be the most relevant approach, and as she had used it previously in a supervised project, she felt confident about using it independently.

This method allows for identifying, analysing and reporting patterns with the data (Braun and Clarke, 2006). There are two types of analysis within this framework, inductive and theoretical. Inductive allows the data to be analysed into themes without preconceived ideas or a pre-existing coding framework , i.e. analysis is data-driven. Theoretical thematic analysis is motivated by the researcher's research question. This can mean that the analysis consists of one particular area of the data rather than the data as a whole. The method chosen here is the inductive analysis. While the researcher may have had some preconceived ideas due to general training in SLT and from reading about the effects of other communication impairments on relatives, the views of PCPs for PwD has not been researched previously and so there are no other thematic frameworks to base analysis on.

Quantitative Data

Using a qualitative means of data collections allows for the phenomenon to be investigated in a data rich context. However, this does not mean that there is no place for a quantitative means of data collection within a qualitative study. Brinton and Fujiki (2003) state that *"using qualitative and quantitative methods in an ongoing research programme can build a body of evidence that is both enlightening and helpful"* (pg. 168). The reasons for using quantitative methods alongside the qualitative were that the views of the relatives would be presented in a more robust way by using the questionnaires to support or refute the opinions gathered from the interviews.

The GHQ-12 was chosen to provide a means of assessing the PCPs general well-being. It has been adapted from the original General Health Questionnaire (GHQ) (Goldberg and Williams, 1988) for use in clinical settings which do not have time to complete longer versions (Goldeberg, Gater, Sartorius, Uston, Piccinelli, Gureje, and Rutter, 1997). Robinson and Price (1982) examined the test/retest reliability for the GHQ-28 and found it to be high when testing post-stroke patients for depression. They initially tested on 103 patients and retested on 83. As a test of validation of the GHQ -28, the authors assessed a subset (30) of the original 103 participants using a psychiatrist to interview and administer other quantitative psychopathology tests (Zung Self Rating Depression Scale, Hamilton Scale and the Present State Exam). The GHQ-28 was found to correlate well with these psychotherapy tests representing the former to be a robust test in measuring depression in these patients. Goldberg *et al.* (1997) reviewed the validity of the questionnaire in comparison to the GHQ-28. They examined studies using the GHQ-12 in many different countries and settings. With just less than 26,000 people completing the questionnaire, they found that there was no significant difference between the two scales if there is no need for a scaled score comparison, which is possible from the GHQ-28 but not the GHQ-12.

The Carer COAST (Long, Hesketh and Bowen, 2009) was chosen as a quantitative measure for investigating how the relative views the impact of the dysarthria on the PwD and on themselves. The questions in the questionnaire cover the carer's insight into their relative's communication post stroke and how the communication difficulty is impacting their own life, e.g. social and family. The Carer COAST can be used as a reliable measure of carer perceptions of their relative's communication after stroke (Long *et al.*, 2009). It has also been developed to measure the impact of the communication difficulties on the carer's quality of life. The Carer COAST was developed involving 58 participants to support the Communication Outcomes after Stroke scale (COAST) (Long, Hesketh, Paszek, Booth and Bowen, 2008), which is used to measure the views of those who had had a stroke on their communication disorder. These 58 participants all had a relative who had a communication disorder (aphasia and/or dysarthria) due to stroke. Two thirds of the patients had aphasia, 16% had only dysarthria. 75% of the carer participants were female and predominantly were spouses (77%). The twenty items comprise three sub-scales. These are – interactive communication, overview of communication and the impact of the stroke patient's communication difficulties on the carer's quality of life.

Methods of data collection

The following methods were employed to collect data in the course of the investigation.

Interview: Interview guides (see Appendix A) were developed by the researcher to facilitate a discussion about the psychosocial effects of being a carer to a relative who is affected by post stroke dysarthria. Denscombe (2007) states that *'interviews are a suitable method when the researcher needs to gain insights into things like people's opinions, feelings, emotions and experiences'.* As this project is researching the effect on the relative's psychosocial wellbeing an interview would need to cover all four of these areas. The use of interview allows the researcher to delve into the area in a way which one or two word answers in a questionnaire, for example, would not be able to. As the participants will be talking about issues and experiences that are very likely to be sensitive or difficult for them the interview process permits a personal and considerate approach by the interviewer (Denscombe, 2007). The participants can be supported and encouraged to discuss their situation in an open and honest way.

General Health Questionnaire (GHQ-12) (Goldberg and Williams, 1988): To be used as a measure of general wellbeing (see Appendix B). The GHQ-12 has twelve questions relating to general wellbeing. Scoring in this study was done using the Likert scoring method. For each question there are four possible responses. For example, question 5: "have you recently felt under constant strain?" The answers, not at all/ no more than usual/ rather more than usual/ much more than usual, are scored from 0 (for ‘not at all’) to 3 (for ‘much more than usual’). The total score is calculated by adding the score for each response, with a score of 12 indicating no change in the relative’s general well-being, less than 12 an improvement and more than 12 that there has been a decrease in wellbeing.

The Communication Outcomes after Stroke (Carer COAST) (Long, Hesketh and Bowen, 2009): This consists of 20 questions all answered using a rating scale (see Appendix C). Each question is rated on a five point Likert response scale. The responses are rated 0-4 and then added together, with the maximum score being 80. This score is divided by 80 and multiplied by 100 to give a final percentage. For every answer that is not applicable, four is taken away from the maximum possible (i.e. 76 for 1 N/A, 72 for 2 N/A etc.), so for 19 items the final score will be divided by 76 to give the percentage.

The Interview Guide

A semi-structured interview guide was devised to assist the interviewer when conducting the interview. The guide provides a focus of the topics and issues to be addressed in the session and it also allows for similar lines of enquiry to be made when interviewing several different people, e.g. assists consistency. Although the interview guide is long and detailed, it was there as a prompt and was not followed precisely. The answers given by the interviewee guided both the progression of the interview and the order of the topics that were covered in the interview.

The interview guide was produced using the interview topics used in research carried out by Dickson and colleagues (2008). The topics were amended to suit the current project and the focus of the relative’s point of view and feelings. These included

- Introduction e.g. time post stroke, what have things been like since the stroke
- Stroke Context e.g. any changes within the household, understanding of stroke and stroke recovery
- Dysarthria e.g. how has X's speech been affected, how does X get on when communicating with family/friends/health professionals
- Situations e.g. any situations that are difficult for the relative because of X's speech, any situations avoided because of the dysarthria
- Impact e.g. any change in social life of the relative because of X's dysarthria, is there the opportunity to talk to others
- Reactions e.g. is it usual to feel isolated/down, did you feel like this before X's stroke, have you spoken to anyone about it
- Management e.g. what information or advice have you received about the dysarthria, have you been included in any of X's treatment for dysarthria

A semi-structured approach was chosen as qualitative research was a relatively new area for the investigator. Unstructured interviews are the most successful way of generating the richest data (Holloway and Wheeler, 2010), but they also generate the largest volume of irrelevant data. Holloway and Wheeler (2010) suggest this is particularly true for inexperienced interviewers. However, structured interviews are thought to be contradictory to qualitative approaches as they use pre-planned questions which direct the responses from the participants (Holloway and Wheeler, 2010). The benefit of semi-structured interview is that it allows the investigator some control over the focus of the topics covered. However, it also provides the participant the opportunity to guide the process in a more natural way. Therefore, fitting the qualitative approach and providing support to a more inexperienced researcher. Before the interviews took place the researcher practised using the interview guide through a mock interview with a fellow post-graduate student. This gave the opportunity to anticipate any difficulties in the procedure and for appropriate changes to be made prior to the first interview with a relative. After the mock interview the researcher implemented two changes to her procedure. These included how the guide was arranged in the folder so that it was easier to scan during the interview to make it less obtrusive, and also deciding on the order of presentation of tasks, e.g. doing the GHQ-12 and CaCOAST.

Procedure

Ethical approval was granted from NHS East of Scotland Research Ethics Service. Prior to the interview session each of the participants consented firstly, to the interview taking place and to completing the CaCOAST (and the GHQ-12 for participants RP02, RP04 and RP06), secondly, to the interview being recorded and, finally, for the information gathered from the interview and questionnaires to be used for the purposes of this study. RP08, RP09 and RP11 completed the CaCOAST and the interview with the current researcher before starting the group sessions as part of the 'Living with Dysarthria' project (please see Participants and Recruitment section for details of the 'Living with Dysarthria' project). The GHQ-12 data for these three participants was collected by the researcher associated with the 'Living with Dysarthria' project and was made available to this research. The current researcher completed the interview and the two questionnaires with RP02, RP04 and RP06 as they had completed the group sessions several months previously and so it was relevant to collect a new GHQ-12 baseline. The questionnaires were administered first so as to give the participants time to settle into the session with the researcher before the interview began.

Interviews

The interviews were recorded using a digital audio recorder in order to record the participant's words as accurately as possible. This meant that the interviewer was able to focus on the participant fully during the interview, keep eye contact and concentrate on what the participant was saying. Each of the interviews was transcribed by the interviewer for analysis.

The Interviewer

As a qualified speech and language therapist the researcher has many qualities which are relevant to this type of data collection. When training and practising as an SLT it is expected that you would develop many different skills, including, listening, observing, investigating, decision making, advising and facilitating, to name but a few (Bray, Ross and Todd, 2005). These skills would provide the professional expertise that would be expected from someone carrying out interviews. It is important to consider the impact that the interviewer has on the success of the interview. A relationship must develop between the interviewer and the participant as the interview is to be viewed as a social interaction, within which the interviewer is very much an active participant (Holloway and Wheeler, 2010). Trust must be built and maintained throughout the process in order for the true representation of the participant's views to be gained.

In this case, the interviewer had two years' post-graduate experience as an SLT. She had not used this particular method of data collection in research previously, but used similar techniques when interviewing patients during clinical work. The three participants (RP02, RP04 and RP06) who had completed the 'Living with Dysarthria' therapy programme had previously developed a relationship with the interviewer as she had been one of the therapists involved in providing the therapy programme. The therapist and the relatives had met a total of nine times for two hours a week before the interview took place. The three participants (RP08, RP09 and RP11) who were about to start the 'Living with Dysarthria' programme met the interviewer for the first time at the interview session.

Each interview lasted between twenty and forty minutes and was drawn to a close naturally, i.e. by following the lead of the interviewee. As RP02, RP04 and RP06 had met the interviewer several times before the interview took place it is plausible that they felt more at ease and so engaged with the interviewer more easily. Therefore, their interviews lasted for longer periods of time i.e. between 30 and 40 minutes.

RP08 and RP09 lasted for 21 and 27 minutes respectively while RP11 was the shortest at 18 minutes. RP11 had limited time available and was offered another meeting time, but she wanted to complete the interview on that occasion. As this was the first time that the interviewer had met RP08, RP09 and RP11 it is likely that they did not feel as comfortable as the other three. However, it did not feel that they rushed their answers or that the answers they gave were not a true representation of their experiences.

It is possible that there were differences in the interviews due to half the participants being known to the researcher and half not being known. This was unavoidable due to the timing of the current research project in relation to the 'Living with Dysarthria' (LWD) project. The application and approval for this research came after the LWD project had already begun. As the participants were recruited as part of the LWD project it was not possible to alter the timing of the interviews. It is possible that the interviewees who knew the researcher previous to interview might not have felt comfortable answering particular questions or would have felt embarrassed to have highlighted certain feelings or experiences. This is not the researcher's feeling on the subject – there was nothing that the interviewees appeared to be concerned about sharing with her and she feels that all information given by the interviewees was true to their experience.

The Questionnaires

The Carer COAST was administered by the interviewer at the same session as the interview for all the participants. The Carer COAST was presented before the interview to give an opportunity for them to relax and in the case of RP08, RP09 and RP11 feel more comfortable with the researcher as this was their first meeting. The questionnaire was given to the relatives by the researcher to complete on their own during the session. However, if they had any queries about the questions, the researcher was available to support them by explaining the question and the response options.

The GHQ-12 was administered to three of the participants RP08, RP09 and RP11, by another speech and language therapist who was carrying out the assessments for the 'Living with Dysarthria' project (see Table 3.1). Her sessions with these participants were at most two weeks before the interview took place. The interviewer completed the GHQ-12 and CaCOAST with RP02, RP04 and RP06 at the time of the interview. The researcher discussed the GHQ-12 data with the 'Living with Dysarthria' assessor. This gave the opportunity for any pertinent information about the relatives at the time of filling out the questionnaires to be noted.

ID	Interview Pre-therapy	Interview Post-therapy	Ca COAST Pre-therapy	Ca COAST Post-therapy	GHQ-12 Pre-therapy	GHQ-12 5 Months Post-therapy
RP02		X		X		X
RP04		X		X		X
RP06		X		X		X
RP08	X		X		X	
RP09	X		X		X	
RP11	X		X		X	

Table 3.1: Administration of Interviews, CaCOAST and GHQ-12, red administered by researcher/interviewer, blue administered by researcher for 'Living with Dysarthria' project.

Participants and Recruitment

Six primary communication partners (PCPs) of people with dysarthria post stroke (PwD) were recruited via their involvement in a funded research project, 'Living with Dysarthria'. The PwD had chronic post stroke dysarthria. They were recruited to take part in an eight week group therapy programme designed to support people with post-stroke dysarthria and, if appropriate, their relatives. Twelve PwD were recruited to the group programme, seven of whom brought a relative with them, from one hospital SLT department. When contacted each patient was offered a place for themselves and for a frequent communication partner. The PCPs were then approached separately by the LWD recruiting therapist to ask if they would be interested in taking part in this project. Six of the seven PCPs agreed to be interviewed as part of this research project after being approached by the therapist who recruited for the LWD project. Ethics approval for this current study was granted as an extension to the 'Living with Dysarthria' project approval.

Inclusion criteria for the relatives recruited to the current project included:

a) Auditory and visual acuity adequacy – so that they would be able to complete the interview and questionnaires easily

b) English as their main language – so that they would understand the questions being asked fully

c) Being recruited to the 'Living with Dysarthria' group therapy programme – due to the limitations of the ethics approval only members of the group were able to be approached to take part in the study

d) Being in communication with the PWD at least three times per week – there needed to be regular contact between the PwD and the participants in this study in order for a true representation of the impact of dysarthria on the relatives. If they were not in regular contact then it would be likely that the impact would be large enough to affect psychosocial well-being.

Each of the relatives had a husband/mother/sister-in-law with post-stroke dysarthria. The patient's dysarthria severity was rated by two speech and language therapists (including the researcher for this project and the therapist involved in running the LWD group therapy sessions) using the Therapy Outcome Measures (TOMs) dysarthria impairment scale (Enderby, Alexander and Pertheram, 2006). Each therapist completed their ratings independently, and then any differences in the ratings were discussed and a consensus agreed (ratings ranged from 2-4). The patient's speech intelligibility was measured using the Speech Intelligibility Test (SIT; Yorkston, Beukelman, and Hakel, 1996). Patients read 11 sentences varying from 5 to 15 words. These were recorded on a digital recorder. They completed this task twice, once before the Living with Dysarthria programme and once after. These sentences were listened to by independent listeners twice and then scores calculated as percentages of words correctly identified. The scores (ranging from 61-98%) used in this study were from the time closest to the interviews with the relatives. So SP02, SP04 and SP06 were from the second set of sentences as the interviews were conducted after the group and SP08, SP09 and SP10 from the sample collected before they attended the group. All the information relating to the participants and their relatives who had dysarthria was accurate at the time the interviews took place, e.g. the time post stroke and their employment status (see Table 3.2). All the interviews, CaCOAST and GHQ-12 (for relevant participants) were completed over a four week period. However, three of the participants (RP02, 04 and 06) had completed the 'Living with Dysarthria' project in phase one and three in phase two (RP08,09 and 11). The interview time period for this project fell between the two phases of the 'Living with Dysarthria' project, meaning RP02, 04 and 06 completed the interview post the 'Living with Dysarthria' project and RP08, 09 and 11 before it. The identification code, RP (= Relative Participant) was taken from the 'Living with Dysarthria' project.

Participant Information

RP02 is in her early to mid-fifties. She works as an administration assistant at the local hospital. RP02's husband is 56 and had a stroke 6 years ago. He presents with moderate dysarthria, TOMs rating 2 and a SIT score of 61.06%. His dysarthria is characterised by imprecise consonants, audible inspiration, short phrases, slow rate, reduced stress and harsh voice. He also presents with an ataxic gate and is able to walk with the use of a walking stick. They have two sons who have both left home. He received SLT intervention in hospital for severe dysphagia and then in the community for dysarthria therapy. The number of sessions is unknown. RP02 was interviewed in a private SLT therapy room at the hospital while she was on her lunch break. *(RP02 – 6yrs, mod)*

RP04 is in her late fifties. She is retired and lives with her 59 year old husband. He had his stroke one year ago and has moderate/mild dysarthria, TOMs rating 3 and a SIT score of 94.85%. His dysarthria is characterised by imprecise consonants, audible inspiration, short rushes of speech, rapid rate, and hypernasality, breathy and harsh voice. He also presents with right paresis. He was seen in hospital for three sessions of dysarthria therapy and subsequently in the community post discharge. The number of sessions is unknown. Since he had his stroke he has taken retirement from work. RP04 was interviewed at home. *(RP04 – 12mths, mild/mod)*

RP06 is in her early seventies. She is retired and lives with her husband. Her sister-in-law is 90 years old and had her stroke two years and one month ago. Her resulting dysarthria is mild, TOMs rating 4 and a SIT score of 94.49%. Her dysarthria is characterised by imprecise consonants, hoarse voice, low and monopitch. She had right side paresis. She was seen at hospital for 12 hospital sessions of dysarthria therapy, six in-patient and six out-patient. She is retired and lives on her own. RP06 met the researcher at the hospital and was interviewed in the SLT therapy room. *(RP06 – 25mths, mild)*

RP08, who is in her late fifties, works in the radiology department at the local hospital. Her husband, aged 61, had a stroke eleven months ago. He has mild dysarthria, TOMs rating 4 and a SIT score of 98.45%. His dysarthria is characterised by imprecise consonants, prolonged phonemes, short rushes of speech and harsh voice. He has right side paresis. He attended one in-patient and three out-patient dysarthria therapy sessions. He failed to attend his final out-patient session. He is currently off work on sick leave. RP08 was interviewed at home. *(RP08 – 11mths, mild)*

RP09 is in her sixties and is a retired teacher. Her husband, aged 63 had his stroke four months ago. His dysarthria is mild, TOMs 4 and a SIT score of 97.88%. His dysarthria is characterised by imprecise consonants and monopitch. He had right paresis. He had three in-patient and four out-patient therapy sessions. At the time of interview he was still registered with the SLT department and has been offered a follow up phone call to determine if he requires any further therapy. He is also retired. RP09 was interviewed at home. *(RP09 – 4mths, mild)*

RP11 is seventeen and is unemployed, she is the only participant under eighteen and is still living at home with her mother and sister. Her mother is 50 years old and had her stroke 4 years ago. Her dysarthria is mild – moderate, TOMs rating 3 and a SIT score of 88.18%. Her dysarthria is characterised by imprecise consonants, monopitch and hypernasality. She had no physical impairments. The exact details of her therapy history are unknown. She was offered community based SLT after her stroke but failed to attend. At the time of interview she was taking part in a six week block of therapy in the community. She is a single parent and had recently returned to work as an assistant in a betting shop. RP11 was interviewed at home. *(RP11 – 4yrs, mild/mod)*

ID	Relationship with PwD	PwD Severity of Dysarthria (TOMs rating)	Time Post Stroke	Occupation	Place of Interview
RP02	Wife	Moderate (2)	6 years	Administration Assistant	SLT therapy room at hospital
RP04	Wife	Mild-Moderate (3)	12 months	Retired	Home
RP06	Sister-in-Law	Mild (4)	25 months	Retired	SLT therapy room at hospital
RP08	Wife	Mild (4)	11 months	Radiology assistant	Home
RP09	Wife	Mild (4)	4 months	Retired	Home
RP11	Daughter	Mild-Moderate (3)	3 years	Unemployed	Home

Table 3.2: Summary of demographic data for relatives being interviewed.

In summary, the three methods of data collection including interviews, the CaCOAST (communication questionnaire) and the GHQ-12 (general well-being questionnaire) have been described. The analysis section will now explore the approach to the analysis of the interview and questionnaire data.

Analysis procedure

Braun and Clarke (2006) describe a six phase process for using thematic analysis and this is the process by which the analysis for this project was carried out. The Phases are as follows:

Phase 1: 'Familiarising yourself with your data'

The analyser should immerse themselves within the data. This can be done via carrying out the initial data collection, by transcribing the interviews or focus group data or by re-reading the data in an 'active' way (searching for meanings, patterns, etc). The analyser can take notes on particular areas of interest throughout this process to help with the coding. For the purposes of this project, in order to complete this phase the researcher completed the data collection and transcribed the data. The recorded interview data was transferred from the recorder memory card onto a file which then required a password for access. Transcription of the data used only coded names e.g. RP02 (for PCP) or SP02 (for Pwd). Any other names, places or people, mentioned were represented with a single letter. These files will then be deleted after the project is completed.

All six interviews were transcribed from the audio recordings taken during the interview, using X.. to indicate the interviewer question and RP.. to indicate the relative. Each of the lines in the interview was numbered which allowed for easy location of data during analysis and discussion. Three example transcriptions are included in Appendix D. Each interview was transcribed in full and then returned to twice more to ensure accurate transcription of the data. During this process observations recorded in field notes were added to supplement the accuracy of the transcriptions. For example, non-verbal information was included using notes made by the researcher after the interview, e.g. times when interviewees were upset or distracted. This part of the data collection and preparation was all carried out by the researcher creating the opportunity to become familiar with the data for coding and thematic description as recommended by Braun and Clarke (2006).

Phase 2: 'Generating initial codes'

After familiarisation of the data there should be an initial list of ideas and what is interesting about them. Coding is part of the analysis where the data is organised into meaningful groups (Miles and Huberman, 1994). At this stage Braun and Clarke recommend that as many themes as possible are coded, that data is coded in context e.g. include surrounding data if relevant, and that data can be coded into as many different themes as they are relevant to. After completion of the transcription, the researcher used the ideas generated in 'phase 1' to begin generating the initial codes. These were then supplemented with further initial codes by closer scrutiny of the transcriptions which focused solely on this phase of the analysis. The researcher used NVivo software to help sort the data into these initial themes. NVivo was chosen as the researcher has knowledge and experience of the software package and it provides a means to organise the data in a systematic and exhaustive way.

Phase 3: 'Searching for Themes'

Once a list of codes has been drawn up, these should be arranged into potential themes. This can be done with visual representations e.g. tables or mind-maps. The relationships between codes, themes and different levels of themes is an important aspect of this phase and decisions are beginning to be made about whether they are going to be regarded as main themes, sub themes or discarded. The codes were sorted into themes and sub-themes by the researcher using mind maps on paper. This allowed the researcher to view all the themes and sub-themes together, which permitted the appropriate distribution of data and allowed the researcher to gain overall insight into the over-reaching themes within the analysis up to that point.

Phase 4: 'Reviewing Themes'

There are two stages involved in the reviewing and refining of themes. Level one involves reviewing at the level of the coded data extracts e.g. reading each of the codes for that theme and deciding whether they are forming a pattern. If they do not form a pattern it is necessary to assess whether there is a difficulty with the theme itself or whether the codes do not fit within that particular theme and therefore they need to go elsewhere e.g. a new theme, another existing theme or discarded. At this point it should be possible to put together a candidate 'thematic map'. Level two assesses whether the thematic map accurately reflects the whole data set. The data set should be re-read to ensure that the themes are accurate and to ensure that all relevant data has been coded to themes. This is appropriate as coding to themes is an on-going process and constant re-evaluation of coded data and the themes throughout analysis and writing of results is possible.

After the initial themes and sub-themes had been decided upon the researcher read through each of the codes and decided on the appropriateness of the theme that they had been assigned to. At this point it was kept within the current theme or reassigned elsewhere (either to an existing theme or to a new one). Thematic maps were generated and the three main themes were decided upon. Each sub-theme was assigned to one of these themes.

Phase 5: 'Defining and Naming Themes'

It is necessary to 'define and refine' each of the themes until the description of each is determined accurately and to one's satisfaction. The description is ordered with a coherent and consistent account supported by examples of data extracts. The description should include what is interesting or noteworthy about the data and why. This is where the story of each theme is presented to show the overall story of the complete data set. The research question is answered within the presentation of this story. Each theme is given a name that defines the data that it represents. At this point, three of the transcripts (chosen at random by the reviewer) were reviewed by the researcher's supervisor. The data in each of the transcript was marked with the appropriate theme (see Appendices D.1, D.2 and D.3). This allowed the reviewer to see what information had been coded easily. Once the reviewer had examined the data and the coinciding themes any disagreements were highlighted to the researcher. These were then discussed and changed accordingly or agreed upon once reasons for the coding had been explained to the reviewer. This ensured that a consistency of coding data to appropriate themes had been achieved and that all relevant data had been assigned correctly.

Phase 6: 'Producing the report'

The final stage is the write up of the dissertation including the story of the thematic analysis showing that the analysis that has been carried out is relevant and valid. The representation of the data for the report should be a *'concise, coherent, logical, non-repetitive and interesting account of the story of the data'* (Braun and Clarke, 2006, pg 93). Examples chosen for this thesis included rich descriptions capturing the substance of the story, which, when encompassed in the analytical narrative, show how the data argues the research question.

Once the analysis had been completed and the resulting themes decided upon by the researcher, the results were written with appropriate quotes to support each theme. This report was then reviewed by two supervisors. On the whole the themes were agreed on. However, when there was disagreement this was discussed in a three way meeting and the researcher was allowed to present reasons for choosing particular themes and supporting quotes. Further discussion was had and appropriate changes agreed by all.

All the information that was deemed relevant to the research topic was coded by the researcher. All unrelated information was not included, for example, when the relative's provided information about the PwD that did not relate directly to the relative themselves e.g. 'Well she always did go to the church and the guild and the coffee mornings. She still does her baking and footers about the house and she's very happy.'

General Health Questionnaire and Carer COAST

Inferential statistics were not suitable for analysis of the GHQ-12 and the Carer COAST due to the small number of participants. Therefore, descriptive analysis of the data was the most suitable way to analyse the questionnaires. The results of each of the questionnaires were compared to each other and to each of the individual's interview data. The questionnaire results were the whole GHQ-12 final score, the whole Ca COAST score and the score from the five quality of life questions from the Ca COAST. The researcher calculated the scores for each participant. These were then checked by the researcher's supervisor to ensure no miscalculations had been made. The whole Ca COAST took into consideration the participant's view on how their relative's communication difficulty impacted the relative's ability to communicate effectively in different situations in conjunction with the quality of life scores. Examining the five quality of life scores independently allowed the researcher to see how the dysarthria had directly impacted the participant's quality of life independent of the PwD. By comparing these results to the interview data allows for inconsistencies or consistencies in descriptions of the interview data to be highlighted by quantitative data e.g. it will provide further evidence to support or dispute possible findings in the qualitative data.

The Results chapter will summarise the data, first the themes and subthemes from interview data with explanations of their meanings and illustrative quotes and then the quantitative data from the two questionnaires, the CaCOAST and GHQ-12.

Chapter 4: Results

All six of the PCPs who participated in the project completed the two questionnaires, the General Health Questionnaire (GHQ-12) (Goldberg and Williams, 1988) and The Communication Outcomes after Stroke (Carer COAST) (Long et al., 2009) and also took part in an interview session with the researcher. The results section includes a summary of each of the main themes and their subthemes and the questionnaire results.

Analysis of the qualitative data using the thematic approach revealed three main themes in the data: 1) Feelings, 2) Relationships and 3) Stroke and Speech. Each of the themes and their subthemes will include a description of what each one means and some illustrative quotations. The most relevant quotation or quotations are used to illustrate the subtheme wherever possible. However, representation of all participants' views has also influenced the choice of quotes on occasion. Each theme has several subthemes attached to it. Some of the subthemes are relevant to each of the PCPs' interview data, while some interviews are relevant to only one or two (please refer to Appendix D for examples of the annotated transcripts).

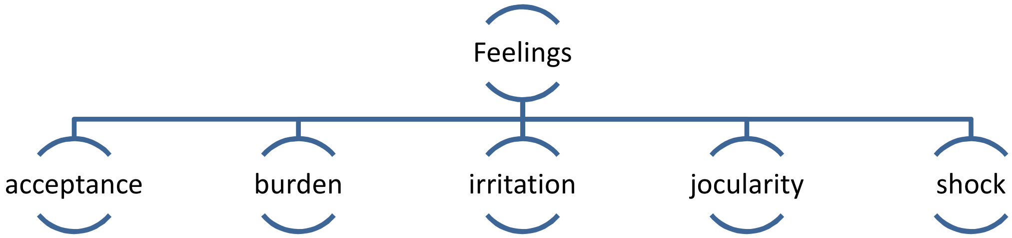

Figure 4.1: Thematic diagram for the Feelings theme illustrating the theme and its subthemes.

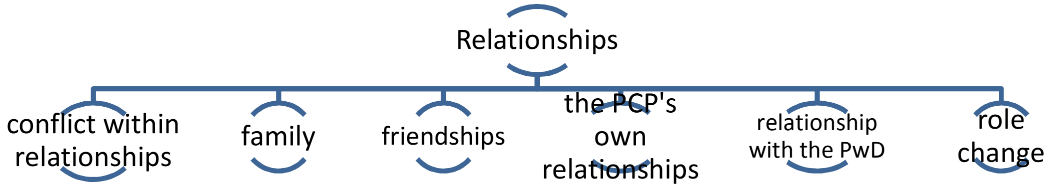

Figure 4.2: Thematic diagram for the Relationships theme illustrating the theme and its subthemes.

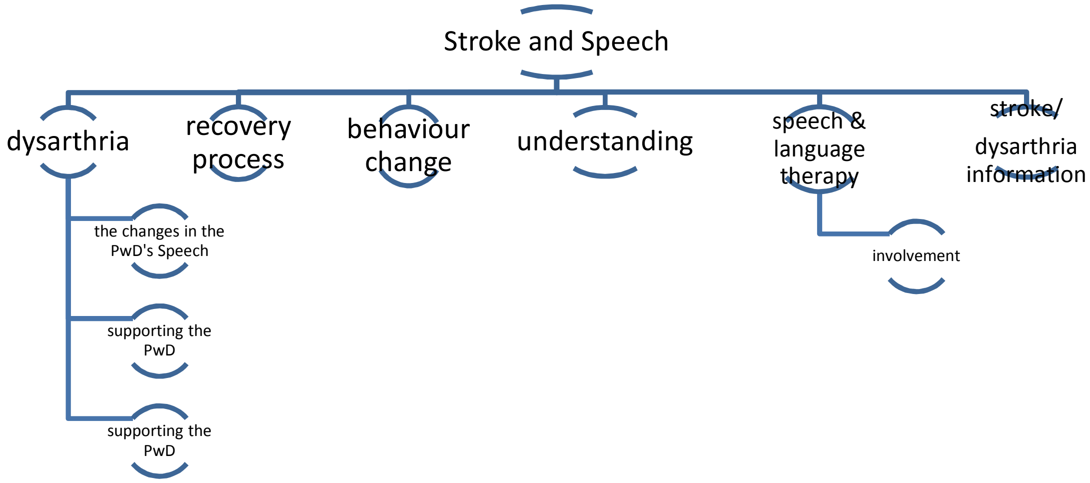

Figure 4.3: Thematic diagram for the Stroke and Speech illustrating the theme and its subthemes.

The interview data themes and subthemes are presented at the beginning of the results section. These are then followed by the questionnaire data. The discussion chapter will bring the data from both the interviews and the questionnaires together to illustrate the resulting conclusions.

Feelings

The participants described a wide range of feelings experienced associated with living or supporting someone with post stroke dysarthria. These include acceptance, burden, irritation, jocularity, shock and understanding.

Acceptance

Interviewees described several different layers or types of acceptance. These included acceptance that there was not going to be any further recovery, acceptance that they had to let the PwD be independent again and acceptance that, for them as PCPs, their life still has to go on as well.

Responses varied according to the type of relationship e.g. wife, mother or sister-in-law (see Table 3.1) with the PwD and what level or type of acceptance they experienced. PCPs whose husbands had had strokes described in more specific terms the difficulties that they have had accepting that the stroke has occurred, than that of RP06 and RP11 who shared different relationships with the PwD (sister-in-law and daughter, respectively). While all of the participants have described difficult situations, the language that RP02 and RP04 use to describe their feelings is more directly linked to the dysarthria. However, for all of the participants at times it is difficult to separate the impact of dysarthria and the impact of the stroke as a whole.

Participants described the difficulty in accepting that the stroke had happened and that there might not be any further recovery. This is particularly apparent for RP02 and RP04 whose husbands had more significant difficulties post stroke and the increasing awareness of the long term impact.

> *"Difficult. Hard……. I think a mixture. Being hard, hard to accept he's actually had a stroke…. I would say it's harder now since he's recovered from his stroke and now being aware of the effects of what he's been left with."*
>
> ***RP04 (12mths, mild/mod)***

> *"Och aye. I think he's accepted his stroke better than I have. I think I've found it harder….. He's accepted that it's happened, but I don't think I accepted it as easily…. Maybe now. I know now that he's not going to get any better….. I don't think he's going to improve, erm, any more than what he is."*
>
> ***RP02 (6yrs, mod)***

RP06's acceptance of her circumstances stems from the realisation that being the carer of an elderly relative who has had a stroke is going to be a long term situation. SP06's stroke has caused her to become more dependent on RP06 and her husband for general support due to increased frailty. This general frailty is what RP06 is concerned about, rather than the direct impact of a particular impairment such as dysarthria.

> *"As I say, it has changed our lives…… And I haven't been able to do what I thought I would've wanted to do [in retirement]….. Because of the situation. But that's life and there is nothing you can do about it, is there?"*
>
> ***RP06 (25mths, mild)***

For one participant whose husband had dysarthria, one part of acceptance was about learning to take a step back and try to give him independence again.

> *"I don't know, maybe about a year. I just kind of took, you can drive now…. It gives the independence……. So I thought I've got to learn to take a step*

> *back, because I can't always be there 24/7"*
>
> **_RP02 (6yrs, mod)_**

For another participant whose mother has post stroke dysarthria, it was about accepting that as a daughter she was still young and although she would have preferred to be out with her friends, she would instead have to be available if her mother called her.

> *"Well, at first I did, I didn't want to go out because I didn't want to leave her in by herself, but over the years, I've kind of learned that she'll be ok. If she needs me she'll let me know. But at first it did kind of change my social life, because I was only fifteen when it happened. So obviously when you're fifteen you want to go out with your friends all the time, but I didn't I stayed in with my mum."*
>
> **_RP11 (4yrs, mild/mod)_**

The change in behaviour that can happen when someone has a stroke has also been highlighted as a hardship which was difficult for the participants to accept. This can have a knock on effect as to how the PwD deals with the impact of the stroke and consequently how the PCP deals with it as well. This is an example of how it may not just be one particular impairment that a carer has to contend with, but multiple difficulties that are all significant to the carer in terms of how they cope.

> *"You know, like, he would never have used bad language. That is something that he would never have, I mean I don't know if he would've when he was out with his friends. But in the house certainly he would never swear or anything like that. And doesn't now, but there have been a couple of occasions where he has actually said things and it's been totally out of character. Adolescent things that you go….. What was all that about? He*

> *wouldn't have even said it when he was, cause I've known him since he was 17. You know. So that's been difficult."*
>
> ***RP04 (12mths, mild/mod)***

Burden

Burden manifested its way into the PCPs' lives in different ways. The relationship that people had with the PwD impacted the types of burden that they felt. Wives felt it a burden as they were considered to be the 'interpreter' for the others interacting with the PwD, and for the sister-in-law it was the unexpected long term impact of the stroke for her and her husband. The burden of having no-one who understood the consequences of the stroke and so therefore no-one to speak to about it was also raised as an issue, particularly for the youngest PCP.

> *"Other folks turned to me as well, it wasn't just the two boys turning to me saying oh god what's he saying? It wasn't just the two boys, it was his mum and his sister. They're better now, and my sister and my brother-in-law are better now. They've learnt to listen to what he's saying."*
>
> ***RP02 (6yrs, mod)***

> *"But I find his mother's the worst because she doesn't listen to what he's said….. He'll turn and say to me she doesn't listen. I know SP02 but I can't always be there….I can't always be there and translate…… I wish she would just listen"*
>
> ***RP02 (6yrs, mod)***

> *"He would probably turn to me and give me a sign like help me out here a wee bit. So you would do it quite discretely by, and women are quite good at that aren't they? (laughter)*

> ***(And how do you feel about that?)*** *Um, sometimes it can make you feel a wee bit, a bit bolshie if you know what I mean? Because I would never have done that in the past. And if I had interrupted a conversation it would be him looking at me as if, let me finish. And it was something I was very, very conscious that I would never have done before……. I would never have done that and it does make me feel quite uncomfortable at times."*
>
> ***RP04 (12mths, mild/mod)***

For RP06, and her husband, the burden she had to endure stemmed from the obligation they felt being the only relatives who were close enough to look after her sister-in-law (the PwD). She felt acutely aware of the impact that this had had on her retirement.

> *"Well, since I retired, I'll be quite honest with you, she's taken over our lives……. But as I say, we're very involved with her. Cause as I say there's only us, my husband and myself as her family…… As I say, it has changed our lives."*
>
> ***RP06 (25mths, mild)***

The lack of suitable people to talk to or share their burden with, that is people who would be able to empathise or understand what they were experiencing, was raised by the PCPs as an area of difficulty.

> *"Sometimes me and my sister talk about it, but it's only usually when we talk about it if, like, we're going to speech therapy or….. Or if my sister is frustrated she'll talk to me about it and we'll talk to each other. But other than that I don't really have anyone else that I can talk to. Other than my auntie."*
>
> ***RP11 (4yrs, mild/mod)***

Frustration

Participants described the frustration of the dysarthria impacting the PwD's ability to communicate effectively with them and with others.

RP02 describes how over time she became increasingly responsible for 'interpreting' for her husband when other people could not understand what he was saying, and the resulting feelings of annoyance for her.

> *"It didn't bother me at first. I think over the length of time it's maybe a wee bit, you know, if you just listen to him."*
>
> ***RP02 (6yrs, mod)***

RP04 describes how her husband was not able to participate as fully in conversations as he would have done prior to the stroke and how this frustrated her.

> *"One being his speech. He finds it quite frustrating and probably as his partner I do as well. He tends now to sit back..… He can't jump from conversation to conversation…… That can cause quite a bit of frustration on my part because then I'll turn around and say were you not listening? Why weren't you listening?"*
>
> ***RP04 (12mths, mild/mod)***

> *"the only time that it can be quite frustrating can be the speech….And the speech, umm, goes a bit when he is tired. And, I think sometimes his mouth droops a wee bit at the side"*
>
> ***RP08 (11mths, mild)***

The PCPs acknowledge not only their own frustration, but also that of the PwD in certain circumstances and the possible role of the PCPs in causing it.

> *"I think it's because everyone is talking at once and because she's so quiet she can't really get a word in….. And when she does, because there are so many people talking she's trying to get it all out….. In one breath and it just doesn't sound right and people are just kind of like shrug it off. But that's*
>
> *about the only frustrating thing."*
>
> ***RP11 (4yrs, mild/mod)***

> *"But obviously he gets frustrated, when I've got to keep saying to him, sorry you've got to say that again... That's got to be really, really annoying for somebody that's had a stroke. I mean, being constantly asked, say it again, say it again, say it again."*
>
> ***RP08 (11mths, mild)***

Further frustration or annoyance is felt by the PCPs when they feel that people are being rude by not listening to the PwD properly or by ignoring them.

> *"It annoys me. (Laughter) Obviously it does, because it's my mum and people are ignoring her and that's just rude…… But I think she'd rather people asked her to repeat herself rather than completely blanking her……"*
>
> ***RP11 (4yrs, mild/mod)***

Jocularity

Humour has been used as a way to help the PwD and their PCPs deal with the difficulties that they face.

> *"What advice would I give? Laugh! If you have to keep asking him to repeat it, you just have to say something like "I'm sorry" because it's new to both of you….But if you don't have a sense of humour, like both of us with our arms, (laughter) we're just a couple of old crocs."*
>
> ***RP08 (11mths, mild)***

> *"If he does have words or sometimes combinations of letters or syllables trip him up….. He just sort of laughs and finds another word. (laughter) So he*
>
> *gets on fine, he gets on really well."*
>
> ***RP09 (4mths, mild)***

Shock

The sudden onset of the stroke and the far reaching consequences of the disease induced feelings of shock in some of the participants.

> *"It wasn't what I was expecting. I don't know what I was expecting, but I wasn't expecting that. Biggest shock of all."*
>
> ***RP02 (mod, 6yrs)***

> *"The first thing I knew was SP09 waking me up and he was trying to tell me something and he was speaking very unintelligibly….. So that was really one of the first signs…… I didn't have to think very long to realise what had happened. Even though it was a total unexpected shock."*
>
> ***RP09 (4mths, mild)***

Relationships

The PCPs discussed how relationships with many different people were affected by the dysarthria. The main subthemes that arose from analysis of the data that were associated with relationships were conflict within relationships, family, friendships, relationship with the PwD, role change and the PCPs' own relationships.

Conflict within relationships

Conflict, or the possibility of conflict, within relationships was raised as a problem. Two of the PCPs described the impact of conflict with their husbands who had dysarthria.

In particular, RP04 reported that, when she was trying to support her husband with his speech by using strategies to increase intelligibility this caused him to get annoyed with her.

> *"Yes. Um, sometimes it can cause a bit of rift because you're trying to put things into place when he's maybe trying to explain something."*
>
> ***RP04 (12mths, mild/mod)***

RP09 said that she had altered her reactions to her husband perhaps insinuating that conflict may have arisen from the anticipated negative response.

> *"There are things that I would be reluctant to say because I would feel it would make him feel bad"*
>
> ***RP09 (4mths, mild)***

RP06 talked about her feelings of resentment at how her relationship with SP06, and the resulting commitments of this relationship, impeded her freedom to do as she wished, when she wished.

> *"But there is an odd time, when you think oh there's my sister she can go away to the hairdresser's this morning but I've got to take SP06 to the hairdresser's. You know….. There is the odd day you have the hump but I don't think that you wouldn't be human if you didn't"*
>
> ***RP06 (25mths, mild)***

Family

The impact of the stroke and dysarthria on family relationships were highlighted by the PCPs. These included the relationships that had already been formed before the stroke and the ones that developed after the stroke. These feelings that the PCPs highlighted are their observations of how family members now interacted with the PwD.

Both positive and negative effects on family relationships were described by the PCPs. Negative effects tended to be associated with relationships that preceded the stroke.

> *"Oh no we're quite open and we do include my two sons-in-laws. One son-in-law is exceptionally good the other son-in-law sticks his head in the sand, this isn't happening and he finds it quite difficult. Whereas before he would've come to his father-in-law and asked him for certain things he prefers now not to put him in that situation."*
>
> ***RP04 (12mths, mild/mod)***

The positive relationships described tended to be with children who had been young at the time of the stroke. The relationships that have developed between the PwD and the children have predominantly been post-stroke and so the PwD has always been the same as far as the children are concerned. Therefore for them there has been no change in how they would have communicated with them.

> *"Ok. They're great* [grandchildren]. *Of course papa is absolutely wonderful, nana's the one to give them the row! (laughter) I mean B was a year and a half and J only four days old when SP04 had his stroke. But I would recommend anybody who has had a stroke to get in amongst children. And things that you think that you can't do they make you do."*
>
> ***RP04 (12mths, mild/mod)***

However, one PCP raised the issue of the effect the stroke had on relationships and speculates about how different things might have been if the person hadn't had their stroke. She felt that the relationship that SP02 had with his nephews and nieces had been impacted on by his dysarthria and by his physical difficulties. This was due to him not being able to communicate with them or to do the activities as he would have done with his own sons. This, therefore, prevented him from becoming the uncle he might have been but for the stroke.

> *"That I think he's missed out on and that's a shame because I know he would've been a good uncle if he was ok. I know he would've done the things that I was doing. Cause he was a good dad and so I think he would've been a good uncle and it's a shame he's missed out on it."*
>
> ***RP02 (6yrs, mod)***

Within family relationships there is a further area of feelings of closeness that have developed since the stroke. This is shown with relationships between the PCPs and other members of the family and with the PwD and members of the family other than the participants in the project.

One of the PCPs describes how her relationship with her sons developed as they relied on each other to get through the difficult period post the stroke.

> *"And the boys and I are more close now as well….. Definitely the boys and I were close because we had four months where we depended on each other….. Uh, huh to get ourselves through. I think if it wasn't for them I don't know what I'd've done because they really kept my head together."*
>
> ***RP02 (6yrs, mod)***

She went on to describe her sons' relationships with their father (the PwD) and how it changed over time. Originally, they were close to their father, but post stroke they drifted apart. However, as time has progressed they have rebuilt their relationship with him.

> *"And I think that now they're beginning to get back to being close to their dad as well. Because they were close beforehand…. So you know I think they're getting back to…..Yeah there was a change and now it's going back to where it was before."*
>
> ***RP02 (6yrs, mod)***

Friendships

The PCPs talked about how friendships (both the PwD's own friendships and friendships that the PwD and the PCP share) had changed since the stroke.

When discussing the friendships that they share with the PwD they indicated that there had not been a substantial change in how they take part in these relationships.

> *"No there hasn't been any change, it's much the same as it was before."*
>
> ***RP08 (11mths, mild)***

For others the situation was different. In the case of RP04, prior to the stroke they had tended to keep to themselves and do things together. The opportunity to socialise had been impacted on for RP04, but she did not seem to be concerned by this as she felt they mostly socialised on their own prior to the stroke anyway. Factors other than the dysarthria (e.g. not being able to drive themselves) seemed to have more of an impact rather than the dysarthria.

> *"Um, no I don't think so. I mean the opportunity to socialise now is not the same. We quite enjoyed socialising on our own (laughter)…..You know we were a bit like that, it came to the weekend we'd jump in the car and away*
>
> *we'd go. SP04 doesn't drive now and I don't drive. So we're reliant on other people."*
>
> ***RP04 (12mths, mild/mod)***

The PwD's own friendships were discussed from the point of view of the PCP. On the whole they felt that friendships had not changed when the PwD had mild dysarthria and therefore the PwD was able to socialise independently and did not rely on the PCP to do so.

> *"In the beginning I think he was quite a bit nervous about how people would react to him….. But as far as they're concerned he's just SP08."*
>
> ***RP08 (11mths, mild)***

> *"I would say fine, but I don't really see it. If I know she's having friends we don't go..... No, because it's only fair, when she see us often enough. I mean when she's got her friends, well I mean, she must be alright."*
>
> ***RP06 (25mths, mild)***

> *"He gets on fine actually. He gets on really very well. I have to say. One of his friend's came to visit him the other day…. I went out to visit mother. But they sat and they chatted."*
>
> ***RP09 (4mths, mild)***

The PwD whose dysarthria was more severe felt the stroke had a greater impact on their friendships.

> *"We're friends with our neighbours…. I think he can talk easier with one couple than the other. T and S he can talk to. If they don't catch what he says they'll say 'what was that?'….. But A and K are a wee bit like his mum they don't listen very well so they aren't always catching him….. And they'll maybe avoid one to one conversations."*
>
> ***RP02 (6yrs, mod)***

> *"Yeah, so like before, she used to go to my aunt's house a lot and just go and sit up there for the night, but now she doesn't do that at all….. She'll only do it once in a blue moon. Basically when we force her to."*
>
> ***RP11 (4yrs, mild/mod)***

The PCPs' own relationships

How relationships that the PCPs have away from the PwD may or may not have changed was discussed.

One of the participants feels that she has only recently started to see her friends or family on her own.

> *"I slowly started to go out for a meal now and again. Or go away for the*

> *day. Maybe go through to a fabric shop in A. So slowly, maybe going out."*
>
> ***RP02 (6yrs, mod)***

Most of the PCPs felt that their relationships have not changed much since the stroke and that they still talked to the same people that they would have talked to prior to the stroke.

> *"No I tend to just probably tend to my immediate family, the girls. You know, we'll discuss it.* ***(Do you think that would have been the case beforehand? Would you have discussed it with the girls?)****…. Oh uh, huh. Uh huh…..* ***(And do you feel that you have the same opportunities to talk to your daughters the way that you had previous to the stroke?)…..*** *Oh yeah uh huh. Within the family we're quite open"*
>
> ***RP04 (12mths, mild/mod)***

> *"No it's the normal thing. You're never out and then suddenly you're out three weekends in a row. And when it comes to it, you think I can't be bothered going. But no, we go."*
>
> ***RP08 (11mths, mild)***

> *"It's just the same as before."*
>
> ***RP09 (4mths, mild)***

RP02 felt that she was able to talk to friends who weren't connected to her husband about her frustrations and that this was a 'safe' environment in which to express her true feelings as they wouldn't be reported back to her husband. The advantage of this situation became more important for her as time went by after the stroke

> *"Probably my friends bear the brunt of what I feel….. Probably, they would have borne the brunt of it before as well! (laughter) But probably more so now because I can sound off to them and I know that won't get back to SP02 because they won't say anything"*
>
> ***RP02 (6yrs, mod)***

The PCP with a sister-in-law with dysarthria felt that her personal relationships with her friends have changed slightly due to the responsibilities that she believed she had with SP06.

> *"I feel as though there are times, two friends in particular that I have that go on to me for being around so much. But I'm just me and I can't help it."*
>
> ***RP06 (25mths, mild)***

With the PwD

Most of the PCPs described the relationship that they now had with the PwD since the stroke. Several of the participants claimed that they now felt closer to the person than they had previously and that they now talked more than they might have done before.

> *"I feel actually that we are better than before…..I can feel that in a way it's brought us closer….. I mean we've been married a long time and we were together a wee while, a good wee while, before we got married. I think this has brought us a lot closer."*
>
> ***RP08 (11mths, mild)***

> *"Um, I'd say we're a lot closer now then we were before, but other than that it's not changed much about our relationship…… Yeah we're a lot closer now"*
>
> ***RP11 (4yrs, mild/mod)***

> *"Yeah, I would probably say it's about the same. No I can't say that we'd talk before, I think that I'd say we talk more now."*
>
> ***RP02 (6yrs, mod)***

Role Change

The PCPs described how the roles that they had in their relationship with the PwD had changed since the stroke.

For the wives of the two men with more severe dysarthria there was a perceptible change in the role that they played in their relationships. They described how they were expected to take more responsibility in conversations with others and they felt resigned to this being the case.

> *"If we're out and about he's very wary he'll not say very much.* ***(So it'll be left to you?)….*** *Uh, huh* ***(And how do you feel about that?)....*** *It's something I've got used to I suppose in the long run. I suppose that's just the way it's going to be"*
>
> ***RP02 (6yrs, mod)***

> *"I would never have had to. You know you get partners who would contradict the partners or husbands and I would never have done that and it does make me feel quite uncomfortable at times……. I think he's quite happy about it just now. I know before the stroke he wouldn't have been and that's the problem I have."*
>
> ***RP04 (12mths, mild/mod)***

The older PCPs acknowledged that compared to the period prior to the stroke their role had changed in that they now took on more responsibility and performed more functions than they might have done previously.

> *"I think going back to the very beginning when we were talking, I think one of the things if your partner, especially if your partner has a stroke. It's a big, big change, to both of you. It's a big, big change within your family setting. And if you rely on each other, being the male or the female, in my situation being my husband it's um, there's a lot of things that you have to do which they would've done. (RP04 is crying here)…… It's difficult."*
>
> ***RP04 (12mths, mild/mod)***

> *"But since the stroke we've been very responsible for her….. But she's happier on her own. But that was her life anyway and she does try to do her own business. We try to let her do as far as possible. But now, like more personal things she's more dependent on you for"*
>
> ***RP06 (25mths, mild)***

> *"Um, in a lot of ways I depended on SP09. I could be of quite low mood myself and SP09 would be the one who would do things and would keep us going, so in terms of doing practical things and doing things it's obviously been a major change."*
>
> ***RP09 (4mths, mild)***

The youngest participant, however, did not feel that there had been any real change in her role with her mother. On the other hand, the fact that she spent more time with her, or that she did not like to leave her on her own suggests otherwise.

> *"Um, no not really. I don't usually like leaving her in by herself. Other than that, not really no."*
>
> ***RP11 (4yrs, mild/mod)***

Stroke and Speech

Stroke and speech was another main theme of discussion in the interviews with the PCPs. Within this theme there were five main subthemes that were highlighted by the PCPs. These were dysarthria (which includes the changes in the PwD's speech, Supporting the PwD and the impact of dysarthria, the recovery process), behavioural changes, understanding, speech and language therapy (which also included involvement in speech and language therapy) and stroke/dysarthria information.

Dysarthria

As highlighted in the literature review, the provision of information to people who have had the stroke and to their carers is viewed as an important aspect of the rehabilitation process. Researchers argue that without a proper understanding of the stroke, its consequent impairments (in this case the dysarthria) and how to manage it, both the PwD and their carers can be more susceptible to the negative psychological aspects of stroke e.g. anxiety and/or depression. By gaining insight into how the PCPs view the dysarthria and what they understand dysarthria to be, the researcher may have a clearer insight into the other factors raised in the data.

The PCPs talked about the PwD's speech, the changes they observed and their feelings about this new situation. This included what is different about their speech, when the PwD has the most difficulties and how they and other family members manage when they haven't understood what the PwD is saying.

The Changes in the PwD's Speech

Most of the PCPs described their relative's speech being slurred or containing unintelligible sounds. They also talked about how it could be difficult to understand due to the speed of the delivery. The dysarthria impacts the ability for the PwD to communicate effectively which in turn impacts their ability to participate fully in relationships, the most important relationship for this research being the one they hold with the participants in the project. With PCPs not being able to communicate effectively with the PwD, the relationship between the two parties is subject to change.

> *"Sometimes it's a stream and it's all joined together and not specific words…."*
>
> ***RP02 (6yrs, mod)***

> *"Like she can't really produce words with /s/ in them. And she slurs her words sometimes"*
>
> ***RP11 (4yrs, mild/mod)***

> *"He's making a lot of improvement compared to what he was in the first instance…. Although he could always communicate, his speech was very slurred and he was having obvious difficulty."*
>
> ***RP09 (4mths, mild)***

The difficulty that affected the PwD's speech the most as far as the PCPs were concerned was when the PwDs were feeling tired. At such times their speech was most obviously impaired, impacting on their intelligibility.

> *"Sometimes he's better than others, but I find that when he's tired it's more slurred. When he's tired"*
>
> ***RP02 (6yrs, mod)***

> *"And the speech, umm, goes a bit when he is tired. And, I think sometimes his mouth droops a wee bit at the side"*
>
> ***RP08 (11mths, mild)***

> *"Later on when he's tired at night. If he's lying down. If he speaks to me late at night and he's lying down, I most often have to ask him to repeat himself. If we're speaking in the car he has to repeat himself."*
>
> ***RP09 (4mths, mild)***

Another difficulty raised by one of the PCPs was being out of the PwD's ideal communication environment, e.g. out of their home or being within a group setting, and how much this accentuated the PwD's lack of intelligibility.

> *"Um, or in a group setting. I think he finds that difficult. I think he can be quite comfortable within your own four walls and with your own family. It's when you go out and about and you realise that's when his difficulties are more obvious"*
>
> ***RP04 (12mths, mild/mod)***

Supporting the PwD

Another aspect of the impact of the dysarthria on the PCPs was how to indicate to the PwD that they had not understood and the subsequent feelings of unease of having to do this.

> *"But the boys found it hard, they just turn to me and go "what's he trying to say mum?"….. But it's better now because they've learnt over time….. if they say to him slow down and speak up a wee bit, he will. And even I've got to say to him "SP02 what was that? I didn't quite catch that.""*
>
> ***RP02 (6yrs, mod)***

> *"Umm, his speech, as I said earlier, um, there are times when I have to ask him to repeat it. And even when he has repeated it I ask again…. I just keep saying, "I'm sorry, I'm sorry"."*
>
> ***RP08 (11mths, mild)***

The PCPs were also able to give examples of strategies that the PwD would use to help them be understood.

> *"But he will say to people 'I've had a stroke' sometimes if they're not and he'll say 'if you don't understand me just say'. But if they're willing to take the time then I think that he'd be willing to make himself understood if he had to."*
>
> ***RP02 (6yrs, mod)***

> *"The techniques that he gets, that SLT has suggested, he knows the things that he can do….. If he does have words or sometimes combinations of letters or syllables trip him up….. He just sort of laughs and finds another word. (laughter) So he gets on fine, he gets on really well."*
>
> ***RP09 (4mths, mild)***

The impact of the dysarthria

The impact of the dysarthria varied from one PCP to another. Some felt that there were other difficulties , specifically physical difficulties, arising from the stroke which had more long term consequences for the PwD, while others felt that both the physical and speech difficulties were impacting the PwD's quality of life.

> *"The speech is better than his arm. His arm is the one that gives him more problems. Um, he was always a very quick speaker, he always spoke very fast….. But, no, I think it's more his arm that's…… The bogey, if you like. He*

> *manages not bad with the speech, but the arm….."*
>
> ***RP08 (11mths, mild)***

> *"I'm at the stage now, where I don't think she believes that her speech holds her back in any way. She's quite happy to chat, because anyone she's chatting to she's obviously confident enough."*
>
> ***RP06 (25mths, mild)***

> *"Probably both of them* [physical and speech difficulties]*, in a way. But I would say probably his speech is one of the things, because he was a talker. And liked communicating with people. I think that he finds that quite difficult now if you are in a social situation or even just out bumping into people, you know people that you meet in the street and what have you….. I think he finds it quite difficult. But I would say that's probably confidence."*
>
> ***RP04 (12mths, mild/mod)***

Recovery process

On the whole the PCPs did not talk about stroke recovery. Only one PCP talked about the general stroke recovery timescales but she did not feel that understanding this was of any importance to her. She seemed to feel that just concentrating on her husband's recovery process was the best way forward for them.

> *"In terms of what you can expect along the lines in progress, my understanding is that everybody is different anyway so you just have to keep doing what people are suggesting you do…. And you basically see what happens. I know that there are timescales that are sometimes quoted. After four months, some people say, up to four months, basically after four months you make significant improvement and then after not very much.... Whether that is true or not I don't know. But I don't try to think of that too much. I*

> *just think about trying to work as hard as we can to get SP09 to the best stage that we can get to. "*
>
> ***RP09 (4mths, mild)***

Two of the PCPs described a fluctuating recovery for their relatives. RP11 did not specify what was changing for her mum, but indicated that she appeared to improve but then deteriorated again. She felt that in order for her mother to make any real recovery she needed to get back to work again.

> *"They get better and then they get worse again and go in between….. But she's doing well just now….. Umm, no not really, I still think she needs a lot of help with a lot of things…... She was off work for a few months. Um, but then she decided to go back one day, because obviously she's not going to get any help just sitting in the house all day every day."*
>
> ***RP11 (4yrs, mild/mod)***

RP06 felt that her sister-in-law made some progress with her speech when she and her husband were living with her as there was plenty of opportunity for conversation, but she felt that her dysarthria deteriorated when they were no longer living with her.

> *"At the very beginning it was very difficult to separate, you had to always listen or ask to repeat…… It gradually improved. Because we were all in the house I think she had plenty of practice. She had conversation and she was making conversation….. But when we moved back home and she didn't have the same amount of visitors I felt it regressed a bit then."*
>
> ***RP06 (25mths, mild)***

Both RP11 and RP06 indicated here that communicating with others appeared to have the most beneficial impact on the PwD and when not having the opportunity to communicate with others, they do not or will not make substantial progress with their recovery.

Behaviour changes

PCPs described behavioural changes, both in the PwD towards speaking and in their own behaviour when supporting the PwD.

One such change was the PwD being reluctant or unwilling to answer the telephone.

> *"And I think he knew himself and so he just wouldn't answer the phone. So I think in effect we just ended up getting an answering machine service so that he doesn't answer the phone, more so for the fact if I'm out as well, erm, the answer phone is there so folk can leave a message."*
>
> ***RP02 (6yrs, mod)***

Another behavioural change was the PwD's willingness to speak to strangers or people that were not well known to them.

> *"But other than that she does pretty well. She just doesn't really like talking in front of people she doesn't really know…..But, like now she just kind of just shrinks into the background, kind of thing."*
>
> ***RP11 (4yrs, mild/mod)***

The change in the PwD's behaviour meant that the PCPs had to adjust their behaviour as well by assuming more responsibility for maintaining the flow or providing information in conversations with relatives or strangers.

> *“If we’re out and about he’s very wary he’ll not say very much….. **[left to her to do the talking?]** It’s something I’ve got used to I suppose in the long run. I suppose that’s just the way it’s going to be”*
>
> ***RP02 (6yrs, mod)***

> *“The woman doing all the talking for the men…… I think he’s quite happy about it just now. I know before the stroke he wouldn’t have been and that’s the problem I have.”*
>
> ***RP04 (12mths, mild/mod)***

> *“I think you get to be able to read the situation, where you know this is going to be a bit awkward here so you’ll work the situation round about.”*
>
> ***RP04 (12mths, mild/mod)***

The PCPs also appreciated that some of the PwDs managed to change their communication to include strategies that helped with making their interactions with others more successful.

> *“No, you know he’s quite confident. He’s quite confident on the phone and in having conversations. And he’s built in the strategies that if we’re in a group situation.”*
>
> ***RP04 (12mths, mild/mod)***

> *“when he tries to annunciate and makes things clearer, when he uses the techniques that SLT has given him he can do it….. But there are times when naturally his speech is not quite so good.”*
>
> ***RP09 (4mths, mild)***

Speech and language therapy

The timing and type of speech therapy offered to PwDs varied according to the amount of time spent in hospital and the severity of the stroke. The PCPs felt that the most beneficial input came after the PwD had been discharged from the hospital. Any intervention in hospital, according to the PCPs, appeared to be minimal or focused on other areas such as dysphagia.

> *"Aye he had the motivation. Speech wise I don't think there was anything there. I think they were more concerned about him learning how to swallow so he could eat…… Uh huh so they were more concerned with that side of it and not the speech. It wasn't until after he was out that he got speech therapy…. He was out before he got speech therapy."*
>
> ***RP02 (6yrs, mod)***

> *"And as far as I am aware he may have had some speech therapy* [in hospital]*…. He was four weeks at the …. hospital. And then when he transferred to the R hospital again the speech and language therapist came did say he had dysarthria and gave us leaflets. And basically said that would be it. When he left the hospital the speech and language therapist came up and she came for several weeks, she came for quite a length of time. And quite a length of session each time she came."*
>
> ***RP04 (12mths, mild/mod)***

> *"Just because it was a word and that was it. She just explained about the speech and she had speech therapy when she came out of the hospital, which she definitely did benefit from. She definitely did."*
>
> ***RP06 (25mths, mild)***

Not all of the PCPs and PwDs were initially clear on what services they would be able to access after the PwDs left the hospital.

> *"Something was, I can't remember how it came about, but something he was at the doctor's* [GP] *and they had said something about speech therapy and he went 'I don't know anything about speech therapy' and they referred him…. He was seen by community."*
>
> ***RP02 (6yrs, mod)***

Most of the PCPs felt that their experience with SLT had been beneficial both for them and for the PwDs.

> *"I think if he didn't have any speech therapy, if he'd come out of the hospital and there had been no follow up from the community I don't think his speech would be as good as what it is now…… It's always been that way where I've thought maybe if he hadn't had that therapy his speech wouldn't be as good and clear as it is now. And he, myself and the family wouldn't have had the understanding."*
>
> ***RP04 (12mths, mild/mod)***

> *"Um, before the SLT she didn't really know what to do, but she's starting to do now, like using breathing exercises and stuff."*
>
> ***RP11 (4yrs, mild/mod)***

One of the PCPs felt that the SLT was the right person to provide support to her husband and herself for his dysarthria and that her expertise provided the correct level of support to her and her husband to enable him to improve his ability to communicate effectively.

> *"I think it's the hospital backup, as I said before, has been very good. She obviously has a lot of experience, she's seen the whole range, she's got the equipment, she's got the techniques. She's provided something which is*

> *appropriate to SP09 at the stage that he's at…… And she'll say that and she'll point out and gives you a good feeling about how well you are communicating compared with the range"*
>
> ***RP09 (4mths, mild)***

> *"I'm SP09's wife, but it's not something that your wife, your sister or your mother can tell you, you'll ignore it quite easily or dismiss it, whereas you can sit and listen to the speech therapist saying exactly the same thing and that's more likely to be taken on board. (laughter)"*
>
> ***RP09 (4mths, mild)***

Involvement in speech and language therapy

When the PCPs talked about their involvement in the therapy process there was a mixed response as to whether they felt that they had been sufficiently involved or whether they would have benefitted from being more fully involved

Three of the PCPs felt that they had been involved from the beginning and that it had been expected that they would like to be involved, but not be obliged to participate. One of the PCPs felt particularly appreciative of been given the opportunity to participate.

> *"I wasn't quite as sure with the SLT, obviously I checked with SP09 that he was happy enough for me to be there….. so SP09 didn't mind and the SLT had no hesitation. She sort of approached it with a view that I would be wanting to come rather than 'do you think you might like to?'. I was actually pleasantly surprised…. You're also very important because you are the person that cares about this person…. Who they are going to be coming back to."*
>
> ***RP09 (4mths, mild)***

> *"Yes, uh huh, I mean she did encourage me to sit and take part….. He was quite happy with that."*
>
> ***RP04 (12mths, mild/mod)***

> *"Um, sometimes she gets me involved, because my mum doesn't really want to do exercises when I'm sitting here listening to her, so she'll try and get me involved as well….. She just says, if you want to get involved you can"*
>
> ***RP11 (4yrs, mild/mod)***

However, some of the other PCPs had not been involved in the treatment. One did not realise that she could have been involved if she had wanted to be.

> *"I didn't know if I was supposed to go with him… So I didn't know, I just thought it was him….. Probably at the start, but nobody really said whether you could go or not so I wasn't really sure whether that was something I should've went to or something I was supposed to have gone to, nobody really sort of said anything."*
>
> ***RP02 (6yrs, mod)***

However, she was not sure whether it had been suggested to her husband that she become involved, but that he had not communicated this fact to her.

> *"I don't think they ever said anything to SP02. Did I want to go or would I like to be involved, nobody really kind of said. And if they did, he never said."*
>
> ***RP02 (6yrs, mod)***

Two of the PCPs felt that it had been beneficial for them not to be involved in the therapy as the PwD would have been inhibited by their presence.

> *"Well, I would've been interested in that* [going to SLT sessions with SP06]*, but on the other hand I think that SP06 would've performed better with the therapist without me. I was too familiar."*
>
> ***RP06 (25mths, mild)***

> *"I stayed in the background and just let him get on with it…. I was happy to sit in the back and just let him get on with and feel as if he was actually doing something."*
>
> ***RP08 (11mths, mild)***

The PCPs who did take part in the therapy process felt that it had been a profitable experience for them.

> *"Well, yes because he'd have work to do for the following week when she came back so it was quite good that we could sit in a daily basis and do some of the work. Because it was quite, he did get quite a bit of work to do….. And exercises and what have you so it was quite good to put that into your daily routine really…… So yes it was very helpful.*
>
> ***RP04 (12mths, mild/mod)***

> *"But generally speaking from the hospital onwards to the speech therapist and the physiotherapist showing me some of the things I can do, um, to help SP09 can do to get his arm to relax and straighten…… And that's been really good because you feel as if you are contributing and you are able to do something practical that will with any luck, help towards the progress. If it helps with SP09 as well….. Because he has to do these things and if it's something that he's not having to do all on his own."*
>
> ***RP09 (4mths, mild)***

> *"Yeah I think it's pretty good….. Yeah, before I didn't really know much about the speech and stuff but now I'm learning a bit more."*
>
> ***RP11 (4yrs, mild/mod)***

Stroke and Dysarthria Information

The PCPs discussed the information that they received about stroke in general and about dysarthria. This included information given in the hospital at the acute stage of the stroke and during the rehabilitation process. Two of the PCPs talked about information provided at this time. RP02 did recall being given a small amount of information, but as her husband had to be moved to intensive care, their whole focus changed.

> *"I think we got stuff on the ward. One time I was in the nurses gave me some stuff. But not really an awful lot….. Because he wasn't really in the ward that long before he got shifted in to intensive care.…. And then intensive care is completely different ball game."*
>
> ***RP02 (6yrs, mod)***

RP11 reported that they hadn't been given any written information and were only told verbally who they should contact and see to get support. Her experience of the support provided did not appear to be positive and she describes a situation that implied her mother was abandoned by the health professionals.

> *"Um, we didn't really get much information really. They basically just told her "you need to go to this person and that person" and then that stopped. So she just got forgotten about."*
>
> ***RP11 (4yrs, mild/mod)***

RP09 felt that information about stroke and stroke recovery was not regarded as their top priority. While she had a general understanding of stroke recovery she wanted to concentrate their attention primarily on her husband's recovery and how that progressed on its own with appropriate support from her and the health professionals.

> *"I know that there are timescales that are sometimes quoted. After four months, some people say, up to four months, basically after four months you make significant improvement and then after not very much…… Whether that is true or not I don't know. But I don't try to think of that too much. I just think about trying to work as hard as we can to get SP09 to the best stage that we can get to."*
>
> ***RP09 (4mths, mild)***

The dysarthria information provided to the PCPs and patients came from the SLT in all of the cases. All of the PCPs felt that the SLT was the appropriate person to give the information and to support them in managing the impairment.

> *"Well we never had experience anyway, because nobody in the family, with other brothers or sisters had any problem like that….. It was only until the speech therapist, the girl, came up and explained to us what dysarthria was."*
>
> ***RP06 (25mths, mild)***

> *"Yeah, before I didn't really know much about the speech and stuff but now I'm learning a bit more."*
>
> ***RP11 (4yrs, mild/mod)***

RP04 researched dysarthria herself after she had been given the name of the impairment and found that this helped her understand the condition.

> *"Yes once they had actually given us a name of what problem he actually had and then it was easy enough to go find out some information. Went to the library and got some books and what have you."*
>
> ***RP04 (12mths, mild/mod)***

Understanding

Understanding has many complex levels in relation to the PCPs' experiences with dysarthria post-stroke. First is the ability to understand the PwD when the PCPs and others are communicating with them in every day environments.

> *"Just sometimes when you are in the car. That can be difficult, when you're in the car. But then sometimes you might have the radio on or you might have a granddaughter sitting in the back seat. Asking hundreds of questions and then grandpa says something, sorry what was it again?"*
>
> ***RP08 (11mths, mild)***

Some of the PCPs described their awareness of the PwDs' difficulties with other people understanding them in social situations.

> *"They just look really confused (laughter). They just kind of nod their head and then turn away from her kind of thing…. They don't outright say anything to her but you can tell just by the way that they are acting…. I know."*
>
> ***RP11 (4yrs, mild/mod)***

> *"I think it's more now if you are out and about socialising. He becomes more aware of, um, difficulties…… Um, or in a group setting. I think he finds that difficult….. It's when you go out and about and you realise, that's when his*

> *difficulties are more obvious."*
>
> ***RP04 (12mths, mild/mod)***

Another facet of this theme is understanding dysarthria as an impairment and how it will impact effective communication.

> ***(Did you feel as though you had an understanding of his dysarthria?)***
> *"Nope..... When we went to that research thing. And that was really it. Six years after it* [the stroke]*."*
>
> ***RP02 (6yrs, mod)***

Finally, one PCP talked about how the level of understanding that she received from the professionals providing care to the PwD supported her in the period following her husband's stroke.

> *"Yeah, I felt, I didn't feel that I was left sitting wondering what was happening.... I wasn't quite as sure with the SLT, obviously I checked with SP09 that he was happy enough for me to be there..... SP09 didn't mind and the SLT had no hesitation. She sort of approached it with a view that I would be wanting to come rather than do you think you might like to. I was actually pleasantly surprised....... You're also very important because you are the person that cares about this person."*
>
> ***RP09 (4mths, mild)***

Thematic Data Summary

The results of the thematic data discussed have shown the three main themes: Feelings, Relationships and Stroke and Speech. Illustrative quotes have been used to show the points raised by the participants in the project. The issues raised have been highlighted to show how each of the PCPs has viewed their experience of the dysarthria post stroke. The three main themes and their subsequent subthemes have been generated from their opinions and descriptions. The following section will focus on the data collected from the questionnaires.

GHQ-12 and CaCOAST

The GHQ-12 and CaCOAST provide the quantitative data results to complement the qualitative data from the semi-structured interviews data. The CaCOAST was used to investigate numerically how the PCP felt about how their own relationships and feelings were impacted upon due to their relative's dysarthria. The results from the whole scale encompassed the third aim of the project, 'how the PCP understands and copes with supporting the PwD', with particular focus on the understanding. The five quality of life questions were examined independently to add further insight into their feelings about the dysarthria and how this has impacted their relationships, the first and second aims of the study. The GHQ-12 was to provide an idea of how the PCP's were feeling about their well-being generally, rather than with specific focus on the dysarthria.

Table 4.1: Carer COAST RESULTS

Participant	Raw Score	% Score
RP02 (6yrs, mod)	48/80 x 100	60
RP04 (12mths, mild/mod)	53/80 x 100	66
RP06 (25mths, mild)	46/80 x 100	58
RP08 (11mths, mild)	63/80 x 100	79
RP09 (4mths, mild)	66/76 x 100	87
RP11 (4yrs, mild/mod)	47/80 x 100	59

Table 4.1: Carer COAST results for the whole scale.

Table 4.1 shows the Carer COAST results for the whole scale, including the participant's rating of the PwD's communication ability, from their perception, as well as their own quality of life. The percentage is based on the five questions with a maximum of 4 points per question e.g. 100% is 80 points. The final scores have been rounded to the nearest whole number.

The three participants whose relative had mild to moderate or moderate dysarthria all scored under 67% in the CaCOAST results. For RP08 (11mths, mild) and RP09 (4mths, mild), whose relatives both had mild dysarthria, results were 79% and 87% respectively. RP06's (25mths, mild) relative also had mild dysarthria, but she rated the lowest score of 58%.

Table 4.2 shows the results of the participants rating their own quality of life and how it has been impacted by the dysarthria using the Carer COAST rating scale. The percentage is based on the five questions with a maximum of 4 points per question so 100% is 20 points. RP08 (11mths, mild) rated her quality of life as predominantly quite good. However she had a relatively low score for being worried/unhappy. RP09 (4mths, mild) scored her quality of life between fair and quite fair. RP02 (6yrs, mod), RP04 (mild/mod) and RP06 (25mths, mild) all rated themselves at 50% on the quality of life questions. These scores indicate that they rate their quality of life to be fair. RP11 (4yrs, mild/mod) rated her quality of life as 45% on the quality of life questions. Her answers indicate that she feels her quality of life is somewhere between fair and quite poor. RP02, RP04 and RP11 all had relatives with dysarthria which was mild/moderate or moderate. It is therefore possible for them to see more clearly that the speech impairment has impacted their quality of life. They also have the longer periods of time post-stroke possibly allowing them to feel the long-term effects of the condition. RP06 is the only person whose relative had mild dysarthria and a low score. However, it is felt that she did not rate herself according to the instructions. This is discussed in more detail below.

Table 4.2: Carer COAST QUALITY OF LIFE QUESTIONS RESULTS						
Questions	**RP02 (6yrs, mod)**	**RP04 (12mths, mild/ mod)**	**RP06 (25mths, mild)**	**RP08 (11mths, mild)**	**RP09 (4mths, mild)**	**RP11 (4yrs, mild/ mod)**
Family life	2	2	2	4	4	2
Social life	2	2	2	4	4	2
Interests	2	2	2	4	3	2
Worried/unhappy	2	1	2	2	3	1
Quality of life	2	3	2	4	3	2
Raw Score	10/20 x 100	10/20 x 100	10/20 x 100	18/20 x 100	17/20 x 100	9/20 x 100
% Score	**50%**	**50%**	**50%**	**90%**	**85%**	**45%**

Table 4.2: Carer COAST quality of life questions results.

Table 4.3 shows the results of the General Health Questionnaire ratings, Carer COAST and Carer COAST QoL questions. For the General Health Questionnaire a score of 12 indicates no change in the PCP's general well-being over the past few weeks, less than 12 indicates improvement and more than twelve indicates that there has been a decrease in well-being.

RP02 and RP04 have slight increases in their GHQ-12 score indicating that they felt slightly negative about their current well-being. As it is only a slight increase it would not indicate that they were having difficulties that would be of clinical concern. RP06 and RP08 both rated themselves as 12, indicating that there had been no change in their wellbeing.

RP09 and RP11 both had a score of 18 indicating that there had been a significant decrease in their wellbeing. It should be noted that at the time of the interview, RP09's husband had had his stroke only four months previously. The occurrence of her husband's stroke was relatively recent and was likely to have been a highly stressful time for her. Unlike the other participants, she had not had significant time to come to terms with the stroke and her focus is likely to have been on helping her husband through his rehabilitation. It is therefore not unexpected that she would view her own general well-being at that time as quite poor.

Table 4.3: GHQ-12, Full CaCOAST and CaCOAST QoL RESULTS

Participant	GHQ-12	CaCOAST	CaCOAST QoL Questions
RP02 (6yrs, mod)	14	60%	50%
RP04 (12mths, mild/mod)	13	66%	50%
RP06 (25mths, mild)	12	58%	50%
RP08 (11mths, mild)	12	79%	90%
RP09 (4mths, mild)	18	87%	85%
RP11 (4yrs, mild/mod)	18	59%	45%

Table 4.3: Summary of the GHQ-12, CaCOAST and CaCOAST quality of life results.

The comparison of the results between the GHQ-12 and the CaCOAST shows the impact of the dysarthria on how the participants view their general health and their well-being. RP06's results are the only ones whose GHQ-12 and CaCOAST do not correspond with her interview data. She has rated her general health as being normal, but her quality of life in relation to SP06's dysarthria as being very low. It is possible that she has misinterpreted the scale and measured her general quality of life. The instructions for the scale clearly state *"Questions 16 – 20 are slightly different; they ask you about how your relative's communication problems have affected your <u>own</u> quality of life"* (Long et al, 2009, pg 2 of CaCOAST Scale Script). The data from the interview with RP06 clearly states that she does not feel the impact of SP06's dysarthria. However, she describes several times how caring for her generally has negatively impacted her retirement plans and her relationships with her family and friends.

RP09 rates her general health as being poor, but she does not appear to be impacted by her husband's dysarthria as her rating on the CaCOAST quality of life questions is quite high. This would fit in with her interview and the information that she provided during it. RP08 does not appear to have any concerns about either her general health or the impact of her husband's dysarthria on her own quality of life. Again, this supports the data from her interview.

RP02 and RP04 both have slightly increased results from their GHQ-12 ratings and only 'fair' ratings from the CaCOAST quality of life questions. This would indicate that they find their husband's dysarthria to be impacting their own quality of life. These results would fit the data from their interviews. RP11 has low results in both the GHQ-12 and the CaCOAST. These results, again, are consistent with her interview data. She described situations that indicate that she found her mother's dysarthria was impacting her well-being which is evident in her low CaCOAST quality of life rating. However, she obviously had more general concerns about her well-being which become evident in her low rating on the GHQ-12. At seventeen, RP11 was the youngest participant in the study. RP11 was 14 when her mother had her stroke. Her interview data seemed to indicate that she did not feel supported by health professionals after her mother left the hospital. However, when asked about who she would feel comfortable speaking to about her concerns or worries, she said she would most likely turn to her sister, who also lived with her and her mum, or her aunt.

Conclusion

Both the interview and questionnaire data have provided relevant points which are to be discussed further. While the sample size is small there appears to be evidence to support the assertion that the PCPs' psychosocial well-being is impacted by post-stroke dysarthria. However, this appears to be more apparent for the PCPs whose PwD had mild to moderate or moderate dysarthria, rather than for the PCPs whose

PwD had mild dysarthria. This was evident in both the interview and questionnaire data. Furthermore, the PCPs whose PwD had mild dysarthria stated other factors as being the main cause of their disruption e.g. through physical difficulties or taking on a more significant general caring role. However, the participants whose PwD had mild dysarthria still had relevant information to provide and their story of the stroke impact has been described in detail.

The discussion chapter will discuss the data from both the interviews and the questionnaires alongside the relevant literature.

Chapter 5: Discussion and Conclusion

The main aims of this project were to investigate the effects of post-stroke dysarthria on the primary communication partner's (PCP) psychosocial well-being. Particularly, insight will be gained on:

- their feelings about the dysarthria and how that impacts them
- how their own relationships have been impacted both with the PwD and independent of the PwD
- how the PCP understands and copes with supporting the PwD

The participant views gained through the semi-structured interviews and two questionnaires, GHQ-12 and the Carer COAST will now be drawn together to discuss these aims fully . As all participants completed all three components the views of all were fully represented and exemplified by direct quotations from the interviews. Using the questionnaire data to support the interview allowed the views of the participants to be represented in both qualitative and quantitative form. This allowed for each data set to be strengthened by each of the others (Barbour, 2001).

Using combined qualitative and quantitative methods for data collection in a study can provide a fuller picture of the research topic (Brinton and Fujiki, 2003). However, qualitative studies focus on a discrete sample size (Holloway and Wheeler, 2010) while quantitative studies tend to have larger sample sizes. In this research project the sample size was limited to the six participants. This allowed for in depth data to be collected via interview. The PCPs had a considerable amount of time with the researcher to fully discuss the topic as they progressed through the interview. Through the comparison of data the similarities between the PCPs answers could then be drawn. The answers from the questionnaires were directly compared to the interview data of the individual participants, but inferential statistical treatment of the data is not appropriate due to the small sample size. The advantage of using questionnaires in this study has been that it has provided support to what the PCPs have said in their interviews. While the CaCOAST is limited in the number of questions focusing on the PCPs' quality of life, it is currently the only available questionnaire specifically for PCP's of PwD. The GHQ-12 provided a baseline for the PCP's general health and well-being. This meant that it was possible to see which participants had been directly impacted by the dysarthria and the extent of this impact and which participants had a general decrease in well-being by comparing the answers to the CaCOAST and the GHQ-12. While the comparison between all three data sets allows for patterns to be found, it is important to acknowledge that the sample size is small.

Summary of Findings

From this sample there is evidence that PCPs are impacted by dysarthria post-stroke and indications that the severity of the dysarthria will determine the significance of this impact. The type of relationship, i.e. spouse, sister-in-law or daughter, which the PCP has with the PwD also appears to affect the impact of the effects of post-stroke dysarthria. A less close familial relationship e.g. the sister-in-law and the PCPs' whose husbands had milder dysarthria placed more impact on other factors, e.g. physical or cognitive difficulties, than on the dysarthria.

Overall, the provision of information about dysarthria was important to the PCPs. It seemed to be something that was required at several points along the rehabilitation pathway as some PCPs did not know or understand the diagnosis of dysarthria until some time had passed post-stroke. Inclusion in speech therapy sessions was something that four of the six participants felt had been helpful. However, it would appear to be something that should be assessed on a case by case basis.

There are three main themes identified in the interview data: 'Feelings', 'Relationships' and 'Stroke and Speech'. These themes highlight the PCPs main interpretations of their lives since their husband, mother or sister-in-law had their stroke. While analysis of this data is relevant it must be acknowledged that the sample size is small and the sample did not include any participants whose PCPs had severe dysarthria. Therefore, while there are themes evident, further study with a larger population size would be required in order to make generalisations.

Feelings and Relationships

The following sections will discuss the data from the interviews and the questionnaires particularly focusing on the first two aims of the study which concentrated on the PCP's feelings and their relationships in relation to the dysarthria. The reason for crossover between the two aims in the discussion is due to how the PCPs described these to the researcher. They often spoke of their feelings and then how this impacted their relationships. While the analysis of the data naturally split them into different themes, when summarising the findings in this discussion they combined together to tell the story of the PCP's experiences in a more succinct and fluid narrative.

Research discussed in the introduction and literature review revealed that the severity of the dysarthria did not influence the PwD view on the impact of their own communication ability (Dickson et al, 2008; Hartelius et al, 2008). PwD who had mild dysarthria felt that the impact was the same, or even in some instances, greater than those who had more moderate or severe dysarthria. However, in the main, for the PCPs in the current study the greater the severity of the impairment (in this study mild to moderate or moderate dysarthria as none of the PwD had severe dysarthria), the greater they rated the impact on their own well-being. This can be seen in the CaCOAST results for RP02, RP04 and RP11 whose relatives all had mild/moderate or moderate dysarthria. They all rated their own quality of life as being 45-50% (see Tables 2 and 3). However, RP08 and RP09 whose husbands both had mild dysarthria rated their own well-being as 90% and 80% respectively. RP06 was an anomaly to these results, rating her well-being as 50% even though her sister-in-law had mild dysarthria. Her results will be discussed in more detail later, with hypotheses for why she has rated herself as such.

The following sections ‘Relationships and Role Change’ and ‘Psychological Impact’ will discuss the first two aims of the study covering feelings and relationships.

Relationships and Role Change

Throughout the research the relationship that the PCPs share with the PwD has been integral to the collection, analysis and discussion of the data. One aim of the study was to investigate whether there was an impact on the relationships that they shared with the PwD due to the dysarthria, e.g. did the dysarthria have an impact? If so, was it positive or negative? This will be discussed in more detail here taking into account the PCP’s point of view from their interview and rating scales and comparing this with what is already known from other studies from other communication disorders e.g. aphasia.

The interview data for those with a lower rating of quality of life supported this score, with RP02, RP04 and RP11 placing more emphasis to the impact of their relative’s dysarthria to their own well-being. For instance, the feelings of irritation that were highlighted by them were connected to situations where they were expected to speak or ‘interpret’ for them when speaking with family, friends or strangers. Some of the PCPs have been left feeling frustrated and annoyed for the PwD and for themselves when other people do not take the time to listen to the PwD, therefore, leaving them out of the conversation or immediately looking to the PCPs to interpret. Specifically, RP02 and RP04 described instances where they were now expected to take on some of their husband’s role in conversations, which at times could be difficult for them.

Dickson e*t al.*, (2008) write of how other people speak directly to the carers rather than speaking to the PwD, which has been the experience of some of the PCPs taking part in this study. Brady *et al.*, (2011) state how initially PCPs take on the role for the PwD as they are the ones who understand them best, but then this becomes unsatisfactory as time progresses as this may not be an appropriate long-term solution for the PwD and their PCP. Again, this appears to be the case in this data, with RP02 and RP04 describing the difficulties that they now face being the main ‘interpreter’ for their husbands and their discomfort with doing this. While previously the perspective from the PwD stated that although at times this was helpful, over time it becomes annoying for them (Brady *et al.*, 2011), this research shows that the PCPs can also find this aspect of supporting someone with dysarthria post-stroke frustrating and uncomfortable.

This is apparent in post-stroke aphasia data as well. Relatives feel that they are required to make a certain amount of effort to help the person with aphasia maintain their role within an exchange (Le Dorze and Brassard, 1995). The relationship of the relative to the person who has had the stroke has been raised in this aphasia research as well, with spouses being highlighted as having particular difficulties with the communication impairment. This is supported by the feedback from PCPs in this research as the spouses in particular mentioned more difficulty being the crutch for their husbands in conversations.

It can be difficult to separate the impact of the dysarthria specifically from the impact of the stroke as a whole. For the participants whose relative had more significant dysarthria, it appeared to be easier to see the direct impact of the speech impairment as their descriptions of the situations they experienced were related more often to dysarthria rather than other aspects of stroke, e.g. physical difficulties.

However, not all changes in relationships were perceived to be negative. Several of the PCPs discussed positive changes in the way that they now communicated with the PwD and how this has developed feelings of closeness. RP11 feels the ‘specialness’ of her relationship with her mother now, while RP02 described her relationship with her sons, and how this developed due to her husband's stroke, as they supported each other through the time after the stroke.

Psychological Impact

Stroke is a very emotive subject. It can conjure up significant feelings for those who have had experience of it, whether it is direct experience from having a stroke themselves or from having a member of their family or friends having had one (Stroke Association, 2013). The impact of a communication disorder post-stroke can also cause many different feelings to occur (Mackenzie *et al.,* 2007). While there is evidence for aphasia having an impact, there is limited information for dysarthria for the PwD and none for the relatives. Previous research has looked at the impact on the person who has had the stroke. The current research focused on the relatives of those who have had a stroke. There is evidence from this research, even though it is of a very small population size, that the impact of dysarthria can affect the PCP's psychological well-being as well as that of the PwD.

PCPs described feelings of initial shock that the stroke had occurred. They also described how these feelings changed to acceptance over time. This included at what point they had to accept things were not going to change and they had to learn to take a step back and allow the PwD to become independent again, as well as accepting that sufficient time has passed (e.g. over a year) and that it is likely that the impairments that are left are going to be long-term. This was particularly pertinent for RP02 and RP04 whose husbands had more significant dysarthria and their focus was more on the impact of this. RP06 talked about how her acceptance of the change in her life as a carer for her sister-in-law and the impact on her own retirement plans.

These PCPs description of their lives since the stroke and how they had changed and developed over time appears to have followed the process which is described in

Tanner and Gerstenberger's (1988) paper about grief response caused by a communication impairment post-stroke, with the initial feelings of shock and the fear of not being able to support the PwD appropriately, through to eventually accepting the situation and taking on their new role or identity as a carer.

In comparison, RP09, whose husband was still relatively early in his post-stroke journey, still spoke of the focus being on her husband's possible recovery and the feelings of hope that there is a possibility of significant change. For her the stroke as a whole was the focus, rather than the dysarthria.

RP06 data showed that there had been a significant impact on her well-being since her sister-in-law had had her stroke. The results of the quality of life questionnaire, CaCOAST were very low at 50% for her own quality of life and 58% when including her rating of SP06's communication. However, interestingly her GHQ-12 results indicated that her well-being had in fact not been impacted with a score of 12. There was evidence in her interview data that she felt very much impacted by the responsibility of looking after SP06 since her stroke. There were several extracts that indicated this including:

> *"But since the stroke we've been very responsible for her….. But she's happier on her own. But that was her life anyway and she does try to do her own business. We try to let her do as far as possible. But now, like more personal things she's more dependent on you for"*
>
> ***RP06 (25mths, mild)***

> *"Well, since I retired, I'll be quite honest with you, she's taken over our lives……. But as I say, we're very involved with her. Cause as I say there's only us, my husband and myself as her family…… As I say, it has changed our lives."*
>
> ***RP06 (25mths, mild)***

However, on analysis of these extracts and of extracts relating specifically to SP06's dysarthria, it can be deduced that it is not the speech impairment that is the cause of her difficulties but SP06's other difficulties e.g. possible cognitive difficulties and physical difficulties, post stroke that have caused her to lose some of her independence. RP06 says directly in her interview that she did not feel that there was any on-going impact of the dysarthria on SP06's ability to communicate effectively and that she had not taken on any responsibility due to the dysarthria.

> *"I'm at the stage now, where I don't think she believes that her speech holds her back in any way. She's quite happy to chat, because anyone she's chatting to she's obviously confident enough."*
>
> ***RP06 (25mths, mild)***

Her responsibilities lay with predominantly having to take SP06 places or to carry out other jobs for her. This was due to the fact that there were no other relatives available to share the load with RP06 and her husband and they felt an obligation to be there to support her. It is possible that when RP06 completed the CaCOAST she focused on the impact of the stroke as whole, rather than on the dysarthria when answering the questions. The instructions clearly state that the person completing the questionnaire should consider the communication disorder e.g. dysarthria and how this in particular has impacted their well-being. RP06's answers here do not relate to her feelings on the dysarthria from the interview and to the data from the GHQ-12.

While the CaCOAST is presented as a resource for capturing carers' feelings on communication post stroke for both aphasia and dysarthria, the main focus of the questionnaire is directed to carers of people with aphasia. However, due to the paucity of appropriate resources towards post-stroke dysarthria, this questionnaire was deemed to be the most relevant and useful for this research. It is apparent that while the Government, stroke charities, clinicians and researchers are in agreement that carer views are an important part of rehabilitation in stroke, better measures for gathering these views are still required in the area of post-stroke dysarthria. While RP06's results from the CaCOAST do not appear to fit with her view evident in the interview data, the other participants seem more consistent. Therefore, it could be viewed that RP06 is an anomaly for this data set.

RP08 and RP09 both had relatives with mild dysarthria. Their scores from the CaCOAST did not indicate any real impact on their own quality of life. However, SP09 scored very low on the GHQ-12 indicating that there had been an impact on her well-being. Her husband had very recently had his stroke (four months previously). The GHQ-12 asks questions about the subject's current general health and wellbeing, while the CaCOAST focused on how the communication impairment (in this instance the dysarthria) has impacted the PCP's quality of life. It can be assumed from these results, in conjunction with the data from the interview, that SP09's stroke as a whole had impacted RP09's wellbeing as opposed to the dysarthria specifically.

RP08 and RP09's interview data showed that they did not feel that the dysarthria had impacted their wellbeing. They rated other difficulties post-stroke, specifically physical impairments, as their main cause of their distress. While they described some instances when their husbands' impaired speech caused some difficulties, they felt that both their husbands were capable of handling the dysarthria and that they did not feel any long term disadvantage to their wellbeing. However, this is not to say that they have not experienced some aspects of frustration or irritation due to their husbands' dysarthria. They have both experienced feelings of conflict due to them not being able to understand their husbands when talking. This was mostly felt to be when their husband was tired and therefore less able to communicate effectively. They both describe using humour as a way to combat their feelings of inadequacy. This was not something that the other participants raised, but RP08 and RP09 both felt that it was a suitable way to combat any negative feelings or situations.

While dysarthria presents itself in a different way to aphasia, they are both communication impairments that can occur post stroke. While the research for dysarthria post-stroke is lacking, comparisons with other communication impairments must be drawn. It is relevant to look at general stroke research and post-stroke aphasia research.

Le Dorze and Brassard (1995) researched the impact of aphasia on the relatives, gathering information from them directly through focus groups. They found that severity of aphasia did not seem to be indicative of the number of problems reported. However, the severity of the impact may very well be different for different people involved in the relationship. Therefore, it is important to consider each person's perspective. While the data from this current project seems to indicate that severity of the dysarthria is impacting the PCP's well-being, the severity is not a guaranteed measure of how the PCPs may be feeling. The aphasia research indicates that it is important to consider each person's perspective when supporting friends and family whose relative has aphasia (Le Dorze and Brossard, 1995). They go on to state that friends and relatives are affected by aphasia and have need for specific attention for dealing with these problems. If these problems are not addressed this can lead to further difficulties down the line. It is worth noting that in this research both the relatives and the person with aphasia agreed that there are communication problems, but they did not always agree the degree of the difficulty. This further supports the idea that all perspectives of the persons involved in the relationship need to be sought as they may not agree and may require a different tact or support.

Coping with Supporting the Person with Dysarthria

This section of the discussion centres on the aim to investigate how the PCP understands and copes with supporting the PwD. This is specific to the role that the SLT will play in intervention and information provision for the PCPs of PwD.

Stroke and Dysarthria Information

With relatives being considered as much a part of the health care team as NHS staff (Scottish Executive, 2006 and 2010; National Health Service in Scotland and Giles, 2007), it seems important to get their view on being given stroke and dysarthria information. It is hypothesised that educating the PCPs on the dysarthria encompassing how they best support the PwD will help reduce their feelings of inadequacy and anxiety, empowering them to feel more positive towards their own wellbeing. However, only one PCP talked about information for stroke recovery in general in any great detail. RP09 felt that this information was not important to her and her husband. She felt that the most important information was just what she could do to support her husband to help with recovery and not the statistics associated with recovery timelines etc. She felt that she just wanted to be focused on him and his recovery process alone. She felt that the information that she had been provided with had been excellent and she had felt extremely well supported by all the health professionals involved in her husband's care and that she had been treated as an equal member of the rehabilitation team at all times. She found this to be a very positive experience during her husband's treatment.

While all the PCPs were asked about whether they received information or whether they felt that it was an important aspect their experiences seemed very variable. RP11 did not remember being given any written information, only verbal. Her description of her experience appeared to be relatively negative with her feeling almost abandoned by the medical services. She was particularly young at the time of her mother's stroke, 13-14 years old, and she had the support of her sister and aunt. Her views on the situation should not have been discounted because of her age, as the views of all family members should be taken into consideration, particularly if they were as directly impacted as she had been. However, as the research implies, stroke information needs to be presented at several different times throughout the rehabilitation process as different people find information useful at different times (IRISS, 2011). The stability of the person who has had the stroke may be variable during the immediate period after the stroke and so the focus is completely on supporting them to get better. When they return home there are other pressures on the PCPs as they all adjust to the new demands of a caring role. In order for families to access the appropriate information it would make sense for health professionals to provide information at regular intervals. With all members of the rehabilitation team providing the information to the relatives it is hopeful that they will eventually access them at the right time, or at least be provided with the information they require to find support when they may need it.

Participation in Speech and Language Therapy

RP04, RP09 and RP11 all participated in SLT sessions which were provided by NHS community therapy SLTs. They all reported finding this a useful process and had enjoyed taking part in the therapy. They felt that they had been helpful towards their relative's recovery process and that this had been a beneficial aspect for both them and the PwD.

RP02 did not realise that she could go to the therapy sessions with her husband. However, she was unsure if this was due to her husband not informing her that she could take part or that the SLT had not suggested it as a possibility. Due to the fact that she had not taken part in the therapy process she did not know or understand her husband's condition until six years after the stroke had occurred. SP02 had suffered a significant stroke putting him in intensive care for a long period of time.

His stroke left him with long-term physical impairments along with dysphagia. While in hospital his dysphagia was the main area of concern for the SLT, so RP02 felt that it was not until he was back home and he settled in again that his dysarthria became more of a focus. It was at this point that they went to see the GP and he supported them in accessing SLT sessions. SP02 went to these sessions independently and so RP02 was not given the opportunity to learn more about his condition at this point. However, when she attended the group therapy sessions for the 'Living with Dysarthria' project, she felt that she learnt a significant amount which she would have been grateful for many years previously.

RP06 and RP08 did not feel that their involvement at SLT sessions was relevant. They both felt that the PwD was more likely to gain from the sessions with the therapist without their input. They felt that they did not need help to interact successfully with the PwD and in supporting them with interacting with friends and family. However, RP08 did highlight issues with understanding her husband at times, specifically when he was tired, but this was not as significant an issue to her as his physical impairments post-stroke. The support of SLT and dysarthria information was not felt by them to be necessary to develop their own wellbeing. Other factors were more concerning to them in terms of their own psychological welfare e.g. physical impairments or ability to function independently.

Both RP02 and RP04, whose husbands' dysarthria was more significant, felt that being well informed about the condition was beneficial. In fact, when asked what advice they would give others who might be in a similar position to them, they both suggested reading and finding out as much information about dysarthria as possible as this would help them understand and support their relatives post-stroke.

This is something which is echoed in the data collected from the *Living with Dysarthria* project (Mackenzie, Kelly, Paton, Brady and Muir, 2013) in which the PCPs taking part in this current study fed back their views of group therapy sessions for dysarthria in focus groups. They felt that while it was difficult at times to talk about the causes, the impact and the recovery process of stroke and dysarthria, it was important to have this information and they benefitted from having improved knowledge and understanding of their relative's communication disorder.

Providing patients and carers with the key skills and independence to manage the condition will allow the impact of their condition to be lessened. The Scottish Executive's framework for Adult Rehabilitation (Scottish Executive, 2007) highlights the importance of acknowledging the patient's and their relative's expert view on their condition and how it impacts their lives. It states the importance of including them as central members of rehabilitation team. They present the argument that by doing this they are able to take greater control of their treatment which in turn will increase their quality of life and decrease their dependence on health care resources.

The central question for discussion here is how the pertinent information is provided to the carers. Frequently information leaflets are disseminated to the carers so they can be educated about stroke, the consequent difficulties and the services that they may be able to access (Stroke Association, 2013). As discussed previously, each patient's presentation is different due to, for example, the location of their stroke within their brain, their capacity to recover and their personality. Therefore, one might question whether one leaflet is really capable of covering everything for each individual patient and their carers. Perhaps it would be more appropriate to consider a leaflet as the starting point, with general information on stroke and its causes and the possible effects. It could then be made clear that if patients or carers have any further questions they could return with these. At this point the information provided could be tailored to the individual. However, it might also be expected that the provision of information would be an on-going exercise as the effects of the stroke are processed and accepted.

There are many ways to provide carers with sufficient information about the impairment, its consequences and the prognosis. This could be done by providing the carers with a special course about the stroke and the communication impairment, by providing family therapy, or by allowing carers to attend speech and language therapy sessions with the patient. This would be a very personal situation, as the patient may not want their relative to be present for certain therapy sessions and so the therapist should provide it as an option and try to provide a rehabilitation programme which suits everyone. Including the family within the therapy programme will allow everyone to develop into the new roles by providing them with information and strategies (Muller and Code, 1989). Certainly carers taking part in the *Living with Dysarthria* group programme (Mackenzie *et al.*, 2013) indicated their appreciation of having been included within their relative's therapy sessions and the resulting benefits to their own knowledge and therefore their ability to support them.

Wahrborg (1991) outlines how information should be provided to patients and carers to ensure that they are having enough time to process all the relevant information. He feels that a suitable information programme should be developed and provided at least twice – the first time at the onset of the stroke and then again a few months later. A third provision of the same information should then be provided during the intervention period. He also suggests that the information is conveyed through the same person at each point, e.g. a key worker, so for a communication difficulty it stands to reason that the main person in contact would be the speech and language therapist. For this type of information it would be best for the trained professional to be giving the information to avoid any misinformation being given or for unrealistic expectations being developed by the patient or the carers. Providing information in this manner will allow for any pertinent questions to be answered and for support to be provided.

Implications for Practice

With the change towards a community based NHS and with family taking on an active role in the caring process for PwD, SLTs working in the area of stroke must be aware of the impact that communication disorders such as dysarthria are having on the PCPs. As no one person will react to a stroke, or, indeed, follow the same rehabilitation path, it will be difficult for SLTs to be instantly aware of who may require support and who does not. However, by investigating the possible effects of dysarthria post-stroke on PCPs, this piece of research suggests a need to provide them with intervention or support. Therapists have a duty of care to uphold to the patients and part of that duty of care is to include PCPs within the intervention package (RCSLT, 2005). While this is the first piece of research looking directly at the impact of post-stroke dysarthria on PCPs, it does not mean that way therapists approach intervention should be altered. For example, if SLTs are following the code of practice and are including PCPs automatically within therapy then they should be able to access the PCPs who require support or be aware of their need and therefore provide them with relevant intervention, e.g. helping them to understand dysarthria and the possible impact of the speech impairment and how to support the PwD. How this support is provided is the question that requires answering. Do SLTs provide PCPs with the opportunity to have a 1:1 session where they can explore these issues with them in depth in an environment which the PCP will feel able to give an honest opinion without the PwD being present? Or would groups with other PCPs be more suitable so SLTs can reach several PCPs at one time, which would probably suit service restrictions better in terms of therapist time availability and for peer support for the PCPs? Again this is really a decision that the SLT will have to come to in terms of their own individual restrictions. The prevalence of post-stroke dysarthria in their caseloads and the availability of suitable candidates for group sessions will also play a part in this.

Certainly the group session that PCPs attended for the '*Living with Dysarthria*' project seemed to provide PCPs with the relevant information and support that they were looking for (Mackenzie *et al*., 2013). They all reported that this had been a successful way for them to learn about dysarthria and also to meet with other PCPs. However, this was done in conjunction with the PwD and so did not lend itself to the possibility of having more in depth conversations with them about the direct impact on their lives. It may be suitable to have an extra session for PCPs separately as part of such a programme to provide sufficient time to have those discussions.

For clinicians who are currently including sessions with the PCP of the PwD in their intervention this research provides them with some evidence to do this. All intervention provided by SLTs should be evidence based practice (RCSLT, 2005), until this point there has been no specific research for this area and so therapists are basing their reasoning for working with PCPs on other research. For example, aphasia research has heavily promoted the necessity of including PCPs in the therapy process (McGurk and Kneebone, 2013). While this research does not indicate what intervention would be necessary, it does indicate that PCP would benefit from support. The *'Living with Dysarthria'* project (Mackenzie e*t al.,* 2013) provides information on intervention for PCPs, as an example of a types of therapy therapists may consider.

As there are currently no published materials or assessments that SLTs can use to measure the impact of the dysarthria on PCPs, other than the Carer COAST, this may be a major barrier to SLTs providing intervention to PCPs. Without a readily available measure which can be easily administered to PCPs investigating the most pertinent areas, it is difficult to see how busy SLTs with serious time constraints would be able to investigate the PCPs' concerns. Using the interview approach would obviously be an ideal situation. Without a published measure it is likely that most therapists may not feel confident in asking PCPs questions about the psychosocial aspects of dysarthria. This is an area which would benefit from further investigation and development.

Critical Evaluation of Study

While one might hope for 'ideal' candidates when planning a research project, the reality was that it was only possible to interview participants when they were available. As stated earlier in Chapter 3 (page 44), due to the researcher recruiting participants from the *'Living with Dysarthria'* project, the PCPs were interviewed at different stages of the programme, with RP02, 04 and 06 having completed the project and RP08, 09 and 11 just about to start. This meant the researcher had previously met with RP02, 04 and 06 several times before they completed the interview, while RP08, 09 and 11 met with the researcher for the first time at their interview. It would have been beneficial to have had all the interviewees at the same point and with the same knowledge of the interviewer.

It was possible that the participants who had not previously met the researcher may have held back more or have felt more uncomfortable, in spite of the researcher attempting to make the interviewees feel as comfortable as possible. It could just be possible that all the information they had to share was shared and that there was no further concern for them other than what was brought up during the interview.

Further to the participants, who had completed the *'Living with Dysarthria'* project prior to the interview, having knowledge of the interviewer, they would also have had further insight and knowledge into dysarthria and communicating effectively with someone who has it. This knowledge may have impacted on their ability to share their experiences with the interviewer.

The use of interview to investigate the topic provided the possibility of getting in depth, relevant information. It provided the opportunity for ideas to be discovered and unravelled and for participants to provide true records of their experience. While it is true that only a small number of participants were able to take part in the project, this does not detract from the relevance of the data collected. It is usual that qualitative research using interviews as the data collection method is done with a small number of participants (Holloway and Wheeler, 2010) to allow for more thorough evaluation of the data and to provide examples of real life experience that would be missed in larger scale projects. However, this means that it is not possible to make generalisations to the larger population, but to consider the possibility that it may be true to some people and not to others. There are ways that this research could be tightened up to investigate particular effects. One such way would be to use an increased group size and to have that group sharing particular characteristics, for example, all spouses with one or two years post-stroke experience. In this research the varied time post-stroke may have impacted the views of each of the participants and therefore the results. This would allow for more direct comparison of data. Again, the stroke population is a heterogeneous population and so it is difficult to control for all aspects and it is likely whatever restrictions are put in place for participant recruitment, there will be many different variations on a theme.

Other aspects that may have impacted the interview process could have been the characteristics of the participants being interviewed. It is possible that the older participants would have preferred an older interviewer and, vice versa, the younger participant a younger one. The dynamics of the dyads could have been impacted by this. Holloway and Wheeler (2010) describe a situation where a younger interviewer with older participants gathered the most relevant data from all their students taking part in qualitative studies. While it may be possible, it is not by any means definite.

In McGurk and Kneebone's (2013) literature review of research in carers to people with aphasia, they indicate that quantitative research has indicated differences between male and female caregivers. However, currently there is no qualitative research in this area and it would be beneficial to further the topic. In this research all the participants were female. Unfortunately this was unavoidable due to the cohort available to the researcher as none of the female patients taking part in the 'Living with Dysarthria' project had a male relative attending with them. Therefore it was not possible to access male interviewees. If further research in this area were to take place, it would be interesting to collect views from male PCPs to see if there are any differences that have been indicated in the aphasia research above.

Further to this was the lack of any participants whose PwD had severe difficulties and/or who used any form of alternative and augmentative communication devices. All participants in the 'Living with Dysarthria' project had mild to moderate dysarthria. Again, this would be a very interesting area to investigate in further research, particularly as the current PCPs seemed to be able to associate more impact with more significant communication difficulties, i.e. RP02, RP04 and RP11.

Family dynamics are likely to have shaped opinions and data provided. While it is possible to control certain aspects of the interview process, the situation of the interviewee and their experiences are impossible to predict. It is also difficult for the researcher to know what kind of relationships the interviewee shared with the PwD previous to the stroke and how this has impacted their feelings. This should not be viewed negatively as it is thought that each life experience provides information to the phenomenon being investigated and that the views of all are still relevant in this particular context.

Another area that could have required further evaluation would be the type and number of measures used in the questionnaire section of the data collection. The Carer COAST (Long et al., 2009) was the most relevant measure for this area as its authors had developed it with both aphasia and post-stroke dysarthria. The five quality of life questions allowed for the PCPs to relate the speech impairment directly to their own well-being which was relevant to this piece of work. However, while the measure has been developed with post-stroke speech and language impairments and has been rigorously tested through the ACT Now project (Long *et al.* 2009), the slant on the general questions (associated with gathering data from the relative on how they view the patient's communication impairment) is very much towards the aphasia aspects of stroke. Due to the paucity of these types of measures for post-stroke dysarthria and the PCP's perspective, this was the most suitable measure available.

Further Study

This project has highlighted some relevant aspects of post-stroke dysarthria and the impact on PCPs. While this study has not made it possible to give definitive viewpoints, it has raised issues associated with ideas and feelings emanating directly from the PCPs. It would be useful to tighten the criteria of the participants to allow for more specific comparisons and indeed to increase the number of participants within the study process. To achieve this would require a larger scale project with more time available to the researcher. A further advantage of conducting a larger project is that it would enable the researcher to focus on specific types of relationships e.g. such as spouses or parent/child. Another aspect to consider could be the severity of the dysarthria, which could be usefully examined in the context of particular relationship dynamics. A longitudinal study could also be useful to see if and how the effects of the dysarthria change over time. Doing two or more interviews with the same participants would allow for the researcher to investigate how they adjust over time and whether time allows them to become more at ease with the situation or if it becomes harder for them to deal with.

Another shortcoming in the current process of intervention for PCPs of PwD post-stroke that has become evident during this research is the lack of suitable measures for collecting data on the PCPs' wellbeing. With SLTs including the PCPs within their regular intervention process, it follows that they should be provided with the means to investigate the PCPs' needs properly. Further development of materials for this is therefore desirable. Adapting the Carer COAST to provide questions which are more directly related to dysarthria rather than aphasia or developing a PCP version of the Dysarthria Impact Profile (Walshe, Peach and Miller, 2009) might achieve this objective.

Conclusion

While this study was constrained by the size of the research sample, the use of interviews in combination with questionnaire data has provided some interesting and relevant points to an area of research that has not previously been researched. The prevalence of post-stroke dysarthria is relatively high, as 20% of dysarthria cases seen by speech and language therapists are caused by stroke. With the focus on the impact on relatives in stroke rehabilitation it seems relevant to be collecting information about how relatives view the impact of post-stroke dysarthria on their own well-being. With evidence from other areas of stroke research indicating the impact of the psychological impact on the relatives, speech and language therapists need to be aware of how this particular speech impairment may be impacting on the relatives of patients on their caseloads.

Further examination of how SLTs collect this data would be beneficial. Within the time constraints of the busy NHS environment it would not possible to expect them to interview all the relatives who enter their clinic. By developing a relevant questionnaire that focuses on the areas raised in this project it would allow them to assess the PCPs needs and therefore provide appropriate support where necessary.

This project seems to indicate that there are some possible pointers towards which relatives may require further 1:1 support from the therapist. These include the type of relationship that the relative holds with the PwD. As with other stroke data it appears that the PCPs whose husbands have post-stroke dysarthria were more aware of the overall impact and effect of dysarthria on their lives.

Another indicator appeared to be the severity of the dysarthria. While PwD appear to feel that even mild difficulties have an overall impact, PCPs whose PwD had a more severe speech impairment, related more readily events which were associated with the dysarthria than those whose PwD had mild dysarthria. These PCPs were more aware of the importance of dysarthria information and wanted to be involved in intervention provided by the speech and language therapist. However, that is not to say that PCPs whose PwD had a milder impairment were not keen to take part, but participation was seen as part of a whole in the rehabilitation process rather than a major focus.

As speech and language therapists we understand the importance of successful communication and our main focus should always be in supporting patients and their families to access this. The stories shared by the relatives in this research have shown how the dysarthria has impacted on their relationships with, not only the PwD, but also their wider community. Therefore it is pertinent to continue researching this speech impairment and the impact that it has on relatives. Using interviews to research the area investigates how each individual taking part views their experiences in detail. It provides the means to evaluate the impact in detail. The drawback is that comparisons to the general population of relatives who care for some with post-stroke dysarthria are difficult as the number of participants is smaller. However, there are some interesting areas which have been raised which may have been difficult to investigate in a larger scale project. There can be no doubt that further research is necessary to see whether the themes highlighted here are relevant to other relatives of PwD or to relatives whose PwD has dysarthria of greater severity, or indeed whether they are specific to these particular participants.

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Appendix A: Relative Interview Schedule

The themes listed below are to be used within a semi-structured interview session. They will be used as a guide for the interview to facilitate the topics covered within the session in a flexible way, through as natural a conversation with the carer as possible.

Thank you for agreeing to take part in this interview today. I would like to talk to you about X's speech difficulty and how this affects you as his/her main communication partner.

Introductory background

(E.g. Time since the stroke, Changes)

Stroke context

(E.g. Recovery process, The effects on the relative)

Dysarthria

(E.g. Difficulties with speech and communication, Relative's views of the difficulties, Strategies)

Situations

(E.g. Difficult speech situations and circumstances)

Impact of dysarthria

(E.g. Social life and activities, Opportunity to talk)

Relative's response to dysarthria

(E.g. Feelings, Support)

Dysarthria management

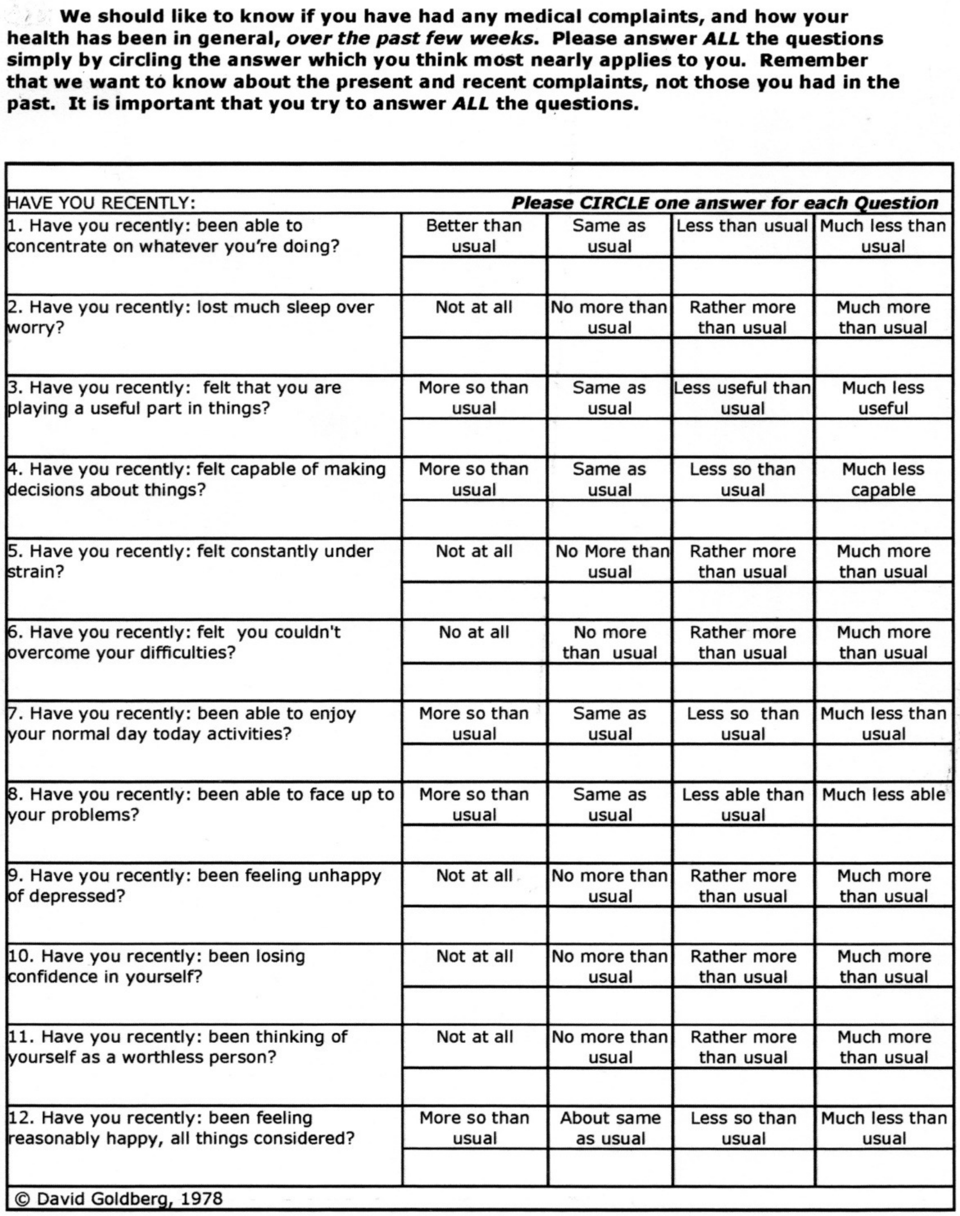
(E.g. Education, Treatment, Relative involvement)

Any additional issues

In closing, what advice would you give someone whose relative has dysarthria after stroke?

Appendix B: General Health Questionnaire

GHQ-12



We should like to know if you have had any medical complaints, and how your health has been in general, *over the past few weeks*. Please answer *ALL* the questions simply by circling the answer which you think most nearly applies to you. Remember that we want to know about the present and recent complaints, not those you had in the past. It is important that you try to answer *ALL* the questions.

HAVE YOU RECENTLY:	***Please CIRCLE one answer for each Question***			
1. Have you recently: been able to concentrate on whatever you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2. Have you recently: lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
3. Have you recently: felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
4. Have you recently: felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
5. Have you recently: felt constantly under strain?	Not at all	No More than usual	Rather more than usual	Much more than usual
6. Have you recently: felt you couldn't overcome your difficulties?	No at all	No more than usual	Rather more than usual	Much more than usual
7. Have you recently: been able to enjoy your normal day today activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
8. Have you recently: been able to face up to your problems?	More so than usual	Same as usual	Less able than usual	Much less able
9. Have you recently: been feeling unhappy of depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
10. Have you recently: been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
11. Have you recently: been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
12. Have you recently: been feeling reasonably happy, all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual
© David Goldberg, 1978				

Appendix C: Carer COAST

Please see:
www.psychsci.manchester.ac.uk/actnow/outputs/resources/

Appendix C.1: Carer COAST Script

MANCHESTER
1824

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of Manchester

The Carer Communication Outcome after Stroke (Carer COAST) scale– 'script' outline ©

Relevant Reference
Long, A., Hesketh, A., Bowen, A. on behalf of the ACT NoW Study (2009) Communication outcome after stroke: a new measure of the carer's perspective. *Clinical Rehabilitation*, 23: 846 – 856

The Carer COAST scale and score sheet that are used in conjunction with this interview script can be downloaded from the following website:
www.psychsci.manchester.ac.uk/actnow/outputs/resources/

This document has been prepared for use alongside the Carer COAST. It gives guidelines on how the scale can be explained to carers to facilitate self-completion. The Carer COAST scale is typically printed on A4 paper with each page laminated. The whole scale is then bound together (landscape orientation, bound at top) to facilitate page-turning.

A lot of the questions on the rating scale could be interpreted as cross modal i.e. using the phone not only requires communication but also the ability to pick up / hold the phone which may be affected by hemiparesis. As far as possible, it is helpful to emphasise this in the introduction to ensure that carers complete the question with reference to the patient's communication.

Introduction

We're going to ask you some questions about your relative's communication and your own quality of life.

Please read each question carefully and choose a response.

We want to know how your relative's communication and your own quality of life is nowadays.

Not just today, but on average around now, over the past week or so.

Let's look at a question together first to give you an idea of how this works

Turn page – Practice question

In the past week or so, how well could your relative

use the phone?

☹ ☺

Couldn't do it at all

With a lot of difficulty

With some difficulty

Quite well

Very well

The questions all look a bit like this. You'll see the question at the top, a picture to give more information and then the responses at the bottom.

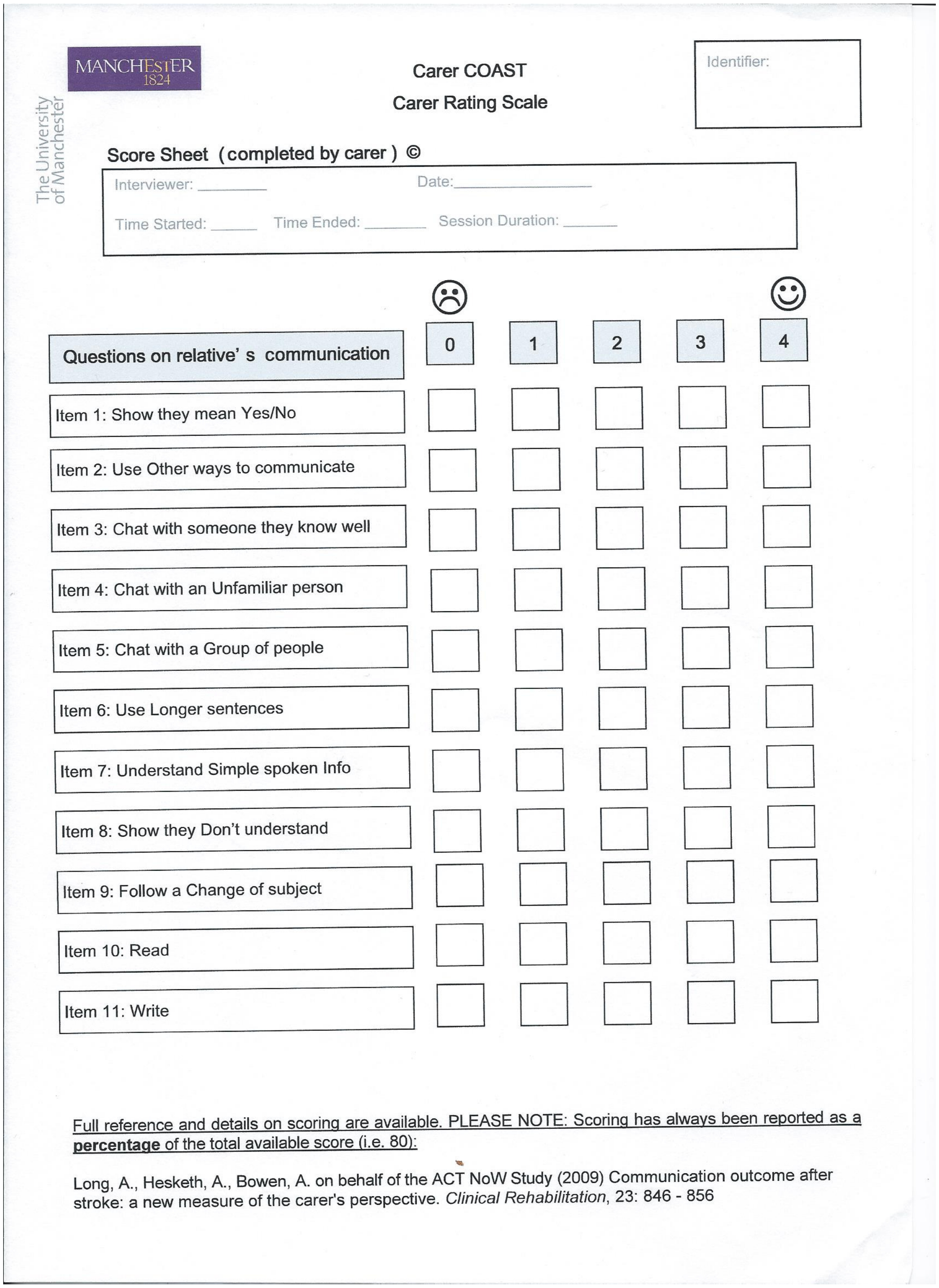
They go from here (left hand box) for the very worst problem up to here (right hand box) if things are good, if there is no problem. The other boxes are stages in between.

Once you have picked the box which is best, use the score sheet to tick and indicate your answer. For example, if you think the extreme left-hand box which says 'couldn't do it at all' is right, tick the extreme left-hand box marked '0' on the score sheet.

Always try and think about your relative's communication problem specifically when completing this. We know your relative may be experiencing other problems as well but these questions focus specifically on the communication issues.

Questions 16 to 20 are slightly different; they ask you about how your relative's communication problems have affected your <u>own</u> quality of life. Please read the questions carefully.

Appendix C.2: Carer COAST Score Sheet



The University of Manchester

Carer COAST
Carer Rating Scale

Identifier:

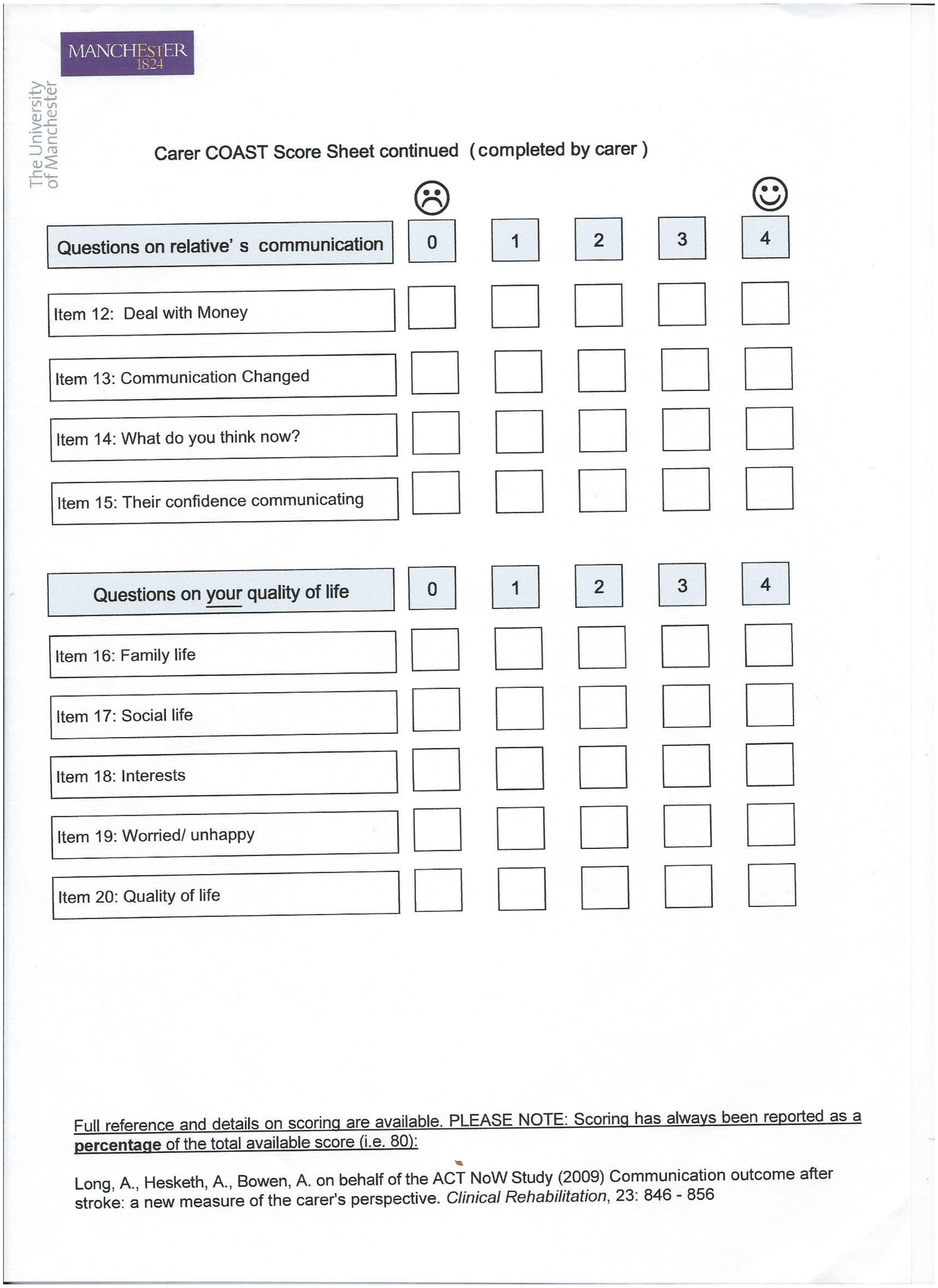
Score Sheet (completed by carer) ©

Interviewer: ________
Date: ________________
Time Started: ______
Time Ended: _______
Session Duration: _______

Questions on relative' s communication	☹ 0	1	2	3	☺ 4
Item 1: Show they mean Yes/No	☐	☐	☐	☐	☐
Item 2: Use Other ways to communicate	☐	☐	☐	☐	☐
Item 3: Chat with someone they know well	☐	☐	☐	☐	☐
Item 4: Chat with an Unfamiliar person	☐	☐	☐	☐	☐
Item 5: Chat with a Group of people	☐	☐	☐	☐	☐
Item 6: Use Longer sentences	☐	☐	☐	☐	☐
Item 7: Understand Simple spoken Info	☐	☐	☐	☐	☐
Item 8: Show they Don't understand	☐	☐	☐	☐	☐
Item 9: Follow a Change of subject	☐	☐	☐	☐	☐
Item 10: Read	☐	☐	☐	☐	☐
Item 11: Write	☐	☐	☐	☐	☐

Full reference and details on scoring are available. PLEASE NOTE: Scoring has always been reported as a **percentage** of the total available score (i.e. 80):

Long, A., Hesketh, A., Bowen, A. on behalf of the ACT NoW Study (2009) Communication outcome after stroke: a new measure of the carer's perspective. *Clinical Rehabilitation*, 23: 846 - 856



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Carer COAST Score Sheet continued (completed by carer)

	☹				☺
Questions on relative's communication	0	1	2	3	4
Item 12: Deal with Money	☐	☐	☐	☐	☐
Item 13: Communication Changed	☐	☐	☐	☐	☐
Item 14: What do you think now?	☐	☐	☐	☐	☐
Item 15: Their confidence communicating	☐	☐	☐	☐	☐

Questions on <u>your</u> quality of life	0	1	2	3	4
Item 16: Family life	☐	☐	☐	☐	☐
Item 17: Social life	☐	☐	☐	☐	☐
Item 18: Interests	☐	☐	☐	☐	☐
Item 19: Worried/ unhappy	☐	☐	☐	☐	☐
Item 20: Quality of life	☐	☐	☐	☐	☐

<u>Full reference and details on scoring are available. PLEASE NOTE: Scoring has always been reported as a **percentage** of the total available score (i.e. 80):</u>

Long, A., Hesketh, A., Bowen, A. on behalf of the ACT NoW Study (2009) Communication outcome after stroke: a new measure of the carer's perspective. *Clinical Rehabilitation*, 23: 846 - 856

Appendix D: Example Annotated Interview Scripts

Appendix D.1: RP04

X..

When did SP04 have his stroke?

RP04..

A year past September, about a year and a half ago.

X..

Ok. How have things been since then?

RP04..

Difficult. Hard.

X..

Yeah? Um, do you think it's got harder since or has it been a level

RP04..

I think a mixture. Being hard, hard to accept he's actually had a stroke (acceptance)

X.

Right

RP04..

I would say it's harder now since he's recovered from his stroke and now being aware of the effects of what he's been left with. (recovery process)

X..

Ok

RP04..

One being his speech. He finds it quite frustrating and probably as his partner I do as well. (irritation)

X..

Yeah, yeah. So it's kind as new things have come along there's been more things to deal with

RP04..

Uh, huh.

X..

Do you feel that there more things that SP04's able to do now that he wasn't able to do at the beginning?

RP04..

Oh, yeah. Yes. He's very independent now probably doing things around the house (recovery process)

X..

Mm

RP04..

His mobility and what have you have got a lot better. Within the house.

X..

Ok good

RP04..

I think it's more now if you are out and about socialising. He becomes more aware of, um, difficulties.

X..

Right

RP04..

Um, or in a group setting. I think he finds that difficult. I think he can be quite comfortable within your own four walls and with your own family. It's when you go out and about and you realise that's when his difficulties are more obvious (dysarthria)

X..

Ok

RP04..

To him

X..

Ok. And is that both his physical difficulties and his speech that he finds, that he becomes more aware of? Or is it more one that the other that you think he struggles with?

RP04..

Probably both of them, in a way. But I would say probably his speech is one of the things, because he was a talker. And liked communicating with people. I think that he finds that quite difficult now if you are in a social situation or even just out bumping into people, you know people that you meet in the street and what have you. (dysarthria)

X..

Ok

RP04..

I think he finds it quite difficult. But I would say that's probably confidence

X..

Right

RP04..

More than his speech, he can make himself quite clearly understood. But I think sometimes it's other people's reactions to him when they realise that his speech not what it was before his stroke. What he'll say is, people know he's had a stroke because they see his mobility, he's got a limp and he can't use his right arm. So they'll see that.

X..

Mm, hmm

RP04..

But he'll say that they only look at the physical disability he's got they're not aware of the actual speech difficulty he has or the mind process. And that's something he'll keep saying. He'll repeat that to me quite often. He'll say "people look at me and they think it's only my arm and my leg, they don't actually realise that I've got brain damage".

X..

Yup, yup. How's that affected you?

RP04..

I think it probably affects you because

(interview was paused here for a five to ten minutes as RP04 got upset. We resumed when she felt ready. She was still keen to take part and complete the interview.)

X..

What information or advice to receive about SP04's speech difficulty? Did you get anything?

RP04..

In the hospital, no we didn't get much at all. (SLT information)

X..

Ok, had he been seeing anybody at the hospital for

RP04..

Um, well he had been at … hospital and the speech and language therapist came and spoke to both of us and gave us leaflets (SLT information)

X..

Mm, hmm

RP04..

And as far as I am aware he may have had some speech therapy

X..

Ok.

RP04..

He was four weeks at the …. hospital. And then when he transferred to the R hospital again the speech and language therapist came did say he had dysarthria and gave us leaflets. And basically said that would be it. When he left the hospital the speech and language therapist came up and she came for several weeks, she came for quite a length of time. And quite a length of session each time she came. (SLT information)

X..

Right

RP04..

Which was very helpful

X..

So he had community therapy then for his dysarthria

RP04..

Uh, huh.

X..

And, uh, were you included in any of that treatment that he had?

RP04..

Yes, uh huh, I mean she did encourage me to sit and take part (involvement)

X..

And how did SP04, did he like you being involved in the therapy?

RP04..

Yes, uh huh. He was quite happy with that. (involvement)

X..

Did you find that quite useful so that you had a better understanding?

RP04..

Well, yes because he'd have work to do for the following week when she came back so it was quite good that we could sit in a daily basis and do some of the work. Because it was quite, he did get quite a bit of work to do (involvement)

X..

Ok.

RP04..

And exercises and what have you so it was quite good to put that into your daily routine really.

X..

Yup, yup.

RP04..

So yes it was very helpful.

X..

Ok good. And did you feel that you had an understanding of what dysarthria was?

RP04..

Yes, uh huh. I did a wee bit of research myself

X..

So you did that yourself rather than being told by the speech therapist?

RP04..

Yeah uh huh.

X..

At what point did you look that up? Was it after he'd started speech therapy?

RP04..

Yes once they had actually given us a name of what problem he actually had and then it was easy enough to go find out some information. Went to the library and got some books and what have you. (information)

X..

Is there any other help or treatment that you felt would have been useful for helping SP04 making his speech better?

RP04..

In hindsight, not I don't think so, I think it's something that would have come on. I think if he didn't have any speech therapy, if he'd come out of the hospital and there had been no follow up from the community I don't think his speech would be as good as what it is now. I know I actually went to one of the carers meetings once and they were discussing various different things and when I was saying what my husband, you know the therapy that he was actually getting (SLT)

X..

Mm, hmm

RP04..

It seemed to be a postcode in a way, dependent on what postcode you were under. So fortunately enough he was in the right one. It's always been that way were I've thought maybe if he hadn't had that therapy his speech wouldn't be as good and clear as it is now. And he, myself and the family wouldn't have had the understanding.

X..

And is SP04 using strategies to help himself make his speech clearer.

RP04..

Yeah. Yes he does. I think the course he did with yourself and SLT I think that was actually more beneficial than anything. He got a lot out of that. That course was excellent. Both of us did. (SLT)

X..

And what about yourself, do you feel able to support him with his speech.

RP04..

Yes. Um, sometimes it can cause a bit of rift because you're trying to put things into place when he's maybe trying to explain something. (conflict) (involvement)

X..

Right

RP04..

He's saying "you know what I mean" and I'm saying no think first. And I he gets a bit agitated. But I think he does know that it is better that he actually thinks for himself rather than me saying when I know what he's trying to say. (understanding)

X..

Mmm

RP04..

I tend to just sit back and let him, some people might think that I am being cruel but I don't think so. I don't believe in speaking for him. (burden)

X..

What about in social situations? How do you find that? Are friends and family able to understand SP04 without your support?

RP04..

Yes, uh huh. He works at it very hard to make himself clear in everything that he says. He does slow down. He has and always has had a very distinctive voice. That was one of his strong points really, he had a very distinct, deep voice. And, um, he will be very clear. But he puts strategies in where he'll use smaller sentences. So his language now is a lot more basic than what it was before the stroke. But no he will participate in conversations. I'd say his problems is if it's a one to one with myself or likes of our daughters. He may stumble or get a bit mixed up and I think that's which everybody does, don't you? You know you tend to get a bit lazier when it's one to one with your partner or your immediate family (dysarthria)

X..

Yeah. If someone isn't understanding, so say you were out and about and it's someone you don't know and they weren't understanding what SP04 was saying, what would happen in that situation if you were there?

RP04..

He would probably turn to me and give me a sign like help me out here a wee bit. So you would do it quite discretely by, and woman are quite good at that aren't they? (laughter)

X..

And how do you feel about that?

RP04..

Um, sometimes it can make you feel a wee bit, a bit balshy if you know what I mean. (with each other) (role change) (burden) (behaviour change)

X..

Ok

RP04..

Because I would never have done that in the past. And if I had interrupted a conversation it would be him looking at me as if, let me finish. And it was something I was very, very conscious that I would never have done before. (with each other) (role change) (burden) (behaviour change)

X..

Right

RP04..

I would never have had to. You know you get partners who would contradict the partners or husbands and I would never have done that and it does make me feel quite uncomfortable at times. (with each other) (role change) (burden) (behaviour change)

X..

Maybe a bit of a burden?

RP04..

uh huh, I think it's just something that probably in the past where we've had conversations about where you've got couples who do all the talking for the men and that's ridiculous. I know that's something he felt very strongly about. The woman doing all the talking for the men

X..

And do you know if this is something that SP04 is uncomfortable with you doing or is happy for you to?

RP04..

I think he's quite happy about it just now. I know before the stroke he wouldn't have been and that's the problem I have. (conflict) (role change) (burden) (behaviour change

X..

So that role change that you know. Ok. If someone isn't understanding, what clues you in to that maybe the other person isn't really getting the whole meaning from what SP04 is saying? Are there any pointers for you that maybe you need to look out for to maybe step in?

RP04..

I think you get to be able to read the situation, where you know this is going to be a bit awkward here so you'll work the situation round about.

X..

Have there been any particular situations where you know that people have had difficulty understanding SP04?

RP04..

No as I say, when he is out and you're in company he'll make himself be clear, so no he's never really let himself down that way.

X..

Ok.

RP04..

No, you know he's quite confident. He's quite confident on the phone and in having conversations. And he's built in the strategies that if we're in a group situation. Whereas before the stroke he would've been the one doing all the talking (behaviour change)

X..

Right

RP04..

He tends now to sit back. And he's well aware that he can't always pick up if there is two or three different topics kind of thing, he's well aware that he can't actually do that. So say that if you've got people up or if just the family is up and they'll go away and he'll say so what is J doing tomorrow? And I'll say but we've just discussed it and he'll say I couldn't pick up that bit. Because there will be too much noise or too many conversations going on. He can't jump from conversation to conversation. From one topic to another. That can cause quite a bit of frustration on my part because then I'll turn around and say were you not listening? Why weren't you listening? Which I would've done in the past. But really it's just he can't when there's too many voices going on he can't take all the information in. (frustration)

X..

Are there any situations that you find particularly difficult because of SP04's speech?

RP04..

On a personal level?

X..

Yeah.

RP04..

Well he's not able to express himself the way he used to. His conversation is now pretty basic. Which he's well aware of and finds it pretty frustrating. I think your relationship changes. Your conversation changes. Again I've got to be very conscious of the way that I speak to him. He's not able to read my emotions in a way and so if I'm saying something in a jokey way he maybe he can't really take that on board. So you can't be flippant if you know what I mean. (with each other)

X..

Right ok, yeah

RP04..

Whereas in a relationship you would say "oh that's right" (sarcasm) and he may take it the wrong way a wee bit so you've got to be quite cautious in what you're saying and the way that you're saying it. And he will comment on the tone of my voice. And say "why are you always so angry"? And it's not that I'm angry it's just my mannerisms that I've got. So he finds that difficult to read, my language. And I would say it's much the same on his part as well cause he can say things and they're quite hurtful. He's not that type of person but it comes out that way. So it can cause quite a wee bit of rift. And you move yourself away from the situation and you're well aware of it but at the time you'll look back and you'll say what did you mean by that, what did I do to deserve that comment? (behaviour change)(with each other)(role change)

X..

Yeah

RP04..

Then you can see the look in his face as if

X..

‘oh I didn’t realise’

RP04..

And you know, and certain things, he would you know my daughters and I have discussed it, his conversation is sometimes quite adolescent. You know he’ll come out with things, things that he would never, ever have said. And he’s not, you know, things that would be inappropriate to me but to people outside wouldn’t be inappropriate. You know, like, he would never have used bad language.

X..

Right

RP04..

That is something that he would never have, I mean I don’t know if he would’ve when he was out with his friends. But in the house certainly he would never swear or anything like that. And doesn’t now but there have been a couple of occasions where he has actually said things and it’s been totally out of character. Adolescent things that you go(behaviour change)(irritation)(role change)

X..

Weren’t quite expecting that

RP04..

What was all that about? He wouldn’t have even said it when he was, cause I’ve known him since he was 17. You know. So that’s been difficult (behaviour change)

X..

Ok and so do you feel that you have people to talk to about?

RP04..

No I tend to just probably tend to my immediate family, the girls. You know, we'll discuss it. (family)

X..

Do you think that would have been the case before hand? Would you have discussed it with the girls?

RP04..

Oh uh, huh. Uh huh

X..

And do you feel that you have the same opportunities to talk to your daughters the way that you had previous to the stroke?

RP04..

Oh yeah uh huh. Within the family we're quite open(family)

X..

Ok so nothing's changed?

RP04..

Oh no we're quite open and we do include my two son-in-laws. One son-in-law is exceptionally good the other son-in-law sticks his head in the sand, this isn't happening and he finds it quite difficult. Whereas before he would've come to his father-in-law and asked him for certain things he prefers now not to put him in that situation. (family)

X..

So he's had a bit of difficulty dealing with the situation himself? Yup, yup.

Um, what about talking to SP04? Do you have the same opportunity to talk to each other that you would've had before?

RP04..

Uh huh, yeah. We do sit and talk about it. And he probably thinks that people look at me differently now and I think that he probably thinks that his intelligence has changed. (with each other)

X..

Mm

RP04..

And it doesn't matter how much I'll say to him, that we know for a fact that it's not it's there, it's just that you can't communicate that the way you did. Um, so now it's just other people getting used to how now you express yourself. Really in a way and no we do talk about it. (with each other)

X..

Do you feel like there has been any change in your own social life or activities?

RP04..

Probably at the beginning, but now no. Because I don't think he would be happy if I wasn't continuing with my social life and seeing my friends or going out and about. That would upset him. (own relationships)

X..

Do you want to go out and see your friends is that?

RP04..

Uh huh, yeah

X..

And we were talking earlier about you have also joined the carers group as well, how do you find that?

RP04..

Well I've only been to a couple. I was invited at the very beginning to a course that they had on. It was actually two of the psychologists. (information)

X..

Mm, hm

RP04..

But I couldn't cope with it. SO I went for two sessions and then had to back, it was just too raw at the time(own relationships) (acceptance) (shock)

X..

Mm, hmm

RP04..

So now I've been in touch with them again, so I think that will be quite helpful now(own relationships) (acceptance)

X..

Ok

RP04..

At the beginning it was a bit too raw

X..

Right ok, so you're going to go and speak to them. Ok great.

Um, do you think that there are any situations that you avoid now that you might not have done previously?

RP04..

Um, no I don't think so. I mean the opportunity to socialise now is not the same. We quite enjoyed socialising on our own (friendships)

(laughter)

RP04..

You know we were a bit like that, it came to the weekend we'd jump in the car and away we'd go. SP04 doesn't drive now and I don't drive. So we're reliant on other people. He also suffers from travel sickness so it's pretty difficult if any of your friends are asking you out, you know I wouldn't put him in that situation where he would probably be sick in the car. The likes of the family are quite aware of it so we just go with a sick bag. You know, he's alright, he wouldn't bother. But with friends and that we wouldn't do that. So. (friendships)

X..

Ok

Is there any advice that you would give to someone whose relative has dysarthria after stroke?

RP04..

Just find out as much information as you can really. I think that would be, and look there is help within the community, your GP I'm sure would put you in touch. I was fortunate enough to be involved in various group sessions and what have you. So we have. He's very well aware that he's very lucky. (information)

X..

How did you find the group sessions? Did you find that useful having meeting other people who had dysarthria and their relatives?

RP04..

Yeah I think that was good. I think that was good. You know, I think that SP04 certainly enjoyed the group, you know regarding other groups and things like stroke groups and things it's not what he wants to do. He wouldn't want to do that. And somebody did say to him that he may find it useful to mix with people like himself which I found a very negative comment to make to him. You know people should respect that people don't like group settings, or don't like going to clubs (involvement)

X..

Ok. I think the group therapy sessions that we ran to what might be

RP04..

Very, very different.

X..

To what might be run at the local stroke club.

RP04..

Oh a big, big difference.

X..

And how about speaking to other relatives at the group sessions.

RP04..

It was good, it was good. I still see one of the ladies when we're up at the hospital, so that's quite nice. That's really been quite helpful.

X..

Yeah it makes that connection, doesn't it, within the community.

RP04..

I think going back to the very beginning when we were talking, I think one of the things if your partner, especially if your partner has a stroke. It's a big, big change, to both of you. It's a big, big change within your family setting. And if you rely on each other, being the male or the female, in my situation being my husband it's um, there's a lot of things that you have to do which they would've done. (RP04 is crying here) (with each other) (role change) (burden)

X..

It’s difficult

RP04..

It’s difficult. (burden)

X..

In terms of support from your family, you’re very close to your daughters as well,

RP04..

Mm, hmm

X..

It’s good that they are there to help you and to have the grandchildren there as well, and by the sounds of things keeping you very occupied.

RP04..

Keeping both of us very occupied. But I would probably recommend if anybody, I am sure if people probably look at us and think she must be mad. It’s not madness it’s probably been the best. (family)

X..

How does SP04 get on with chatting with the little ones?

RP04..

Ok. They’re great. Of course papa is absolutely wonderful, nana’s the one to give them the row! (family)

(laughter)

Away you go to your grumpy papa, “my papa’s not grumpy”.

X..

Do you think that would’ve been the same previously?

RP04..

Oh, uh huh. Exactly the same. It would’ve been exactly the same. I mean B was a year and a half and J only four days old when SP04 had his stroke. But I would recommend anybody who has had a stroke to get in amongst children. And things that you think that you can’t do they make you do.

X..

They don’t have the same level of complication in terms of communication that maybe adults do as well. They don’t over think things

RP04..

Oh aye they process things entirely differently

X..

Yes and they just carry on as if things are normal whereas adults think about saying things wrong

(Phone goes off here, RP04 moves to switch it off)

RP04..

Yes kids they say papa put the telly on, and he says oh I have difficulty getting up and they just grab his hand and pull him up.

Appendix D.2: RP06

X..

When did SP06 first have her stroke?

RP06..

Two years past

X..

Two years ago, right ok. What have things been like since the stroke?

RP06..

Well her whole person has changed. I'd say she's lost a bit of confidence

X..

Right ok.

RP06..

Going out. But as time goes on I think she's accepted her situation

X..

Ok

RP06..

She's quite happy, she's happy enough in herself. But, em, she was never an outgoing person.

X..

Mm, hmm

RP06..

She was quite happy to stay in the house and do the house work, but eh, if she goes to the shops and that, then I'm always with her. You always watch what she's doing, but I never, ever answer for her. (with each other)

X..

Uh, huh

RP06..

Unless she's stuck. Like yesterday, somebody asked her for her postcode and she got the first part but she looked at me to answer, we were sitting in the three (her husband) and I turned to him close your lips and let her answer. She gets there in her own way.

X..

Ok. So, obviously, she's able to make a few changes and she's adapting a bit more now, but do you feel as though there have been some changes within the household? I know you don't strictly live with her, but maybe the responsibilities that you didn't have before the stroke?

RP06..

Well we never had really the same responsibility before the stroke (burden)

X..

Right

RP06..

We were just there and visiting as you normally would. But since the stroke we've been very responsible for her. (role change)

X..

Right ok

RP06..

Because we've lived with her and helped her with it, you know, as much as possible (burden) (role change)

X..

Right ok

RP06..

But she's happier on her own. But that was her life anyway and she does try to do her own business. We try to let her do as far as possible. But now, like more personal things she's more dependent on you for, (role change)

X..

Right

RP06..

Like her mail and her bank sort of things. Which we never, ever dealt with before, but now if anything comes in she'll let you read it.

X..

Ok

RP06..

And then you can say put that out, that can go in the bin or hold on to that. But she was always organised on her files things like that.

X..

Ok, ok. So you've taken on more around the house that you might not necessarily have done

RP06..

Uh, huh, no and before we left last time we managed to talk her into having a cleaner. So she's got a cleaner who comes in once a week. That means, and I said to her, if you have that person in they're doing your big heavy hoovering and big heavy stuff

X..

Yup

RP06..

And you can do what you need to do. And she's happy at that.

X..

Ok. That's good.

RP06..

She's contented enough with the lady.

X..

Ok good. Has there been any times, any particular times, when SP06's stroke has affected you more, or maybe even less so?

RP06..

No I don't think. I think its been the same all the way through. (recovery process)

X..

Ok

RP06..

I think there is times that you try to step back and let her do, but there's other times that you feel as though you've got to say well you can do this or you can do that. But no I would just say that before her stroke she was happy that you visited and you went out for lunch and that sort of thing, but after the stroke we were definitely more responsible for her. Her well being. (role change)

X..

Ok, was she quite independent before the stroke then?

RP06..

Yeah. And she's still independent considering she's 91 years old

X..

I know, she does very well for herself

RP06..

She's got her guild and her church and she's taken in and taken back. Coffee mornings, that she's out and we're happy that she's out and she's amongst people and will be chatting away and quite happy.

You know yourself, she's quite funny at times.

X..

Yes very funny, she's got a wicked sense of humour

(laughter).

What do you, this isn't necessarily particularly for SP06, but um, what can you tell me about the recovery process following stroke?

RP06..

Well as I say, when she came home, we stayed with her and more or less so that she was alright. No, but she still got up at her usual time and she ate well enough and she's always immaculately dressed, for her age group. I must admit that these things matter to her, put pride in herself.

X..

Uh, huh

RP06..

But when we were in the house, it was just the three of us and it was just normal. You just carried on. And sometimes, for a laugh, we'd go out for a wee walk and then I'd say to her we'll go to the café. It's just a wee tea room not far. It gave us a wee walk round and gave us a rest, let her sit and her and I sit and talk, you know.

X..

Yup

RP06..

I never really thought. You were just there and you just did. Everyday normal things, just because somebody wasn't well in the house and we were just helping out.

X..

Ok. Can you tell me why SP06's speech was affected by the stroke? Do you have any understanding about what it is about the stroke that's caused her to have some difficulties?

RP06..

I know, just trying to get it right. Something to do with the blood vessels in the brain, is that right?

X..

Yup.

RP06..

That was obviously what was affected there.

X..

So the blood vessels, there was a blockage and it cut of the blood supply so the cells have been damaged and that's just causing the signalling etc. to be interrupted

RP06..

Well we never had experience anyway, because nobody in the family, with other brothers or sisters had any problem like that. I mean they all died of cancer, there's nothing like that had happened. It was only until the speech therapist, the girl, came up and explained to us what dysarthria was. You weren't really taking it all in (dysarthria) (stroke info)

X..

Yes, yes. It's hard to take it all in one go isn't it?

RP06..

Just because it was a word and that was it. She just explained about the speech and she had speech therapy when she came out of the hospital, which she definitely did benefit from. She definitely did. (dysarthria) (SLT)

X..

Ok

RP06..

But as I say the sad bit was that when we left she didn't have the flow of conversation (dysarthria)

X..

Hmm, mm. Were you involved in any of the therapy that the therapist was doing with her?

RP06..

No

X..

Would you like to have been involved?

RP06..

Apart from, I brought her in and I waited for her and she got her homework and as I say, I explained to you before I made sure that she did it. (SLT involvement)

X..

Mm, hmm

RP06..

In the beginning I did it with her and then latterly I said away upstairs and do it yourself. She obviously did, because she wasn't involved in making meals or doing the housework. (SLT involvement)(recovery process)

X..

Yup

RP06..

So that was her. So she did and she'd come back down or sometimes you'd go up and she'd be sleeping. (laughter)

But at that time I made sure that she did do it, cause that girl will know when you go back there next week whether you've been practicing or not(SLT involvement)

X..

Ok

RP06..

But she definitely did

X..

Ok and would you have liked to be involved in the therapy at all?

RP06..

I never actually thought about it to be honest. What do you mean involved? (SLT involvement)

X..

Um, to have gone to the therapy sessions with SP06 so that you could've learnt what the therapist was doing with her so you could've had a better understanding of what was going on?

RP06..

Well, it would've been interested in that, but on the other hand I think that SP06 would've performed better with the therapist without me. I was too familiar. (SLT involvement)

X..

Ok so

RP06..

It was the same when we went to the group in ….. I felt as though she would've performed better with another group member or somebody she didn't know. (SLT involvement)

X..

Ok

RP06..

Whereas with me if it was role play or anything, she just couldn't get into it. (SLT involvement)

X..

She may have felt a bit self-conscious maybe?

RP06..

That's right. No matter how hard you try to involve and make it fun she never saw it as that. (SLT involvement)

X..

Right, ok

RP06..

We should have been doing it for yourself or with someone else. I think that she would've entered into it more. (SLT involvement)

X..

Ok

RP06..

And pushed herself more(SLT involvement)

X..

Ok, so in terms of SP06 getting most out of the therapy sessions it probably wouldn't have been beneficial for you to have gone

RP06..

No I think she would've performed better. (SLT involvement)

X..

Right, ok.

RP06..

But she always got, the girls were always very positive when she came back and I think that that gave her a boost as well. (SLT involvement)

X..

Yup, yup

RP06..

As long as I made sure she did her homework (laughter) was the main thing for the following week (SLT involvement)

X..

How was SP06's speech affected by the stroke?

RP06..

As I say, when she came home from hospital when we were in the house, there was a lot of speech (dysarthria) (recovery process)

X..

Mmm

RP06..

When she came to the… At the very beginning it was very difficult to separate, you had to always listen or ask to repeat (dysarthria) (recovery process)

X..

Ok

RP06..

To make up the bits that were missing

X..

Ok and what was different in the speech in comparison to before the stroke do you think?

RP06..

Well she wasn't fluent in anything, but she obviously knew in her head what she wanted to say, but it never came out.

X..

Ok, what did it sound like? What was the difference?

RP06..

I would say a babble at times. And then there would maybe be a word you could maybe say and then you would repeat it back to her and she would say yes or no, that's what she was wanting.

X..

And that was right at the beginning?

RP06..

When she was in hospital

X..

And when she was back at home, what was her speech like then?

RP06..

It gradually improved. Because we were all in the house I think she had plenty of practice. She had conversation and she was making conversation. When she came, like in here, to the speech therapy girls the girls always gave her whatever she had to do. And she never had a long time in here, I wouldn't say (recovery process) (SLT)

X..

Mm

RP06..

So obviously they were happy with her

X..

Yeah

RP06..

The girls were obviously happy with what she was doing. But when we moved back home and she didn't have the same amount of visitors I felt it regressed a bit then. (recovery process)

X..

Because she wasn't having

RP06..

Because she wasn't having the practice. So I used to say to her, just sing. But she's not the type to sing (Laughter) (recovery process)

X..

I can't imagine SP06 singing on her own

RP06..

No.

X..

Did you feel that you were able to support SP06 in making her speech better?

RP06..

Yes

X..

Yeah, you felt quite

RP06..

Quite confident (involvement)

X..

And was she able to adapt strategies, or use strategies to help make herself clearer as well?

RP06..

Yes, uh, huh, She did she did. But as I say, when she was only in the house herself I think that was where her greatest difficulty. As I say she did regress at that point.

X..

Ok, ok. How does SP06 get on when she's communicating with friends?

RP06..

I would say fine, but I don't really see it. If I know she's having friends we don't go.

X..

Ok. So maybe you wouldn't be around in that situation.

RP06..

No, because it's only fair, when she see us often enough. I mean when she's got her friends, well I mean, she must be alright. (friendships)

X..

Mm, hmm. And what about when she's with family? I assume you would probably be around?

RP06..

She's not got any family.

X..

What about when she's with, is it her niece and her nephew?

RP06..

There is a niece and nephew, but we're seldom there. Maybe when the nephew is but seldom with niece.

X..

What about with your husband? Because he's her brother, yeah?

RP06..

Yes.

X..

How does she get on when she's chatting to him?

RP06..

Oh fine, fine.

X..

Does your husband find it ok understanding her? Does he have any problems?

RP06..

No, funny enough, yesterday I was asking him. And he said if she's on the telephone and there's something that he doesn't understand (dysarthria)

X..

Mm

RP06..

What she's trying to explain, he'll just say to her, SP06 just start again, explain that to me again till he gets the gist of what she's trying to say. (dysarthria)

X..

Ok, so he feels quite comfortable to ask her to repeat what she's saying?

RP06..

Oh, uh huh. Oh aye.

X..

Ok, good. Have there been any other situations where people have had difficulty understanding SP06 when you've been there?

RP06..

Maybe at the beginning when we went out to the shops.   (dysarthria)

X..

Ok

RP06..

If she met a neighbour or somebody that she had known for years, eh, you could see them looking as if to say ‘oh dear what’s happened here?’. But, um, they just sort of glossed it over. (recovery process)

X..

Ok, so you probably would know that they weren’t understanding by their body language maybe?

RP06..

Yeah, that’s right. But then they just glossed it over and tractored on, maybe they made most of the conversation. (understanding)

X..

How did you feel when they were glossing it over? Did that bother you?

RP06..

Not really, because I felt as though I couldn’t really explain anything to them, because she was there.

X..

Right, ok

RP06..

So I guess I was like them and just ignored it. I mean I’m being honest. When you’re in the supermarket and there are people that she’s speaking with and they obviously know that’s not her normal self and they can’t turn around and say oh she’s had a stroke. So you just left it for them to work it out for themselves. (burden)

X..

That’s fine, yeah.

RP06..

That’s how I dealt with it, because I didn’t feel like I could turn around and say, oh she’s had a stroke. Sometimes they would ask her if she’s not been well and she would say she’s been in the hospital. I would say she's had a wee stroke. Not out loud, but just so they knew. (burden)

X..

Ok, ok.

Are there any particular situations that you find difficult because of SP06 speech?

RP06..

No. And I've never been embarrassed about anything. There are maybe times that you feel tempted to speak for her, but personally I don't. Regardless of where she is, other than, I mean I go to the doctors with her. I go everywhere with her. And I just sit (understanding)

X..

Mm, hmm

RP06..

Sit at the side and nobody's objected to me being there, and they'll just say if it's alright with her to come. Sometimes if she's lost for an answer, she'll look at me and I will answer. But if there is something particular I want to ask, I ask her then before we go out. But then I do let her explain to the doctor how she feels (with each other)

X..

And does she get on ok communicating with the doctor? He understands her fine?

RP06..

Oh yes. Obviously in their profession they're used to dealing with people like herself.

X..

So I guess you guys have figured out a good system to know when she feels she needs help she'll turn to you, but at the same time she has her independence.

RP06..

Oh, yes. Because she has her own person. I mean it's just like a child you wait till they tell you, you know. And she just gets it herself across. (with each other)

X..

Ok

RP06..

And if it's not what they're after then they have a different way and ask.

X..

Ok, good. How has SP06's speech difficulty affected your life do you think?

RP06..

Her speech? Or her life? Well, since I retired, I'll be quite honest with you, she's taken over our lives. (burden)

X..

Mm, hmm, a lot of support she's requiring?

RP06..

Uh, huh. But as I say, we're very involved with her. Cause as I say there's only us, my husband and myself as her family. Although as I say she's got a niece and nephew, she's got other nieces and nephews but they're down south and abroad. But she's not in the habit of seeing them, other than at a special occasion. . (burden)

X..

Ok

RP06..

As I say, it has changed our lives. And being honest, there is sometimes, when I look back I used to think, oh great I will be able to do this and I'll be able to do that. And I haven't been able to do what I thought I would've wanted to do. . (burden)

X..

Ok, yeah

RP06..

Because of the situation. But that's life and there is nothing you can do about it, is there? (acceptance)

X..

No, no

RP06..

It's family.

X..

Do you think it's, we sort of touched on this before, it's a lot to do with her physical impairment and just her general well-being that requires your support? As opposed to her speech is causing her difficulty in functioning in an everyday situation?

RP06..

I'm at the stage now, where I don't think she believes that her speech holds her back in any way. She's quite happy to chat, because anyone she's chatting to she's obviously confident enough with. (dysarthria)

X..

Ok

RP06..

Over the length of time, because at 91 all her friends have disappeared, you know and that it quite sad, but that is just a fact of life. But I think for anybody who visits her, like I say when she's at the guild or the church, people know and they obviously just respect and there is nothing they can do about it.

X..

Yup

RP06..

Just to be patient with her and understand (dysarthria)

X..

Well it definitely sounds as though she has a very good social life, she's off out and about and doing things.

RP06..

Well she always did go to the church and the guild and the coffee mornings. She still does her baking and feuters about the house and she's very happy.

X..

Mm, hmm

RP06..

And I think she's very comfortable. Going these places with because the people she's dealing with are people that knew her and people like ourselves that have seen the change and accepted the change

X..

Right ok. That's good that she's getting the opportunity

RP06..

Like I say, we always try to get out, we'll go for lunch or if we're out for a shop we'll maybe pop in garden centre. And that takes her out in amongst people and invariably there is always somebody. Because SP06 used to work in a clinic in b….. medical center and invariably there is always somebody who comes to say hello. No doubt if someone who she's not see for a while they might get a wee bit taken aback and maybe say oh what's happened to SP06, sort of thing. But she's quite happy to chat to them and quite delighted that she's met somebody. (dysarthria)

X..

Oh well that's good. That's excellent.

Um, from yourself, do you feel that you have the opportunity to talk to other people, so may be other family members or friends about SP06's stroke and SP06's difficulties?

RP06..

Well you can get mixed receptions, mixed receptions (own relationships)

X..

Ok

RP06..

I feel as though there are times, two friends in particular that I have that go on to me for being around so much. But I'm just me and I can't help it. (own relationships)

X..

Uh, huh

RP06..

And over Christmas I wasn't well and I just couldn't go cause I just was never out. But [her husband] went to see what and of course you couldn't bring her up because the weather was so awful at that particular time, but to me it's just life and it's just part of my life and I've just got to deal with it as it is. There is nothing you can change. And as you said earlier on maybe if these people find themselves in that situation then their ideas might change. (burden)

X..

I think it's very difficult for people to understand when they haven't experienced it themselves.

RP06..

But there is an odd time, when you think oh there's my sister she can go away to the hairdressers this morning but I've got to take SP06 to the hairdressers. You know. (burden)

X..

Yup

RP06..

There is the odd day you have the hump but I don't think that you wouldn't be human if you didn't (burden) (conflict)

X..

No, true, it's very true. You can't be sunshine and light all the time

RP06..

No you wouldn't be natural.

X..

But do you feel that you have the opportunity to talk to SP06? That hasn't really changed?

RP06..

Oh, no no. that hasn't. We've always got on fine. She's confident, as [her husband] always says, oh nevermind RP06 she's the one who always solves all the problems and she's happy with that. As long as she's happy I don't mind. I don't bother lifes too short. (acceptance)

X..

What advice would you give someone whose relative has dysarthria following stroke? What do you think would be useful to know?

RP06..

Well it would depend on the situation. She's a single person on her own. If there was a husband and family there, you would be able to say oh it's alright if she does this and she'll go to the speech therapist, you know, she'll be well enough tended to. But it's difficult. The situation is difficult. (burden)

X..

It's a different sort of relationship isn't it?

RP06..

Uh huh. Although it's family it's different. If you got your husband that's the person you look to first. But if you're a single person and you don't have family then it must be difficult. And let's face it, other families, suppose there was a family there. One might say oh that's ok, my mother's fine and one might say, they would agree to disagree (burden)

X..

Yeah

RP06..

Or one might be understanding and one might be obnoxious and not want to know anything. So it's only people's nature isn't it?

X..

Yup, yup

RP06..

But as I say, from what I've learnt from it, I've enjoyed and to be at [group sessions] and I thought that was a good thing

X..

Mm, hmm

RP06..

As I said to you earlier on, I felt SP06 could have got more out of it if she had put more in to it. But there is no way that you would change anybody at 91.

X..

No

RP06..

I think at the time her speech has improved people aren't saying what are you saying or making up sentences. I hope you were doing the right answer. She's confident on the telephone. So what else can you do?

X..

It doesn't seem to be impacting her life to go out and enjoy her life

RP06..

Oh no, as you say she's quite happy to go. But as you say it's familiar places she goes

X..

That’s good as long as she’s happy that is the main thing.

RP06..

Plus the fact that I was saying just be patient and saying to people encourage them and say there will be improvement. You’ve got to be confident enough. There is no point in being pessimistic about it. If you’re confident then SP06 will get confident. You can’t turn around and say you can’t do that. You have to say no come on you can do it and you’ll be fine. (dysarthria) (recovery process)

X..

Sort of encourage the independence

RP06..

Yup, you’ve got to make her. As we say, she is an independent lady and her speech, she’s obviously confident enough to do and to speak. If she met you she’d be quite happy to say oh that’s X

Appendix D.3: RP11

X..

When did your mum have her stroke?

RP11..

I think it was three years ago.

X..

Three years ago.

Rp11..

Yeah it was about three or four Christmas's ago.

X..

Ok

What have things been like since your mum had her stroke?

RP11..

They get better and then they get worse again and go in between (recovery process)

X..

Ok

RP11..

But she's doing well just now

X..

Yeah? Um, are there things that she feels more able to do now that maybe she didn't at the beginning?

RP11..

Umm, no not really, I still think she needs a lot of help with a lot of things. (recovery process)

X..

She's gone back to work now, hasn't she?

RP11..

Yeah she has. She was off work for a few months. Um, but then she decided to go back one day, because obviously she's not going to get any help just sitting in the house all day every day. (recovery process)

X..

Mmm, hmm. How is that going for her?

RP11..

Yeah she's enjoying it. She's going back full time soon.

X..

Oh really

Rp11..

Yeah

X..

Oh ok so it's worked out quite well for her then, because I know she had only been doing a couple of afternoons a week

RP11..

Um, three afternoons a week

X..

Three afternoons a week. Ok, that's good. That's excellent.

RP11..

I know, (laughter)

X..

She'll be happy about that.

RP11..

Yeah

X..

Do you feel as though there has been any change around the household since your mum had her stroke?

RP11..

Um, well, me and my sister have to do a lot of things now (role change)

X..

Right

RP11..

Whereas, like, my mum would usually do it before. But because she had her stroke she can't use her body right we kind of have to do it for her. (role change)

X..

Ok

RP11..

But, sometimes she just tells us to go away. She kind of wants to do it herself. (role change)

X..

Ok, so she's starting to take more on than she had before?

RP11..

Yeah, whereas before she didn't used to do anything, but now she'll tell my sister and I to go away and she'll do it. (role change)

X..

Ok and how do you feel about that?

RP11..

I think it's quite good for her, but it's not like she wants to do it. It's just housework and stuff, but me and my sister don't do it the way she likes it. So she's just kind of like, go away I'll do it myself. (laughter)

X..

Ok. Are there any particular times when you feel that your mum's stroke affects you more? Or less?

RP11..

Um, no not really. I don't usually like leaving her in by herself. Other than that, not really no. (burden)

X..

Ok. What about the recovery process following stroke? How do you feel about your understanding about that?

RP11..

Um, we didn’t really get much information really. They basically just told her “you need to go to this person and that person” and then that stopped. So she just got forgotten about. (information)

X..

Right, ok.

RP11..

I don’t really know much about the recovery process. (recovery process)

X..

Ok

What has the recovery process been like for you?

RP11..

Um, it didn’t really affect me up until a few weeks ago when she started having the speech therapy and stuff. Other than that it’s not really affected me. (involvement)

X..

Ok, so that’s more like the treatments, you feel like that hasn’t really affected you.

RP11..

Yeah

X..

Ok. So your mum is obviously seeing an SLT, that started quite recently didn’t it?

RP11..

Yeah.

X..

Was she seeing anybody else?

RP11..

No.

X..

So she didn’t have any physiotherapy or…

RP11.

At the start she did but not recently no.

X..

Ok.

Rp11..

She needs it, but she not had any,

X..

Ok has she tried to access any help?

Rp11,

She goes to the dr a lot and asks him but he never really does anything about it

X..

Ok, he hasn’t put her in contact with anybody or

RP11..

No he says he will but he never has. (laughter)

X..

Can you tell me how your mum’s speech was affected by the stroke?

RP11..

Do you mean how does she speak now?

X..

Um, more what the stroke did to cause her to have speech difficulties. So for example, the bleeding in the brain caused her right arm to be damaged and so she has difficulty moving it.

RP11..

Yeah, because of the stroke she can’t move her right leg properly and so this side of her body (indicating down her right side) is a bit weaker than this side is

X..

Yup ok.

RP11..

But she writes with her right hand and so her writing isn't very good either.

X..

Ok,

RP11..

And she can't really pronounce certain words properly. (dysarthria)

X..

Ok and so that's the speech that's been affected. And when you say she can't pronounce certain words properly what sort of things do you mean?

Rp11..

Like she can't really produce words with /s/ in them. And she slurs her words sometimes (dysarthria)

X..

Right, ok

RP11..

Sometimes she'll get all mixed up and use the wrong word for something.

X..

Ok

RP11.

But other than that she does pretty well. She just doesn't really like talking in front of people she doesn't really know. (dysarthria)

X..

Ok and is she using any strategies to help her make her speech clearer?

RP11..

Um, before the speech therapy she didn't really know what to do, but she's starting to do now, like using breathing exercises and stuff (dysarthria)

X..

Ok

RP11..

But before speech therapy she didn't really know what to do

X..

So its only really quite recently that she started seeing an SLT isn't it?

RP11..

Yeah, about just over a month ago.

X..

And how is it going?

RP11..

Yeah its going well. You can tell she's getting beter.

X>.

Yeah?

RP11..

Yeah.

X..

So she's able to think a lot more about how to say things to help her sound a bit clearer?

RP11..

Yeah. And because when she goes to the SLT group, because there are obviously other people like her she'll feel a lot more comfortable talking (dysarthria)

X..

Ok so it's helping her confidence.

RP11..

Yeah

X..

And how do you feel about being involved in the slt?

RP11..

Yeah I think it’s pretty good. (involvement)

X..

Yeah? Is it helping you?

RP11..

Yeah, before I didn’t really know much about the speech and stuff but now I’m learning a bit more. (involvement) (info)

X..

Ok and what about when the SLT comes here to see your mum, are you involved with that?

RP11..

Um, sometimes she gets me involved, because my mum doesn’t really want to do exercises when I’m sitting here listening to her, so she’ll try and get me involved as well. (involvement)

X..

Ok

RP11..

She just says, if you want to get involved you can (involvement)

X..

Ok. Is your mum quite happy with that?

RP11..

Yeah.

X..

And do you feel like you’re a bit more able to support your mum with her speech?

RP11..

Yeah

X..

How does your mum get on when she’s communicating with friends?

RP11..

If its one on one she's ok, but if it's a big group of people she'll start to slur her words and it's as if she's trying to get it all out in one breath. And people just kind of ignore that kind of thing, brush past it. (irritation)

X..

Right, so they don't always understand what she's saying

RP11..

Yeah so they just ignore it

X..

So they just ignore her basically?

RP11..

Yeah. If they don't understand her they won't ask her to repeat it.

X..

How do you feel about that?

RP11..

It annoys me. (Laughter). Obviously it does, because it's my mum and people are ignoring her and that's just rude (irritation)

X..

Yeah

RP11..

But I think she'd rather people asked her to repeat herself rather than completely blanking her

X..

Yeah, and is that with people that she knows?

RP11..

Yeah, sometimes it's as if they don't want to be rude and ask her, but they're being rude anyway by not asking her.

X..

Yeah, yeah. Sometimes people have real difficulty, they feel like they are overstepping themselves by asking, but in actual fact, by not it's worse.

RP11..

Yeah more rude. (irritation)

X..

What about family? How does she get on communicating with family?

RP11..

Yeah, she gets on pretty well. Sometimes like, my uncle and stuff, he'll get frustrated and annoyed when he doesn't understand what she's saying. But at least he'll ask her to repeat what she's saying. (family)

X..

Ok.

RP11..

But the rest of the family, like my wee cousins and stuff they don't mind it. They don't really notice it. (family)

X..

Ok

RP11..

They talk to her, um, normally (laughter). They don't ask her to repeat anything, because they understand her. (family)

X..

Ok, well that's good.

RP11..

Yeah

X..

So do you think she feels more comfortable when she's with the younger ones?

RP11..

Yeah

X..

Do you think the way that your mum communicates with friends and family has changed at all since the stroke?

RP11..

Yeah, so like before, she used to go to my aunt's house a lot and just go and sit up there for the night, but now she doesn't do that at all. (friendships) (behaviour change)

X..

Oh really?

RP11..

She'll only do it once in a blue moon. Basically when we force her to. Just like, get out the house and do something. But other than that, she used to do it all the time, but now she doesn't do it. (friendships) (behaviour change)

X..

Do you think now that she's out and about working that might encourage her to go out and about a bit more?

RP11..

Yeah, because even though all the people that go into her work are kind of, she's sees them every day kind of thing, there's still new people going in so she has to speak to new people anyway. She's getting there(friendships)

X..

Yeah?

RP11..

Yeah

X..

Getting more confident?

RP11.

Yeah

X..

How do you know when people are having difficulty understanding your mum?

RP11..

They just look really confused (laughter). They just kind of nod their head and then turn away from her kind of thing. (irritation) (understanding)

X..

Ok, so it's their body language?

RP11..

They don't out right say anything to her but you can tell just by the way that they are acting (irritation)

X..

Yeah, yeah. It's quite frustrating isn't it?

RP11..

I know

X..

I can imagine. How does your mum react in those sort of situations?

RP11..

She acts as if it doesn't really bother her, but obviously it does.

X..

Hmm, hmm, yeah.

RP11.

It would bother me (irritation)

X..

Yeah I know it's a really difficult thing. And I think the problem is, is that people don't realise

RP11..

How bad it is

X..

Yeah, it's kind of like taking someone's voice away from them. Their ability to give their point of view

RP11..

Yeah

X..

All it takes is, sorry can you

RP11..

Repeat that?

X..

Yeah. Has your mum ever told them that if they don't understand they should just ask her to repeat it?

RP11..

No, usually if they ignore her she'll say it again and a bit more clearer and obviously they'll understand her then and start talking to her. But usually she doesn't say anything to them because it's as if she doesn't want to bother them. (irritation)

X..

Do you think it would be better if she said something?

RP11..

Yes it annoys me and my sister when she doesn't say anything to anyone,

X..

Yeah

RP11..

It's just (sigh)

X..

Yeah its quite, mmm, difficult, isn't it?

RP11..

Yup

X..

Would your mum have said something before do you think?

RP11..

Yeah she definitely would've. She wouldn't have even hesitated before.

X..

Yeah

RP11..

But, like now she just kind of just shrinks into the background, kind of thing

X..

Yeah, yeah.

Are there any particular situations that you find particularly difficult because of your mum's speech?

RP11..

Um, just when we're in big groups of people.

X..

What is it about these situations that is difficult?

RP11..

I think it's because everyone is talking at once and because she's so quiet she can't really get a word in.

X..

Right

RP11..

And when she does, because there are so many people talking she's trying to get it all out (irritation)

X..

Mm

RP11..

In one breath and it just doesn't sound right and people are just kind of like shrug it off. But that's about the only frustrating thing. (irritation)

X..

Yeah

Has your mum's speech difficulty affected your life at all?

RP11..

Not really. Sometimes I get annoyed and stuff if she phones me and she'll shout down the phone.

X..

Ok

RP11..

And it's like, you don't need to shout at me I can hear you. She says, I'm not shouting at you. And it's really annoying. It annoys me. Other than that it doesn't really affect my life personally. (irritation) (understanding) (with each other)

X..

Ok

Rp11..

I think it's more wanting her to get better. (acceptance) (recovery process)

X..

Right ok, so you don't feel as though you've changed your own social life or activities?

RP11..

Well, at first I did, I didn't want to go out because I didn't want to leave her in by herself, but over the years, I've kind of learned that she'll be ok. If she needs me she'll let me know (acceptance) (with each other)(recovery process)

X..

Yeah, yeah

RP11..

But at first it did kind of change my social life, because I was only fifteen when it happened. So obviously when you're fifteen you want to go out with your friends all the time, but I didn't I stayed in with my mum. (burden) (acceptance) (with each other)

X..

Has that changed your relationship with her do you think?

RP11..

Um, I'd say we're a lot closer now then we were before, but other than that it's not changed much about our relationship (with each other)

X..

But that's a positive thing

RP11..

Yeah we're a lot closer now (with each other)

X..

Yeah a couple of people have said that, it's made them realise that, because they are spending more time with them

RP11..

Precious time

X..

Exactly. Do you feel like you have opportunities to talk to other people about your mum's stroke, like maybe your sister or

RP11..

Sometimes me and my sister talk about it, but it's only usually when we talk about it if, like, we're going to speech therapy or

X..

Mm, hmm

RP11..

My sister will ask how it was and stuff like that. Or if my sister is frustrated she'll talk to me about it and we'll talk to each other. But other than that I don't really have anyone else that I can talk to. Other than my auntie. (burden) (own relationships)

X..

Ok. Do you wish that there were other people that you could talk to?

RP11..

I wish there was yeah. But sometimes I don't really like talking about it. (burden)

X..

Mmm

RP11..

I just kind of keep it to myself. (burden)

X..

Right, ok. If there were other people that you… If you felt the need to talk to somebody would you prefer it to be someone that you knew, or would it be someone that's a professional?

RP11..

I think I'd prefer it if it was someone that I knew.

X..

Yeah? Right ok. So who would that most likely be? Your sister or you aunt?

RP11..

My sister and my auntie.

X..

And do you feel that there are quite able to

RP11..

Because, obviously, my sister knows. We're both going through the same thing so it's a lot easier to talk to each other about it. (own relationships)

X..

Yeah, so you can offer each other support

RP11..

Yeah

X..

Ok. Do you talk to your mum as much as you used to before the stroke?

RP11..

I probably talk to her more now. I tell her a lot of things that I would never have told her years ago. (closeness) (with each other)

X..

Yeah

RP11..

But I tell her a lot more. We're a lot closer than we used to be(closeness) (with each other)

X..

Do you think that's because of the stroke or do you think that's actually just because maybe you're getting older

RP11..

I think it's a mix of both, because obviously I am getting older and because obviously she had the stroke and I spend more time with her. But, um, it's nice that we're closer (closeness) (with each other)

X..

Yeah, that is good. That is really nice.

Do you think that you avoid going in to social situations where there are big groups

RP11..

Um, not really. Sometimes, you don't really think about it until your there.

X..

Ok

RP11..

And then you think, obviously she's starting to slur her words and she's not getting a word in, but other than that you don't really think about it until your there. And then you think, oh right ok, maybe she isn't very good with big groups. (friendships)

X..

But you don't specifically think, oh we're not going to go now because it's a big group and it will be uncomfortable.

RP11..

No, no.

X..

Ok, good.

So, just as a closing question, what advice would you give someone whose relative has dysarthria after stroke?

Rp11..

I’d just say, stick by them and help them in any way you can. Obviously don’t let it take over your life, but try and help them as much as you can, because then they’ll obviously get better and they’ll thank you in the end. (With each other)