Cardiff Metropolitan University

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B.Sc. (Hons) Speech and Language Therapy

How aphasia affects quality of life and identity: a family member’s perspective

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Dissertation submitted in partial fulfilment of the requirements of Cardiff Metropolitan University for the degree of Bachelor of Science.
DECLARATION

I hereby declare that this dissertation is the result of my own independent investigation under the supervision of my tutor. The various sources to which I am indebted are clearly indicated. This dissertation has not been accepted in substance for any other degree and is not being submitted concurrently for any other degree.

Candidate’s signature: ____________________

RESEARCH DATA PRIVACY

I acknowledge the issue of research data privacy and undertake not to share research data in any form without the explicit approval of their supervisor.

Candidate’s signature ____________________
Acknowledgements

I would like to thank the participants for giving up their time to make this study possible. Furthermore, I would like to thank my project supervisor, for the ongoing advice and guidance throughout this project. I would also like to thank my family and friends for their continued support and encouragement.
Abstract

**Background:** The impact of aphasia is frequently recognised for the person with aphasia (PWA), but there has been little research focusing on how the life of family members of PWA are affected. This is even less acknowledged in terms of quality of life (QoL) and identity.

**Aims:** This study aims to investigate how aphasia affects QoL, and specifically identity, from the perspective of family members of PWA.

**Methods and Procedures:** This study used a qualitative research design in order to explore how the lives of PWA and their family members have changed. Four family members (two wives of people with aphasia and two mothers) participated in semi-structured interviews. The interviews were analysed using thematic analysis.

**Outcomes and Results:** Analysis revealed three core themes: (1) loss; (2) change of role; and (3) availability of social network.

**Conclusions:** This study showed that aphasia affects the QoL and identity for both the person with aphasia and their family members. Clinically, these results emphasise the importance of addressing QoL and identity in aphasia intervention, and including support for family members in order to provide a more family-centred approach to management.

*(Aphasiology)*
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1.0 Introduction

“Strokes cause more prolonged disability than any other medical condition” (Caplan, 2006. p 4) and are the second most common cause of death in the world (Stroke Association, 2017). Strokes are also a common cause of aphasia (Watila & Balarabe, 2015). Aphasia is an acquired disorder of language processing which may affect comprehension, expression, reading or writing (Papathanasiou, Coppens & Potagas, 2013). There are different types of aphasia. In expressive aphasia, an individual may present with impaired speech production, for example, loss of fluency, difficulties with grammatical elements or word finding difficulties. In receptive aphasia, typically the individual may use jargon words but have correct rate and intonation, and may also have difficulty with auditory comprehension. Global aphasia combines features from both expressive and receptive aphasia, resulting in difficulties with understanding and producing speech (Damasio, 1992).

Aphasia can impact various aspects of an individual’s life. The consequences of aphasia can be linked to the International Classification of Functioning, Disability and Health (ICF) domains of participation, activity and wellbeing (World Health Organisation, 2001). The ICF framework adopts the social approach of management as it takes the whole client into consideration, not just the impairment. This allows the clinician to support all aspects of the individual’s life. The ICF domains also link to Therapy Outcome Measures (TOMs) (Enderby & John, 2015), which is the Royal College of Speech and Language Therapists’ (RCSLT) chosen tool for measuring the impact of speech and language therapy (Gadhok & Moyse, 2017).

Simmons-Mackie (2001) reported that people with aphasia (PWA) have to deal with social isolation, loss of autonomy, role changes and stigmatization. Traditional impairment based aphasia intervention rarely focuses on these psychological and social problems, yet it is these
issues that can contribute to diminished social reintegration and limit responses to rehabilitation (Sandin, Cifu & Noll, 1994). It is important to investigate the effects of aphasia as it is such a widespread issue, with around a third of stroke survivors experiencing it at some level (Stroke Association, 2017).

Family members’ lives are also affected by aphasia. Grawburg, Howe, Worrall and Scarinci (2013) interviewed family members of PWA and found seven categories of negative aphasia-related changes, including effects on their emotions and health, and a change in their relationship and social life.

The RCSLT (2009) advocate that aphasia intervention should increase participation, activity and wellbeing of the PWA. Widening research to include family members will provide better understanding of their needs, which may lead to better information and support services for families. This is relevant as currently, family members rarely get support themselves (Shadden, 2005). By including family in management, clinicians will be embracing the social approach to aphasia intervention.

The aim of this study is to investigate how aphasia affects the daily life and quality of life (QoL) of PWA and their family members, as well as how aphasia affects the way the family members view them self.
2.0 Literature Review

2.1 Aphasia and quality of life

Many aspects are incorporated into the term QoL, and there are numerous definitions which try and articulate it. The World Health Organisation Quality of Life Group (1998) define QoL as an individual’s perception of their self in the context of culture and value systems and in relation to their goals, expectations, standards and concerns. Felce and Perry (1995) state that QoL can be categorised within five dimensions: physical wellbeing, material wellbeing, social wellbeing, emotional wellbeing, and development and activity.

Aphasia, therefore, impacts QoL as it can affect some of the five dimensions as stated by Felce and Perry (1995). Physical wellbeing can be affected by mobility issues such as difficulty with walking, or with fine motor skills which may affect activities like writing. It may impact on social wellbeing as PWA could be socially isolated due to their communication difficulties. Emotional wellbeing can be affected as aphasia may make people more emotional, and may even change people’s personalities. Activity may be affected as they may have difficulty with certain tasks (Hilari, Byng, Lamping & Smith, 2003).

There has been numerous research regarding PWA adjusting to life post-stroke. Simmons-Mackie (2001) reported that PWA have to deal with social isolation, loss of autonomy, role changes and stigmatization. Cruice, Worrall, Hickson and Murison (2003) found that PWA had a reduced QoL, which was due to low psychological wellbeing, depression and reduced activity levels. Ross and Wertz (2003) tried to determine the specific differences in regard to QoL between people post-stroke with aphasia, and people without. They used two quantitative measures with thirty six participants and found that QoL differed on three main domains: level of independence; social relationships; and access to aspects of their
environment. These results can be used to determine specific intervention that best enhances QoL for people with chronic aphasia. Although findings to this study are valuable, the results were all measured quantitatively. They may not have assessed all aspects of QoL as the researchers chose the domains and so may not have included aspects that participants found important. Also, the domains of QoL that were chosen, were not ranked in their significance, therefore relative importance cannot be established. Participants should have been able to amend their responses if they felt another aspect of QoL was important and was not included. This demonstrates a limitation to all quantitative research regarding such a personal concept as QoL.

Hilari and Byng (2009) researched health-related QoL of people with severe aphasia and found that overall QoL is severely compromised. They found that compared to people with mild aphasia, aspects relating to communication and physical health are significantly worse for people with severe aphasia. This is useful as it allows a comparison to be made between severe and mild or moderate aphasia, thus emphasising the need for severity to be taken into consideration when working with clients. However, Hilari and Byng (2009) did not take into account the physical disabilities of their participants. It has been shown that physical disabilities do indeed have an impact on QoL (Hilari & Byng, 2009) and so the validity of their findings is affected.

It is important to talk about aphasia in terms of QoL as The Royal College of Physicians’ National Clinical Guidelines for Stroke state that one of the key aims of rehabilitation is to maximise the individual’s QoL and their social roles (RCSLT, 2005).

Identity is a specific component of QoL that will be examined further in this study. The importance of identity to QoL is revealed in a study by Robichaud, Durand, Bédard and Ouellet
(2006) who found that respect for an individual’s identity is the most important feature when choosing a nursing home. This came before having access to a private room and having support. Therefore, it is clearly an important facet of QoL to explore further.

### 2.2 Theories of identity

As with the term QoL, there is not one definition of identity. The definition depends on what approach is being used, for example, sociological or psychological. Taylor (1994. p 23) defines identity as “the fundamental defining characteristics as a human being,” whereas Costanza, Fisher, Ali, Beer, Bond, Boumans and Danigelis et al. (2007) state that identity is comprised of our status, our recognition, our sense of belonging and sense of place.

Our identities change throughout our life (Burke, 2006). They are dynamic, and are constantly changing due to social interactions and personal revelations. We can also have different identities at one time. Thoits and Virshup (1997) state that we can describe ourselves in terms of different categories, such as sociodemographic characteristics (e.g. gender), social roles (e.g. wife, friend), social types (e.g. cyclist) or personality qualities (e.g. funny). These different identities can be part of an individual level or collective level. Individual level identities are how one defines their self in terms of personal qualities, whereas, collective level identities are when one defines their self in terms of a group (Thoits and Virshup, 1997). Every individual has numerous identities that make up their sense of self. To lose our identity is to lose part of oneself.

Burke and Reitzer (1981) describe identity from a sociological approach, and state that identity is made up from the meanings that we attribute to our self in a role. These meanings
are emphasised by others. Burke and Reitzer (1981) state that identity is formed and maintained due to social situations. This can include establishing oneself in socially recognisable categories. These categories can be hierarchical. The hierarchy of identities is based on varying importance and context of the situation, as well as the demands of the situation. For example, a spouse of a person with aphasia may have numerous roles such as wife, mother, carer, employee, sister and friend. These roles vary in their importance depending on what the person is doing. If they are at work, employee may be at the top of the hierarchy, and then the wife and mother role may shift to the top once they have returned home. Therefore, people’s identity shift depending on what the social environment dictates as the most salient role for that specific situation. According to Korostelina (2007) the salience of identity is described as the level of awareness and importance among other identities.

From a more psychological approach, identity can be described as “the person we think we are” (Christiansen, 1999. p 548). This is often referred to as personal identity. It is different from the terms self-concept and self-esteem, although these are related to it. Self-concept incorporates our understanding of our personality traits and is created in our mind, whereas self-esteem refers to the how we evaluate our self-concept and how our self-concept gains social approval. Personal identity on the other hand, includes our roles and relationships, and can be seen as a more superordinate view of our self (Christiansen, 1999).

It is important to use theories relating to both social and personal identities in order to gain a greater understanding of the relationship between identity and aphasia.
2.3 Identity and aphasia

Aphasia may mean a person cannot engage in conversation using spoken language, and as Shadden (2005) states, control and use of language is a crucial aspect of everyone’s identity. Mackay (2003) supports this by expressing how communication leads to an empowered identity for everyone. Taylor (1994) states the importance of language in identity definition, validation and reframing, and highlights the need for significant others to recognise our identity and validate it. This is why relationships are crucial to identity theory, and why identity and language are closely linked and so cannot be seen as autonomous when treating aphasia.

Loss of language may lead to some loss of identity as an individual loses the ability to be an effective communicator. This may lead to the person identifying as inferior, which may lead to discouragement of social participation (Taylor, 1994). Therefore, lack of participation could in fact be a result of an altered sense of self, rather than the language difficulty, which is what is often said to be the cause.

If examining identity from this point of view, it is vital to explore the importance of social relationships on identity. Research has indicated that aphasia causes a loss of social relationships (Northcott & Hilari, 2011). It was found that PWA had, on average, nine fewer social contacts and three fewer social activities compared to people without aphasia (Cruice, Worrall, & Hickson, 2006). Therefore, if PWA are having fewer social relationships, then there are fewer people to help define and validate their identity, which may be an explanation as to why social relationships are so important to identity and QoL (Bramston, Chipeur, & Pretty, 2005).
Identity and aphasia have been well researched, and it has been found that aphasia does affect the identity of the PWA. Musser, Wilkinson, Gilbert and Bokhour (2015) researched identity and found that aphasia can lead to changes in three aspects of identity: occupational; family; and social. Participants commented on the fact that aphasia influenced the way they saw themselves and the way other people saw them, and they found that they had to recreate their identities. Several factors helped with this such as previous interests, aphasia severity and level of support. However, selection bias is a potential concern in this study as Musser et al. (2015) only recruited upper/middle class, well educated people. Therefore, perhaps some of the findings could be related to their socio-economic background, and so it is difficult to establish whether other individuals, with a different socioeconomic status, would report similar findings. Thus, more research is needed to investigate the importance of socioeconomic status on aphasia and identity.

2.4 Research on family members

Shadden (2005) states the importance of recognising identity change for family members, as well as for PWA, and how little it has been studied. This study also comments on how often after a stroke, family dynamics change and family members may need to re-calibrate their identity as it may be defined in part, in relation to the PWA’s. Eifert, Adams, Dudley and Perko (2015) talk about the concept of shared identity, which they define as an identity based on a relationship. Shadden (2005. p 219) describes shared identity as forging ‘the identities of two persons into a third ‘us’. ’ This relationship could be a couple, or a parent and child. The importance of this is that the shared identity cannot function without each of the two people, and this needs to be considered in terms of intervention, as National Institute for Health and
Excellence (NICE) guidelines (2013) state that speech and language therapists (SLTs) should support the PWA to rebuild their identity, however, it does not include support for family members who may have had a disruption of their shared and individual identity.

There are also studies that investigate how family members and their identity are affected by other health conditions. Heward, Gough and Molineux (2011) investigated family members of people with multiple sclerosis and found that they felt their identity had shifted, and that they also found it difficult to balance their different identities. This study therefore continues to highlight the need for more support and advice for family members in order to avoid excess pressure within the home, as some family members reported difficulty with adjusting to their new role. More advice and support will help the whole family to function positively. The fact that it was a literature review is promising as findings from fourteen studies were used, meaning the conclusions are reliable. However, this study mainly uses spouses and so it fails to take into account the opinions of other family members. This is relevant as the type of relationship may influence how the illness affects the individuals.

The importance of the family member’s perspective in general is explored in relation to numerous other disorders that affect communication. For example, in literature related to dementia, family members commented that communication breakdowns often lead to a reduction in interactions (Orange, 1991, cited in Savundranayagam, Hummert, & Montgomery, 2005). These communication breakdowns can lead to family members feeling burdened, and ultimately impact the relationship between the family and person with dementia (Savundranayagam et al., 2005). This can affect QoL of the family members (Farina, Page, Daley, Brown, Bowling, Basset, Livingston et al. 2017), as well as their identity, if referring to the previous theory that lack of social interactions impacts identity validation.
These results highlight how family member’s QoL can be affected by communication, and how important it is to both the family and the PWA to understand how they are feeling. However, these findings are regarding dementia, so consideration needs to be given when examining these results in relation to other communication disorders. Although dementia affects communication, other aspects of the disease need to be considered. The sense of burden and relationship change may be partially due to communication difficulties, but other aspects, such as cognitive decline may also play a part and it is difficult to disentangle the two.

2.5 Aims of study

In reviewing the literature surrounding QoL, identity and aphasia, it is clear that more research needs to be conducted, and the impact on family members should be considered. It has been established that family member’s lives are considerably affected by aphasia, and research into other health conditions suggests that their QoL, and specifically, identity has the potential to change. The aims of this project are to investigate from a family member’s perspective, how aphasia affects QoL and in particular, how aphasia affects identity. This includes exploring how their life has changed since the stroke and the key differences that impact their sense of self, and their sense of self within social roles. Family member’s views on how the QoL and identity of the PWA will also be considered. The anticipated outcome of this research study is better understanding of the needs of family members, which could lead to better information and support services for families.
3.0 Methodology

3.1 Introduction

A qualitative approach was used to investigate how aphasia affects QoL and specifically, identity. This method of research has been used effectively in similar studies in order to examine how identity changes for PWA after a stroke (Musser et al., 2015). Qualitative research is suitable for studies which focus on exploring views (Loder, Groves, Schroter, Merino, & Weber, 2016), thus, giving rationale for this research design. In this chapter, participant information will be discussed, as well as information regarding materials used, procedure of the research and how the data were analysed. Ethical considerations will also be reviewed.

3.2 Participants

Four participants were used in this study. A sample size of four is justified as Smith, Flowers and Larkin (2009) suggest between three and six participants for an undergraduate study, due to the fact that having more participants can be very time consuming. The participants were selected using purposive sampling. Palinkas, Horwitz, Green, Wisdom, Duan and Hoagwood (2015) emphasise the importance of availability and willingness to participate for purposive sampling. Participants were initially recruited through Stroke Association support groups, but due to insufficient numbers of participants, more participants were recruited through a university speech and language therapy clinic.

Inclusion criteria for the study were for participants to be aged eighteen or above and be family members of PWA. The PWA must have aphasia due to a stroke and their stroke must
have occurred within the last five years. Table 1 below summarises the participant characteristics.

<table>
<thead>
<tr>
<th>Participant number</th>
<th>Relationship to person with aphasia</th>
<th>Months/years post stroke</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Mother</td>
<td>6 months</td>
</tr>
<tr>
<td>2</td>
<td>Wife</td>
<td>1 year</td>
</tr>
<tr>
<td>3</td>
<td>Wife</td>
<td>1 year</td>
</tr>
<tr>
<td>4</td>
<td>Mother</td>
<td>3 years</td>
</tr>
</tbody>
</table>

*Table 1: Summary of participant characteristics*

### 3.3 Materials

An interview schedule (Appendix 1) was used during data collection. It was a semi-structured interview, meaning follow up questions could be asked if the researcher felt it was appropriate. This allowed the researcher to gain more detailed information. Three general topics were covered during the interview: home life; social life; and occupational life. The interview schedule was designed to ask open questions in order to explore how different aspects of the participant’s life have changed. These potential changes could then be considered in terms of QoL and identity. The interviews were recorded using a Zoom H5 audio recorder. The data were transcribed using Express Scribe Transcription Software.
3.4 Procedure

A pilot study was undertaken to ensure the questions were appropriate and to determine if changes needed to be made. However, no changes were made as it was felt that the questions were suitable in order to investigate the research aims. As no changes were made, the interview from the pilot study was used in the data collection because the participant gave some insightful answers that were thought to be valuable in examining how aphasia affects QoL and identity.

Semi-structured interviews were used to gather data. Semi-structured interviews are useful as they allow the researcher to explore the experiences of the participants (Doody & Noonan, 2013). Semi-structured interviews are effective as interview questions can be adapted depending on the direction of the conversation. Coolican (2014) describes advantages of semi-structured interviews as being able to collect more realistic information from the participant due to the less constrained nature of questions. However, limitations include problems with reliability. In qualitative research, reliability refers to consistency of the methods for all participants (Leung, 2015). This potential problem was minimised by using an interview schedule so the same core questions were asked to every participant. Questionnaires could have been used, but due to the sensitive nature of the topic, it was decided that interviews would be more appropriate due to the fact that they are more informal and personalised, and allow collection of more detailed information.

The interviews were held in a quiet room. The door was kept shut to maintain confidentiality. The interviews took place at a convenient time for the participants, and were conducted by the researcher. Each interview lasted between twenty and forty five minutes. Before the
interview, each participant was given an information sheet (Appendix 2), which explained the study and what would happen if they agreed to take part.

When transcribing each interview, any details that could make participants identifiable were anonymised. The interviews were transcribed using edited transcription, meaning pauses and false starts were not recorded.

3.5 Analysis

The data collected from the semi-structured interviews were analysed using thematic analysis (Braun & Clarke, 2006). This meant that themes were identified by the researcher. Thematic analysis was chosen as it allows the participant’s viewpoints to be explored, and is useful in exploring similarities and differences between participants (King, 2004). It also allows patterns to emerge throughout the process of data analysis without researcher interpretation.

Transcripts were read numerous times while making notes of the researcher’s initial thoughts. During this stage, the researcher identified important sections of text and coded them. These codes relate to basic elements of the data that were then grouped into broader themes, and possible patterns were identified, such as similarities between participant responses (see Appendix 3 for coded transcripts). Finally, the researcher analysed each theme and identified its relevance (Nowell, Norris, White & Moules, 2017). Relevance was decided by noting how many participants had mentioned aspects relating to the theme, and how much detail the participant went in to.
3.6 Ethical considerations

This research study gained ethical approval from Cardiff Metropolitan University Ethics Panel prior to data collection (Appendix 4). See Appendix 5 for the application for ethical approval.

All participants gave informed consent in writing (Appendix 6). This means that they read and understood the participant information sheet (Appendix 2), and agreed to take part. They also agreed to have the interview audio recorded. Participants were informed of their right to withdraw, and were assured that all of their information would remain anonymous. After each interview was transcribed, participants were sent a copy to validate, and had two weeks to contact the researcher notifying any changes.

There were minimal risks to this study, however the topic had the potential to cause distress. The risks of this occurring was minimised. The participants were told that they could have a break or the interview could be brought to a close. There was no need to employ these strategies with any of the participants. The interviews were all held in a safe location, and the project supervisor was aware of the location and time of the interviews. Audio files were stored securely and destroyed upon completion of the project.
4.0 Results

4.1 Introduction

In order to meet the aims of investigating how aphasia affects QoL and in particular, how identity is affected, four interviews were carried out with four different participants. Two of the participants were wives of PWA and two were mothers. From the four interviews, three core themes emerged from the data. The core themes and subthemes are shown below in table 2. From the data, it is clear that aphasia has a considerable impact on PWA and their families. All participants commented on changes in a variety of aspects that affect their daily living. References to the data are presented using participant number and line number in the transcript. To review the full transcripts, see Appendix 3.

<table>
<thead>
<tr>
<th>Core themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss</td>
<td>Loss of self</td>
</tr>
<tr>
<td></td>
<td>Loss of previous life</td>
</tr>
<tr>
<td></td>
<td>Loss of privacy</td>
</tr>
<tr>
<td></td>
<td>Loss of independence</td>
</tr>
<tr>
<td>Change of role</td>
<td>Change of occupational role</td>
</tr>
<tr>
<td></td>
<td>Change of family role</td>
</tr>
<tr>
<td>Availability of social network</td>
<td>Availability of friends</td>
</tr>
<tr>
<td></td>
<td>Availability of family</td>
</tr>
</tbody>
</table>

Table 2: Themes and subthemes as a result of thematic analysis

Each subtheme will be discussed in turn, stating what was found and potential implications this may have.
4.2 Loss

4.2.1 Loss of self

Loss of self refers to numerous aspects, such as loss of previous personalities as well as loss of abilities, and loss of previously important hobbies. Participant 2 (P2) mentioned hobbies, whereas other participants did not have many hobbies prior to the stroke. P2 specifically emphasised the fact that she was now unable to continue with hobbies that used to be very important to her. She reported feeling “so frustrated” (P2, 203) as she was used to keeping herself fit and she can feel herself not being as fit as she had once been. This is in contrast with P3 who did not have any major thoughts about having to give up her previous hobby of swimming. When asked how she felt about swimming less often, she responded by saying that “I just got on with it. There was no thinking about it, my husband came first” (P3, 84-85). This appears like she is expressing a sacrifice, but not one that she actively made. Linking to sacrifice, changes in priorities were also expressed. P2 commented that she used to be “very house proud” (P2, 350), but now only has time to do the basics around the house. She then elaborated by saying that “I feel bad about it because I’ve always done it. And always been proud of how well I kept the house” (P2, 356-357).

The participants were also asked how they feel that their relative has changed since the stroke. Like the family members, the PWA have since stopped doing hobbies that they previously enjoyed. P1’s son “was a great reader […] but he doesn’t seem to be doing any reading now” (P1, 268-270). Reading was a topic that also came up with P4, who mentioned that her son is “reading books for seven year olds and he is struggling” (P4, 227-228). Change in abilities was discussed in all of the interviews, and participants expanded further than solely communication difficulties. P1 spoke about how “aphasia is not just that you can’t say what
you want to say. It’s that some things are lost, like he had to re-learn to use the microwave and he can’t use his phone yet” (P1, 59-61).

Participants also commented on how the PWA’s personalities have changed since the stroke. P4 commented that she feels her son “is more like an adolescent teenager now, not the bright intelligent man that he was” (P4, 201-202). P4’s son’s previous wife also found his personality changes difficult, as she “called a halt on their marriage because she said he wasn’t the person she married” (P4, 44-45). This change must have huge implications for her son, considering the fact that breakdowns in marriages are difficult for anyone, never mind people who are also learning to deal with communication difficulties and other effects of a stroke.

Emotional changes were a topic that came up with two of the participants, specifically how the PWA was now more emotional. P3’s husband “tends to get very upset over, sometimes nothing” (P3, 147).

### 4.2.2 Loss of previous life

A theme for two of the participants was how different their life is now. P2 commented on how it’s “so sad thinking of what we had. We had a lovely lifestyle, and it’s sad that we’ve lost it. Never ever thought we’d end up like this” (P2, 386-388). P3 even used the term grieve in reference to her previous life saying “part of you has to grieve for what’s lost” (P3, 172-173).

Participants also referred to the previous life of their family member. P2 commented that before his stroke, her husband always keep himself busy and would never be sat down, but since his stroke, “he’s just sitting in the armchair trying to keep himself warm” (P2 121-122). He is now unable to do simple tasks around the house such as making snacks, washing the
dishes or using the vacuum cleaner. He also cannot go for walks, which he used to do regularly, due to the fact that “he’s losing his balance and he’s falling over a lot” (P2, 132-133). This could therefore mean that P2’s life has changed as she now has to do more for her husband.

However, P2 and P3 remain very positive about the future. Both participants talk about “accepting it” and “just pushing forward” (P3, 172-174), and the fact that they have “just got to carry on” (P2, 373).

4.2.3 Loss of privacy

Loss of privacy was particularly evident for the two sons of P1 and P4. P1 commented that her son is unable to use his phone. He can read text messages but he cannot send messages. She stated that herself and her husband “are acting as his social secretary” (P1, 66-67) as they have to respond to their son’s messages on his behalf. This must have a big impact on her son as he is unable to contact his friends without his parents. This may mean that the dynamics of his friendships change due to the fact that his friends always know that his parents will be involved in the conversation. This topic of privacy also came up with P4, who said that she put a tracking app on her son’s phone so that she always knows where he is. Her reasoning for this was that she worried about him when he was out, and so by tracking him, it gives her “a lot more peace of mind” (P4, 77). However, the impact of this means that her son has no privacy because his mother always knows where he is. This could potentially affect their relationship as he could see it as lack of trust.
Loss of privacy was not apparent with the participants whose husbands had a stroke, potentially due to the different dynamic of their relationship. Spouses are more likely to share aspects of their lives with each other, but often, between children and parents, there are likely to be more boundaries on privacy.

### 4.2.4 Loss of independence

Loss of independence was spoken about in different terms. From the perspective of the PWA, loss of independence may mean the inability to carry out simple daily tasks without the help of others, but some participants spoke about their loss of independence and the fact that they are now unable to leave the PWA.

P2 talked about all the things that her husband now needed help with saying “I soap him down but he will rinse himself off. He dries the front. I have to dry his back. He can clean his teeth if I prompt” (P2, 80-82). This must have a huge impact on her husband’s autonomy as he is now unable to do simple tasks such as showering without help.

The two participants who were mothers commented that their sons still have a lot of independence. P1 spoke about the fact that her son still goes out by himself. P4 said that her son has “got a bus pass and he does go out on his own” (P4, 69), however they are not completely independent. P4 reported that she lives on top of a hill and the bus only stops at the bottom, and so when her son has been out all day, he cannot walk up the hill because he is too tired. Therefore, he still has to rely on his mother to pick him up and drive him home. This will then have an impact on his mother as she has to be available, which may have implications on her daily life and her social life.
P2 in particular spoke about how her own independence has changed. When asked what the biggest change since the stroke was for her, she replied “not having my freedom” (P2, 347). This is due to her being unable to leave her husband. This topic of not leaving the PWA came up in most of the interviews. P1 explained that her and her husband feel they cannot leave their son for hours on his own. P2 went on to explain how leaving her husband makes her feel, saying she feels “guilty about doing it because anything could happen” (P2, 209). Aphasia was the main cause of the participant’s worry and reason for not leaving them, as “if there was a problem, he can’t communicate that problem to anybody” (P1, 140-141). P1 gave the example of their house catching fire and her son not being able to call anyone. She recognised that “these things aren’t likely to happen but you think, what if it did happen when we weren’t there” (P1, 152-153). This feeling of not being able to leave the PWA must affect the participants’ lives in a number of ways. It may affect their social life, and potentially, their relationship with the PWA, as they are not able to have a lot of time to themselves without the PWA.

4.3 Change of role

4.3.1 Change of occupational role

Change in occupational role of the PWA was relevant to three out of the four participant’s family members, as three of them had worked before having their stroke and subsequently had to give up working which had big repercussions, such as frustration and money worries. The three participants’ relatives with aphasia who had worked all commented that their relative wants to return to work. Reasons for not being able to return to work focused on
their aphasia. P1’s son, who worked in a shop, “wouldn’t be able to respond” (P1, 235) if a customer asked him something. She recognised that it could “cause frustration, not being able to go back to work” (P1, 226). When P4 was asked how she thought her son feels about not being able to return to work, she replied with “I think he’d rather have lost the use of his legs than his speech” (P4, 111-112). This emphasises the importance of communication in the eyes of the PWA, and demonstrates the extensive effects of not being able to communicate effectively.

For some of the participant’s family members with aphasia, occupational role appeared to be very important to them. When asked what they thought the biggest change for their family member was since the stroke, the two mothers replied with their sons being unable to work. It is interesting that this was the response of the two mothers and it could be said that the fact that the sons were young when they had their stroke, both under the age of forty, could influence this as employment is a large part of life at that age, and they were likely unprepared for this huge change of their daily life.

Change in occupational role for the participants was not as relevant as all participants had retired before their family member had their stroke. However P3 stated that she was “going to have to go back out and work” (P3, 107-108) due to financial difficulties of her husband not being able to work. She reported that she felt “frightened” as “it’s been five years since I gave it up, but needs must” (P3, 112-113).


4.3.2 Change of family role

Change in family role appeared most relevant to the participants themselves, and refers to the different roles the participants now take on, as well as the role of mother or wife. One such role that emerged from the interviews was the role of carer. The two participants who were wives spoke about the fact that they were involved in their husband’s personal care, such as washing and dressing. P2 referred to this carer role by saying that her life now involved “24 hour caring for my husband” (P2, 92). When asked how P3 felt about doing more for her husband, she replied with “I think I’ve just got used to it [...] It’s my role” (P3, 48-49). She mentioned that it was her role three times, which emphasises her thoughts on how caring for her husband was her responsibility, which is shown further by the fact that she did not let her family share this duty. P3 also mentioned that she had previously cared for her mother, who had Alzheimer’s disease, and said “I seem to always be a carer” (P3, 53). This is interesting as it could be said that she feels so strongly about her responsibility as a carer, as she has found herself in a similar role previously.

Another role that arose from the participants was the role of tutor. All participants spoke about prompting their family member to do either physical exercises or exercises that focus on communication at home. P3 described herself as “quite a bully” (P3, 165) when it comes to practising tasks at home because her husband is not very motivated. This role of tutor appeared to cause friction in the relationships of all participants and their family member with aphasia. P1 reported how her son gets fed up when doing exercises at home. P4 went into detail of how her son gets grumpy with her when doing tasks, but not with anyone else, and how “it hurts” (P4, 254) when this occurs. P2 commented on how her husband is not motivated to do tasks, so she then raises her voice and then “he gets frustrated” (P2, 331).
P3 summarises how huge the effects of a change in her role are, especially in terms of her relationship with her husband. When asked what the biggest change in her life has been, she replied with “our lives as a couple really, I think that’s the biggest […] It’s hard to put it into words. It’s just completely different” (P3, 152-154).

4.4 Availability of social network

4.4.1 Availability of friends

Availability of friends was mentioned by all participants. Sometimes in relation to the PWA, and at other times relating to the participant themselves. P3 and P4 commented that their social life involving friends had not been affected as they did not see many friends before the stroke. Two participants spoke about the fact that their social life had changed since their family member had a stroke, and specifically how it restricted their social life due to not being able to leave the PWA alone. P2 in particular was unable to see friends often as she does not live near them, and it takes too much time to travel. She talked about situations where she had to leave early to get home to her husband, and how that makes her feel, commenting that she feels like she misses out. This could therefore affect her QoL if she is becoming more socially isolated.

The two participants who were mothers commented that their sons still have an active social life. However, P1 commented that her son relies on his friends to instigate plans. P4 said “he goes out every Monday. He goes to another place and plays board games. He meets people from [his previous place of work]” (P4, 119-120). It is interesting to note that the PWA who are the participant’s sons are the ones with an active social life, and the two PWA who are
the participant’s husbands did not see much change in their social life as they did not have many friends prior to the stroke. It could be argued that the sons have an active social life due to their age, or potentially due to the relationship dynamic of parent and child versus spouses. Spouses are more likely to spend a lot of time together and have potentially more mutual friends, whereas adult children will often have social circles that do not involve their parents.

4.4.2 Availability of family

Availability of family was spoken about by most participants. Two participants spoke about having family nearby and how important this was, whereas P2 commented on what it was like to not have family who live nearby. P1 only briefly mentioned family and so her feelings on the importance of family are unclear.

Family isolation was particularly felt by P2, who reported that her daughter lives away and works full time, so “has her own life” (P2, 222), and her family live elsewhere, as well as her husband’s family who live away. When asked how she feels about not seeing family much, she commented on feeling sad, and touched on the fact that she was the only one who moved away so all her family are together. This is in direct contrast to P3, who commented that “one daughter lives next door but one, and the other daughter lives just round the corner” (P3, 87-88). This couple appeared very family orientated, saying “we are just always with our family” (P3, 115), and commented on how lucky they were to have such good family support. P4 spoke about the fact that during the week, her son lives with her, but he spends every weekend staying at his sister’s house. This availability of family appeared valuable to her as she reported that “I do need those breaks because it is so tiring” (P4, 271-272), but also spoke about the benefits of him spending time with his two sisters which included being around
people his own age as “a 35 year old lad doesn’t want to be doing things with his 70 odd year old mother” (P4, 124-125). Family appeared important to this participant and her children as her oldest daughter decided to move closer to home after the PWA’s stroke because “she realised that she needed to be near family” (P4, 188-189).

Only P3 spoke about the potential negative effects of spending too much time with family. She commented that her husband has only been around family, and “at the beginning, we kept him in a bubble, and we need to open that bubble now” (P3, 121-122), due to him being reliant on his wife to answer for him.

4.5 Summary of results

The data revealed that the lives of both PWA and their family members have drastically changed since the stroke. Some of these changes are due to the aphasia, and others are from the effects of the stroke. It could be argued that the two are so closely linked that assigning the cause to just one is impossible. There was not one overriding theme as different participants emphasised different aspects. For some participants, isolation appeared to have the biggest impact, and for some PWA, change in occupational role appeared most prominent. These themes will be further discussed in the discussion chapter.
5.0 Discussion

5.1 Introduction

This research sought to investigate the relationship between aphasia and QoL, and specifically, identity, from the perspective of family members of PWA. Previous research has suggested that aphasia affects QoL (Simmons-Mackie, 2001), and the identity of PWA (Musser et al., 2015). It is clear that aphasia impacts families, yet there needs to be more consideration on how their QoL and identity are affected. This study involved four interviews with relatives of PWA in order to explore how daily life and QoL have changed for them and their relative with aphasia, as well as how their view of themselves has changed. From the interviews, it was found that aphasia does impact QoL and identity for the PWA and their family members.

The ICF model (WHO, 2001) will be used when discussing findings from this study, as the RCSLT (2005) promote its use as a framework for practice due to its whole client approach of taking the impairment, activity, participation and wellbeing of the individual into account, which is adopting the widely used social approach to aphasia management. Activity describes an individual’s ability to perform a task or action, such as communicating their thoughts, and participation describes their involvement in a situation, for example, in decision making (RCSLT, 2009). Limitations, clinical implications and suggestions for future research will also be discussed.
5.2 Aphasia and quality of life

In addressing the first aim, the current study supports previous findings that aphasia impacts the QoL for PWA (Simmons-Mackie, 2001). QoL is comprised of numerous domains, such as independence, social activity and privacy. These domains will be discussed further, as well as how they are affected by aphasia.

This study had similar findings to Simmons-Mackie (2001) as it was found that PWA have to deal with a loss of independence (see section 4.2.4). Loss of independence was reported due to PWA not being able to do certain tasks without help, such as personal care tasks. Independence is an important aspect of QoL as it affects the activity of an individual, which then causes participation restrictions. This issue is difficult to resolve as PWA may not be able to do tasks independently, but SLTs can help by facilitating decision-making. This ensures PWA still have control over some aspects of their life.

Simmons-Mackie (2001) also reported social isolation for PWA, however, this was not found in this study. Instead, it was the family members that reported feeling socially isolated. For some PWA, it was perceived that they did not see many friends before their stroke and so little had changed, and for other PWA, their relatives commented that they appeared to have an active social life. This contradicts Northcott and Hilari (2011) who found that aphasia causes a loss of social relationships. The small sample size of this study could have resulted in the inconsistent results and so cannot be seen as representative of all PWA. Also, Northcott and Hilari’s (2011) participant sample of PWA consisted of people over the age of fifty, while in this study, some participant’s relatives with aphasia were under forty. Therefore, age could affect people’s social experiences, thus explaining the differences in the results. It also has to be noted that in this study, the social activity of PWA can only be perceived by their family
members, whereas, in Northcott and Hilari’s (2011) study, participants were PWA. PWA may feel that their social life has been drastically affected due to aphasia, but this cannot be known as only family members were interviewed. One participant even commented that she did not know how her son felt about his social life now. It could be argued that it is easier to perceive social isolation when it is personal and so this could explain the differences in results from previous research.

The claim that it is easier to perceive social isolation when it is personal and coming from the individual concerned is supported by the fact that it was the family members of PWA who reported a restriction on their social life. This was due to not being able to leave the PWA alone. They worried that the PWA would not be able to communicate if there was a problem. Grawburg et al. (2013) also found that family members of PWA experienced negative changes to their social life, however, this was not due to concerns over leaving their relative with aphasia alone, but because they were too busy caring for their family member to see friends.

Having social relationships is important to QoL as it has psychological benefits such as social support. Social support is vital as it aids personal growth and development as well as self-acceptance (Cruice et al., 2003). Social isolation is also linked to depression (Northcott & Hilari, 2011), and so this aspect of QoL is important to consider when managing aphasia. This outcome indicates that a communication difficulty can indirectly affect family members’ participation as well as PWA’s participation. This highlights the importance of understanding how families are affected. In order to support family members who feel social isolated, there should be more support groups available to relatives. This will encourage social inclusion and would provide vital social support from people who are going through similar things, as well as promoting psychological benefits such as encouragement and discussions about different coping strategies.
This study also adds to current research by identifying loss of privacy for PWA. This has not been found in previous research. It was found that PWA potentially have a lack of privacy due to their communication difficulty. For example, one individual with aphasia was unable to respond to text messages and so family members had to reply on their behalf. This means that they have little privacy when communicating with their friends, and may even cause a change in relationship dynamic between the PWA and their friends. Prior to the stroke, they may have been a confidant, and now they are unable to carry out that role due to friends knowing that what they say is being seen by others. This participation restriction could be resolved by using speech to text apps on phones or tablets, however this would not be possible for all PWA, as it would depend on the severity of aphasia. If an individual had severe aphasia and could not say a sentence to be converted to text, then it would be difficult to use.

5.3 Aphasia and identity

In addressing the second aim, this study supports findings that identity is affected by aphasia. It supports Musser et al. (2015) who found that the identity of PWA changes, but also supports Shadden (2005) who states that family members of PWA also experience identity changes. Aphasia can cause changes in different aspects of identity, such as social identity, personal identity and family identity.

As stated previously, there are different theories of identity (see section 2.2). Burke and Reitzer (1981) state that identity is formed and maintained in social situations. The effect of aphasia on the identity of PWA cannot be explicitly established due to the fact that only family members were interviewed, and the PWA may feel differently to how their relative perceives them. Thus, the impact on their identity can only be speculated. However, it can be stated
that the identity of family members of PWA may have been affected, as they commented on restrictions in their social life. This impacts their identity as they have fewer people to help validate their identity, which Taylor (1994) states as crucial in identity definition. Consequently, it could be argued that social participation plays a huge role in both QoL and identity validation, and therefore should be an essential part of management for PWA and their family. This would support the proposal of providing more support groups for relatives of PWA.

When describing identity from a psychological approach, it could be argued that both PWA and their relatives experience a change in personal identity. This is shown in the theme of loss of self in section 4.2.1, where it was reported that PWA experience changes in their personality, often becoming more emotional. This links to personal identity as changes in personality traits affect self-concept, which is an aspect of personal identity (Christianson, 1999). Family members’ personal identity changed due to having to give up previously important hobbies.

In light of the identity theories from a sociological and psychological approach, it is clear that SLTs should facilitate both PWA and their families in identity redefinition if they feel it is appropriate. Shadden (2005) states the importance of language in identity definition (see section 2.3), and so although PWA did not appear socially isolated, the fact that their language use is impaired, may affect identity validation. Therefore, in terms of PWA, identity renegotiation could be supported by SLTs through the use of Alternative and Augmentative Communication (AAC), which includes technology that assist communication, such as a communication book. This is useful as it gives PWA a tool to communicate which then allows more social interactions which is necessary for identity validation. Total communication,
which encourages the use of multiple modes of communication such as sign, gesture and drawings, would again promote social interactions in the same way. Using AAC and total communication will help to improve PWA’s activity, which then gives them the tools to increase their participation. If they choose to use these tools to increase their participation, this is then promoting self-confidence and control which is likely to increase their wellbeing. Thus, the use of support groups for family members and AAC and total communication for PWA appear highly beneficial in identity definition.

Similarly to Musser et al. (2015), this study found that relatives of PWA experienced a change in their roles as a consequence of aphasia. However, Musser et al. (2015) did not specify the different roles, instead just commenting that roles and responsibilities had changed. In this study, different roles emerged from the interviews, including role of carer and tutor. The relationship between the participant and the PWA could affect how each relative feels about these new roles. In this study, two participants were mothers and two were wives. It could be argued that the role of mother is presumed to be a caring role in which they look after their child. However, children grow up and are expected to become more independent, meaning that mother’s caring responsibilities reduce as children age. However, in this study, the children who have aphasia had to move back home, meaning the mothers had to recommence their caring responsibilities which they may have assumed were behind them. This is interesting as it could be argued that parents assume it will be their children looking after them rather than the other way around. This is in contrast to spouses who may expect to care for each other as they age and illness becomes more inevitable. This change in role for a spouse may therefore affect their team dynamic more than their personal identity, however this change in team dynamic may affect their shared identity, which is an identity based on a relationship (Eifert et al. 2015). This is supported by one of the participants who
commented on the change in their lives as a couple as the biggest change after the stroke. It would be interesting to further investigate this with different family members. In this study, only mothers and wives were interviewed, but potentially perspectives from other family members would be different, such as males. This is particularly relevant for the case of family roles as women are traditionally associated as the carer and so experiences of males may present with different results.

5.4 Clinical implications

This research provides strong evidence for addressing QoL in aphasia intervention for PWA, and their families. It should be used by PWA when setting goals in order to directly improve activity and participation. If goals are related to QoL, then QoL should also be routinely assessed before and after intervention to allow the impact of therapy to be measured. This would link well with TOMs (Enderby & John 2015), which is the RCSLT’s chosen tool for measuring the impact of SLT (Gadhok & Moyse, 2017), as it describes the abilities and difficulties of clients in the four ICF domains of impairment, activity, participation and wellbeing. Different scales could be used to assess QoL, such as the Stroke and Aphasia Quality of Life Scale-39 (Hilari et al., 2003).

Addressing QoL is central to the social approach, which includes a more family-centred approach to aphasia management. By gaining an insight into the effects of aphasia on family member’s activity and participation, SLTs can have a better understanding of how their QoL is affected and therefore provide specific support and guidance. From this study, it could be said that family members may need more support to avoid social isolation, and help with respite to enable them to continue with hobbies so as to avoid a loss of independence.
The clinical implications of SLTs not treating PWA and their families using the social approach and addressing QoL could lead to the individual being unable to participate in family life and society, which could potentially result in unemployment, breakdowns in families and psychological issues such as depression. All of these issues have a large impact on health and social services.

This study also provides evidence for addressing identity in aphasia intervention, in regard to the PWA and their families. This should include promoting social relationships by signposting to support groups as it has been established that social interactions are vital for a good QoL and in identity definition.

5.5 Suggestions for further research

To provide greater evidence for more support for family members, future research should consider investigating the views of more parents of people with communication difficulties because in previous research, often only spouses’ views were explored and as the findings from this study demonstrate, not all family roles experience communication difficulties in the same way. It could also be argued that with an ageing population and people living longer, parental carers may become more common. In this instance, it would also be interesting to explore the views of children of people with communication disorders, in order to investigate how their QoL and identity are affected, as they may have to care for their parents for longer, again due to the ageing population and longer life expectancies.

Previous research has explored how families of people with other communication disorders have been affected. However, it would be interesting to explore this further, specifically to
establish whether QoL and identity of family members are affected differently depending on the communication disorder. Strokes affect communication very suddenly and without time to prepare, whereas illnesses that cause a more progressive change to communication, such as Parkinson’s disease or motor neurone disease, may mean that families have different reactions. This would establish whether communication disorders in general affect the QoL and identity of relatives, or if there is a difference depending on the illness. This could then provide evidence for either offering general support for all family members, regardless of the communication difficulty, or providing specific guidance and support services for different illnesses. This is relevant as different support services are provided for the individual with the communication difficulty, but at a time where healthcare providers are continuously suffering from economic pressures, it would be more economical to offer general family support and information, and therefore still providing much needed services.
6.0 Conclusion

In conclusion to the research aim of investigating how aphasia affects QoL and identity of PWA and their family members, the findings of the current study suggest that QoL and identity change for both people. Some of these changes could be due to the stroke, whereas others are a direct consequence of aphasia.

Changes to QoL can include changes in independence and privacy, as well as changes in social life. The effects of these changes can have big implications for both PWA and their relatives, as activity and participation are affected.

The findings also suggest that changes to identity include numerous different features. PWA and their relatives may experience a change in their previously held sense of self, in terms of their social and personal identity, and so therefore may need support in redefining their identity. The importance of social interaction for this task is fundamental as relationships are crucial in identity validation.

These findings therefore suggest that QoL and identity should be addressed more in aphasia management by SLTs, and should not only be considered in terms of PWA, but also their relatives. It is clear that aphasia impacts more than just the individual with aphasia, and so better information and support services should be available for families in order to provide a more family-centred approach.
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### Interview Schedule

#### Introduction. Explain the purpose of the study

**Background**
- Relationship to Person With Aphasia (PWA)?
- How many years since stroke?
- Tell me a bit about what happened?

Tell me what it’s like when you talk to [name of PWA]

What are their main difficulties when it comes to talking?

#### Home/family identity

- What types of things did [name of PWA] do around the home before the stroke?
- What about now?

What do you do around the home now, that maybe you didn’t have to do before the stroke?

How do you feel about these changes?

#### Social identity

- What about going out and about and seeing friends? What is that like now? Is that different to before?

How do you feel about this?

How do you feel when you both go out together?

#### Occupational identity

- How about jobs? What have you done in the past? Do you still work, or are you retired?
- Do you have any other commitments? Like any volunteer work?

How is that all going?
- Is it different to before?
- How do you feel about the working/volunteering aspect of your life?

How about [name of PWA]? Did they work before the stroke? Do they have any commitments at the minute? Like work, or volunteering roles?
- If so, how do you think they feel about it?

#### Summarise. Clarify key points.

Explain what I will do next.
Participant information sheet

Reference number: 9997

Title of project: How aphasia affects identity: a family member’s perspective.

My name is Amy Hughes. I’m a year 4 student studying Speech and Language Therapy at Cardiff Metropolitan University. For my final-year research project, I have chosen to look at how aphasia affects daily life from a family member’s perspective. This is an invitation for you to take part in my research. The following information will let you know what this involves.

What the project is about
My project will involve exploring how aphasia has affected your daily life and that of your family member. I have invited you to take part because you have a family member with aphasia, who had their stroke within the last 5 years.

What will you have to do?
Your participation is entirely voluntary. You should not feel obliged to take part. If you decide to take part, the interviews will last approximately 30-40 minutes. It will involve having an informal chat about your personal experiences. You can withdraw from the study at any time during data collection and up to two weeks afterwards, without giving a reason why. I will record the interview using a small device with a microphone then I will write a script of what we both said. You will have a chance to read the script afterwards and check you are happy with it. You will have two weeks to let us know if you would like there to be any changes.

Are there any risks?
There are minimal risks involved if you decide to take part. We will be talking about your experiences after your partner’s stroke which may be difficult for you to talk about however I will make sure that the conversation is as relaxed as possible by following your lead.
throughout. I will appreciate any information you are willing to share. If at any point you feel unable to continue, we can stop and have a break or bring the interview to a close.

**How will your privacy be protected?**

The interview will be audio recorded and the audio recordings of the interview will be transferred to a password protected laptop. No one will be able to tell from the script that those were your words and when I write-up my findings you will not be identifiable in any way. The data will be destroyed upon completion of the project but the consent forms will be kept securely by the University in line with their regulations.

**What happens next?**

If you agree to take part, we can agree on a time and place for the interview that works for you.

**Further information**

If you have any questions regarding this research project, please contact my supervisor:

Email address:

Phone number:

Thank you for your time!
Participant one

...
65
BSc (Hons) Speech & Language Therapy  
Cardiff School of Health Sciences

Dear Applicant

Re: Application for Ethical Approval: How aphasia affects identity: a family member’s perspective

Project Reference Number: 9675

Your ethics application, as shown above, was considered by the Health Care and Food Ethics Panel on 22/11/2017.

I am pleased to inform you that your application for ethical approval was APPROVED.

Minor issues may still need addressing before you commence any work – if so these will be listed below.

N/A

Where changes to the information sheet, consent form and/or procedures are deemed necessary you must submit revised versions to the relevant ethics inbox. If you are a student – your supervisor must do this on your behalf.

Note: Failure to comply with any issues listed above will nullify this approval.

Standard Conditions of Approval

1. Your Ethics Application has been given a Project Reference number as above. This MUST be quoted on all documentation relating to the project (e.g. consent forms, information sheets), together with the full project title.

2. All documents must also have the approved University Logo and the Version number in addition to the reference and project title as above.

3. A full Risk Assessment must be undertaken for this proposal, as appropriate, and be made available to the Committee if requested.

4. Any changes in connection to the proposal as approved, must be referred to the Panel/Committee for consideration without delay quoting your Project Reference Number. Changes to the proposed project may have ethical implications so must be approved.

5. Any untoward incident which occurs in connection with this proposal must be reported back to the Panel without delay.

6. If your project involves the use of human samples, your approval is given on the condition that you or your supervisor notify the HTA Designated Individual of your intention to work with such material by completing the form entitled “Notification of Intention to Work with Human Samples”. The form must be submitted to the PD (Sean Duggan), BEFORE any activity on this project is undertaken.

Monday, 27 November 2017  
cbs/ethics/approved
This approval expires on 22/11/2018. It is your responsibility to reapply / request extension if necessary.

Yours sincerely

[Name redacted]

Chair of Department of Healthcare and Food Ethics Panel
Cardiff School of Health Sciences
Llandaf Campus
Western Avenue, Cardiff CF5 2YB

PLEASE RETAIN THIS LETTER FOR REFERENCE
Amended ethical approval

Monday, 05 March 2018

Amended ethical approval

Bsc (Hons) Speech & Language Therapy
Cardiff School of Sport and Health Sciences

Dear Applicant

Re: Application for Ethical Approval: How aphasia affects identity: a family member’s perspective

Project Reference Number : 9997

Your ethics application, as shown above, was considered by the Health Care and Food Ethics Panel on 21/02/2018.

I am pleased to inform you that your application for ethical approval was APPROVED.

Standard Conditions of Approval

1. Your Ethics Application has been given a Project Reference number as above. This MUST be quoted on all documentation relating to the project (E.g. consent forms, information sheets), together with the full project title.

2. All documents must also have the approved University Logo and the Version number in addition to the reference and project title as above

3. A full Risk Assessment must be undertaken for this proposal, as appropriate, and be made available to the Committee if requested.

4. Any changes in connection to the proposal as approved, must be referred to the Panel/Committee for consideration without delay quoting your Project Reference Number. Changes to the proposed project may have ethical implications so must be approved.

5. Any untoward incident which occurs in connection with this proposal must be reported back to the Panel without delay.

6. If your project involves the use of human samples, your approval is given on the condition that you or your supervisor notify the HTA Designated Individual of your intention to work with such material by completing the form entitled “Notification of Intention to Work with Human Samples”. The form must be submitted to the PD (Sean Duggan), BEFORE any activity on this project is undertaken.

This approval expires on . It is your responsibility to reapply / request extension if necessary.

Yours sincerely

[Signature]
Chair of Department of Healthcare and Food Ethics Panel
Cardiff School of Sport and Health Sciences
Llandaf Campus
Western Avenue, Cardiff, CF5 3WB

PLEASE RETAIN THIS LETTER FOR REFERENCE
Appendix 5 - Application for ethical approval

CARDIFF METROPOLITAN UNIVERSITY
APPLICATION FOR ETHICS APPROVAL

When undertaking a research or enterprise project, Cardiff Met staff and students are obliged to complete this form in order that the ethics implications of that project may be considered.

If the project requires ethics approval from an external agency (e.g., NHS), you will not need to seek additional ethics approval from Cardiff Met. You should however complete Part One of this form and attach a copy of your ethics letter(s) of approval in order that your School has a record of the project.

The document Ethics application guidance notes will help you complete this form. It is available from the Cardiff Met website. The School or Unit in which you are based may also have produced some guidance documents, please consult your supervisor or School Ethics Coordinator.

Once you have completed the form, sign the declaration and forward to the appropriate person(s) in your School or Unit.

PLEASE NOTE:
Participant recruitment or data collection MUST NOT commence until ethics approval has been obtained.

PART ONE

<table>
<thead>
<tr>
<th>Name of applicant:</th>
<th>[Hidden]</th>
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</thead>
<tbody>
<tr>
<td>Supervisor (if student project):</td>
<td>[Hidden]</td>
</tr>
<tr>
<td>School / Unit:</td>
<td>School of Health Sciences</td>
</tr>
<tr>
<td>Student number (if applicable):</td>
<td>[Hidden]</td>
</tr>
<tr>
<td>Programme enrolled on (if applicable):</td>
<td>BSc (Hons) Speech and Language Therapy</td>
</tr>
<tr>
<td>Project Title:</td>
<td>How aphasia affects identity: a family member’s perspective</td>
</tr>
<tr>
<td>Expected start date of data collection:</td>
<td>20/11/2017</td>
</tr>
<tr>
<td>Approximate duration of data collection:</td>
<td>8 months</td>
</tr>
<tr>
<td>Funding Body (if applicable):</td>
<td>N/A</td>
</tr>
<tr>
<td>Other researcher(s) working on the project:</td>
<td>N/A</td>
</tr>
<tr>
<td>Will the study involve NHS patients or staff?</td>
<td>No</td>
</tr>
<tr>
<td>Will the study involve human samples and/or human cell lines?</td>
<td>No</td>
</tr>
</tbody>
</table>
**CARDIFF METROPOLITAN UNIVERSITY**  
**APPLICATION FOR ETHICS APPROVAL**

<table>
<thead>
<tr>
<th>Does your project fall entirely within one of the following categories:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Paper based, involving only documents in the public domain</td>
<td>No</td>
</tr>
<tr>
<td>Laboratory based, not involving human participants or human samples</td>
<td>No</td>
</tr>
<tr>
<td>Practice based not involving human participants (eg curatorial, practice audit)</td>
<td>No</td>
</tr>
<tr>
<td>Compulsory projects in professional practice (eg Initial Teacher Education)</td>
<td>No</td>
</tr>
<tr>
<td>A project for which external approval has been obtained (e.g., NHS)</td>
<td>No</td>
</tr>
</tbody>
</table>

If you have answered YES to any of these questions, expand on your answer in the non-technical summary. No further information regarding your project is required. If you have answered NO to all of these questions, you must complete Part 2 of this form.

In no more than 150 words, give a non-technical summary of the project:

Aphasia is the loss of language abilities, likely due to a stroke. This loss of language can either mean that the individual has difficulty talking, and may need to use other forms of communication, for example, writing or gesture. Or it can mean difficulties understanding when other people talk to them. They might understand some of what is said, but not the more complex language. My study aims to explore experiences of aphasia from a close family member’s perspective, with a particular focus on changes in identity. My project will involve interviewing family members of people with aphasia and exploring indirectly how different aspects of their identity have changed, for example, their home, social and occupational identity. This will be done by semi-structured interviews, and then using thematic analysis to establish themes.

**DECLARATION:**

I confirm that this project conforms with the Cardiff Met Research Governance Framework

I confirm that I will abide by the Cardiff Met requirements regarding confidentiality and anonymity when conducting this project.

STUDENTS: I confirm that I will not disclose any information about this project without the prior approval of my supervisor.

Signature of the applicant: [Blank]  
Date: 19/10/2017

FOR STUDENT PROJECTS ONLY

Name of supervisor: [Blank]  
Date: 09/11/17

Signature of supervisor: [Blank]
Research Ethics Committee use only

Decision reached:  
- Project approved  
- Project approved in principle  
- Decision deferred  
- Project not approved  
- Project rejected

Project reference number: Click here to enter text.

Name: Click here to enter text.  Date: Click here to enter a date.

Signature:

Details of any conditions upon which approval is dependant:  
Click here to enter text.

PART TWO

A RESEARCH DESIGN

A1 Will you be using an approved protocol in your project?  No

A2 If yes, please state the name and code of the approved protocol to be used1  
Click here to enter text.

A3 Describe the research design to be used in your project

Sample and sampling  
-I will use purposive sampling. My participants would be family members (preferably, spouses) of people who have aphasia due to a stroke. Their family member with aphasia will have had their stroke within the last 5 years, and will still have aphasia.

Recruitment of participants  
-I will aim to find 4 family members. I will recruit participants through the Stroke Association, particularly from a communication group. I have received confirmation from the Stroke Association that they would be able to disseminate a request for participants to their clubs and groups once ethical approval has been gained (see attached p.6). Following ethical approval, I will contact the group coordinator to explain my project, then ask if I can attend the meeting. At the meeting, I will provide the participant information sheet (see attached) to potential participants, then invite them to take part. I will explain in detail what will be involved and tell them about their right to withdraw and the fact that all information gathered will be kept confidential. If they consent to be a part of my study, we will arrange a suitable time and place for the interviews.

Research methods  
-I will gain informed written consent using a consent form (see attached). I will conduct recorded semi-structured individual interviews (see attached interview schedule) with participants, then transcribe their responses using edited transcription. This means that I

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1 An Approved Protocol is one which has been approved by Cardiff Met to be used under supervision of designated members of staff; a list of approved protocols can be found on the Cardiff Met website here
will not transcribe pauses and false starts, but the meaning of the interview will stay the same. I will collect my data by recording their interviews using a Zoom H5 audio recorder. The audio file will then be transferred to a password protected computer and destroyed at the end of the study, following the exam board. Interviews will be conducted either at the Stroke association location if suitable, or in a quiet public place e.g. a café. I will use software that will help me to transcribe, e.g. express scribe. The transcript will be validated by the participants following the interviews, a timescale of two weeks will be given for this validation.

**Analytical technique**

From the transcription, I will conduct a thematic analysis of their answers, which will allow me to identify key themes.

I will do a pilot study, where I will check whether my questions are suitable and that they lead to the type of information that I am expecting. From this, I will make any amendments necessary. If my pilot study is successful, I will use this data in my study.

| A4 Will the project involve deceptive or covert research? | No |
| A5 If yes, give a rationale for the use of deceptive or covert research |
| Click here to enter text. |
| A6 Will the project have security sensitive implications? | No |
| A7 If yes, please explain what they are and the measures that are proposed to address them |
| Click here to enter text. |

**B PREVIOUS EXPERIENCE**

B1 What previous experience of research involving human participants relevant to this project do you have?

Year 2 IPA assignment – I had to interview one individual and use IPA to find themes. I have completed various clinical placements that have involved communicating with people with communication difficulties and their families.

B2 **Student project only**

What previous experience of research involving human participants relevant to this project does your supervisor have?

Doctoral research project involving collection of longitudinal data from bilingual children and their parents. Supervision of multiple undergraduate projects involving human participants e.g. parents/carers, teachers, school-aged children.
C POTENTIAL RISKS

C1 What potential risks do you foresee?

1) Risks could include the fact that this may be quite a sensitive topic for some people.
2) Another risk is to do with protecting the participant’s privacy.
3) Risks to do with lone working

C2 How will you deal with the potential risks?

- 1) The interview schedule has been designed in such a way that the questions asked are broad, in order to minimise the likelihood of causing distress. If a participant did appear distressed, I would stop the interview, and offer them some time out. I would then ask if they are happy to continue. It will be made clear at various stages along the way that they have the right to withdraw from the study at any time during data collection and up to two weeks afterwards, without giving a reason. 2) To protect the participant’s privacy, if they mention a name or place during the interview, I will take out the location and change the names to initials in the transcript. The audio recordings of the interview will be transferred to my password protected laptop. All quotes will remain anonymous, and all participants will not be identifiable in my project as I will use an initial to identify each participant. Consent forms, which will be the only thing with the participant’s name on it, will be kept in a locked cabinet at Cardiff Metropolitan University. Audio files will be destroyed at the end of the project, following the exam board. The consent forms will be retailed by the University in line with current regulations. 3) I will arrange to meet the participants in a suitable public place so as to minimise the risk to me, this could be a quiet cafe or a community space close to where they live. I will inform my supervisor of the date, time and location of these meetings.

When submitting your application you **MUST** attach a copy of the following:

- All information sheets
- Consent/assent form(s)

An exemplar information sheet and participant consent form are available from the Research section of the Cardiff Met website.

**Attachments**

- p.6 Permission from the Stroke Association to disseminate information about the study to its members to invite them to take part
- p.7-8 Participant Information Sheet
- p.9 Participant Consent Form
- p.10 Interview Schedule
From: Research Enquiries <Research@stroke.org.uk>
Date: 27 November 2017 at 10:20:12 am GMT
To: [Redacted]
Subject: RE: Recruiting participants for final year project

Dear [Redacted],

As stated on the request form you completed, we would not recommend that this is your primary method of recruitment as we cannot guarantee that members of our clubs and groups will be willing or able to participate in your research.

I’m afraid that as we are not the funder or sponsor of this study we would not provide a letter of support. However I can say that we would be able to disseminate the request to our clubs and groups once you receive ethical approval for this study, but we cannot guarantee that this will lead to the successful recruitment of participants.

Best Wishes,
Application for amended ethical approval

Cardiff School of Health Sciences

APPLICATION FOR AMENDMENT TO EXISTING ETHICS APPROVAL

PLEASE NOTE: This form must be completed by the Project Leader and submitted with all relevant documents to the relevant school ethics panel inbox. Participant recruitment or data collection MUST NOT commence until amendments to the existing ethics approval have been obtained.

| Name of applicant: | [Redacted] |
| Supervisor (if student project): | [Redacted] |
| School / Unit: | School of Health Sciences |
| Full Project/Study Title: | How aphasia affects identity: a family member’s perspective |
| Funding Body (if applicable): | |
| Other researcher(s) working on the project: | If your collaborators are external to Cardiff Met, include details of the organisation they represent. |
| Ethics /Project Approval Reference Number: | 9675 |
| Date Study Commenced: | 28/11/2017 |
| Amendment Number: | 1st |

Type/s of amendment
Due to insufficient numbers of participants having been recruited so far, I would like to change the method of participant recruitment.

Additional relevant information
The original application stated that the participants would be recruited through the Stroke Association and while this method had led to the recruitment of 2 participants so far, it is felt that more participants are needed to meet the aims of the study. I would like to approach the family members of the clients who attend the clinic run by [Redacted] (Speech and Language Therapist). She has given permission for this (see attached).

Once this amendment has been approved, the participant information sheet (see attached - no change from the one previously approved) will be provided to potential participants and they will be invited to take part. The remainder of the process will be exactly the same as before – no change to consent form (see attached for your information).
APPLICATION FOR AMENDMENT TO EXISTING ETHICS APPROVAL

List of enclosed documents

1. Confirmation from clinician responsible for clinic that she is happy for the family members of her clients to be approached.
2. Participant Information Sheet (no change)
3. Consent Form (no change)

DECLARATION:
I confirm that this information in this form is accurate to the best of my knowledge and take full responsibility for it.

Name:  
Date: 12/02/2018
From: Earing, Katie
Sent: 12 February 2018 13:52
To: Lewis, Rhonwen
Cc: Hughes, Amy Louise
Subject: Re: Undergraduate Student Project - How aphasia affects identity: a family member’s perspective

Dear Rhonwen,

Thanks for your email. I would be happy for Amy to approach family members in the adult clinic at CMU to support her research project. I look forward to receiving further information in the future.

Best Wishes

Katie

From: Lewis, Rhonwen
Sent: 11 February 2018 23:05:38
To: Earing, Katie
Cc: Hughes, Amy Louise
Subject: Undergraduate Student Project - How aphasia affects identity: a family member’s perspective

Dear Katie,

One of my project students, Amy Hughes, is undertaking a study investigating how aphasia affects identity. The project involves interviewing family members of people with aphasia and exploring indirectly how different aspects of their identity have changed, for example, their home, social and occupational identity.

I am writing to ask whether you would be happy for Amy to approach the family members of the clients who attend your clinic at to ask whether they would like to take part? Participation is entirely voluntary and will involve a semi-structured interview lasting around 30 minutes.

The project has been given ethical approval but we are in the process of making an amendment application due to a change in the method of participant recruitment. If you are happy with the above, we will contact you with further information once ethical approval has been given for the amendment.

With best wishes,

Rhonwen Lewis
Therapydd Iaith a Lleferydd| Speech and Language Therapist
Cyfarwyddwr Clinigol ar y Cyd | Joint Clinical Director
Darlithydd Coleg Cymraeg Cenedlaethol| Coleg Cymraeg Cenedlaethol Lecturer
Appendix 6 - Participant consent form

PARTICIPANT CONSENT FORM

Reference Number: 9997

Participant name or Study ID Number:

Title of Project: How aphasia affects identity: a family member’s perspective

Name of Researcher:

Participant to complete this section: Please initial each box.

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw within two weeks of the interview, without giving any reason.

3. I agree to take part in the above study.

4. I agree to the interview being audio recorded.

5. I agree to the use of anonymised quotes in publications.
Signature of Participant ___________________________ Date

Name of person taking consent ___________________________ Date

Signature of person taking consent ___________________________

* When completed, 1 copy for participant and 1 copy for researcher site file
**CONFIDENTIALITY CHECKLIST**

**Speech and Language Therapy**

**Student number:** [redacted]  
**Date:** 20/4/18

**Module leader:** [redacted]  
**Module number:** SLP6080

**Assignment:** Project

Evaluate your submission and any supporting documentation, appendices etc. by answering the following questions:

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  Have you identified any person by their real name?</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>2  Has any organisation been identified by its real name?</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>3  Has any place been identified by its real name?</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>4  Have any exact dates of birth been stated?</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>5  Have any addresses and / or postcodes been included?</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>6  Have any identifiable logos or letterheads been included which might identify any individuals, places or organisations?</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>7  Has any other documentation been included with this submission that might enable any individuals, places or organisations to be identified?</td>
<td>✓</td>
<td></td>
</tr>
</tbody>
</table>

If you have answered ‘yes’ to any questions, please explain why you feel this does not constitute a breach of confidentiality in the space below.

The supervisor’s name has been included in the acknowledgements, application for ethical approval, application for amended ethical approval, ethical approval letter, and amended ethical approval letter and participant information sheet for participants to contact if they had any questions or concerns about the study. The Chair of Ethics Panel is also identified on the ethical approval letters.

Cardiff Metropolitan University’s logo has been included on some of the appendices as this was a requirement. Its name and address is also on the ethical approval letters.

The Stroke Association has also been identified for participant recruitment so has been mentioned on the application for ethical approval.
Appendix 8 – Word count

Introduction: 484

Literature Review: 2325

Methodology: 1081

Results: 3248

Discussion and conclusion: 2791

Total: 9929