Social Participation in Adults with Aphasia

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Declaration

I declare that this research report is my own work and that it has not been submitted for any other degree or to any other university.

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ABSTRACT

Social participation is one of the most debilitating effects of aphasia. Yet, to date no clear definitions or models of social participation have been developed that can be applied within aphasiology. In addition, generic stroke scales are still the outcome measures of choice within research. There is a need for patient-centred measures that accurately document and assess the experiences and perceptions of those with aphasia. Therefore, the current research aimed to investigate the social participation of adults with aphasia by extending patient-centred measures and encompassing the views of the families, particularly the spouses, of those with aphasia. Four cross-sectional parallel single case studies were conducted that involved a protocol combining the quantitative measure of the ASHA FACS with the qualitative tools of semi-structured interviews and observations. In addition, social network analyses were completed for each participant. Overall, open coding of the individual participants' results produced common themes among the people with aphasia and common themes among their spouses. Each participant reported significantly altered social participation, which permeated throughout the family unit and was felt considerably by the spouses of those with aphasia. The results are discussed in relation to current social models and approaches to intervention, while professional role expansion and the needs of the South African context are also considered. Furthermore, the concept of resilience and its implications for future research are discussed.

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CHAPTER 1

INTRODUCTION

An extensive amount of literature exists that focuses on people with aphasia. This literature includes research on the effects of the person's post-stroke physical status and the effects of the person's language status. However, new approaches to stroke and aphasia are looking at effects beyond the physical and linguistic levels. It is known that aphasia alters a person's social participation and attempts have been made to develop models within this area. However, social participation as a construct has not been clearly defined and models have not been fully developed. The methodology implemented in many stroke studies involves quality of life scales, language scales and generic stroke scales. It would appear that research has not focussed specifically on the person's life socially before and after the stroke. Although much theory has been inferred from the existing literature, little research seems to have regarded aphasia from within a family structure.

It is evident that aphasia has an extensive impact on all aspects of the person's cultural and social life, as communication is an undeniable and irreplaceable social act that impacts on the dignity of individuals (Simmons-Mackie, 2001). Consequently, recent research and models in aphasiology have offered an extended view of aphasia as not merely a language impairment, but as a set of circumstances that impact on all areas of life (Pound, Parr, Lindsay and Woolf, 2002). The invaluable purpose and human necessity of language is encapsulated in the statement that "Language enables one to carve out one's place in society" (Lafond, Ponzio, DeGiovani, Sarno and Joanette, 1993, p.216). Therefore, one of the most isolating long-term effects of aphasia is exclusion from social activities in which the person participated prior to the stroke (Lafond et al, 1993).

Parr, Byng, Gilford and Ireland (1998) explain that language distinguishes humans from other mammals and is thus devastating to lose. The use and understanding of language are two vital elements of the broad domain of communication. Communication is the means through which people initiate and maintain human relationships (Fritz and Penn, 1992) and it thus contributes to the foundation of social structures (Simmons-Mackie, 2001).

Lomas et al (1989, cited in Chapey, 1994) classified communication as having four primary intentions. These include meeting basic needs, giving or receiving information regarding one's physical health, giving or receiving information necessary for everyday living and communicating with others to fulfil a social need. LaPointe (1999) echoes these intentions with his view that the communication impairment of aphasia impacts on the person's activities of daily living, the ability to learn (via auditory comprehension or written language) and interpersonal relationships.

Through investigation, Lafond et al (1993) have illustrated the profound ramifications of communicative deficits. They found that impairment in verbal abilities, more than physical motor abilities, is the most difficult outcome for the person with aphasia to accept. Similarly, difficulties with social reintegration, and not activities of daily living, are commonly reported by adults with chronic aphasia and their caregivers (Lai, Studenski, Duncan and Perera, 2002). Furthermore, aphasia can affect both activities and participation in social roles for years after its onset (Hinckley and Packard, 2001). Unlike physical impairments, difficulties within the psychosocial and emotional spheres of functioning do not necessarily improve with time (Wahrborg, 1991). In addition, Hinckley (2002) claims that the level of severity of the person's aphasia is not necessarily an indicator of the level of social participation that the patient will achieve.

Consistent with the pivotal nature of communication, is a sense of isolation being one of the earliest experiences of people with aphasia**.** Due to a sudden loss of communication, people with aphasia are unable to share their thoughts and feelings with others. In addition, they may feel as though they are being 'talked over' or 'talked down to'. However, the full impact of the aphasia may only be realised on

returning home from hospitalisation or rehabilitation (Parr et al, 1998) and attempting to reintegrate into their social surroundings (Code, Hemsley and Herrmann, 1999).

Therefore, due to the intricate functions of communication, aphasia can profoundly effect a person's social participation on an individual, familial and societal level. In order to understand the nature and scale of this impact, existing descriptions and definitions of the concept of social participation should be considered. Social participation depends on the ability to engage with others, interact, share and maintain equality, and acceptance during those interactions (Lyon and Shadden, 2001). According to Avlund, Holstein, Mortensen and Schroll (1999) social functioning comprises participation in social activities, adjustment to social and cultural norms, the maintenance of social relations, the ability to form new friendships and the ability to exchange help and support.

Avlund et al (1999) operationalised their definition of social functioning and participation by measuring three areas, namely visiting others, receiving visitors and participating in social activities outside of the home. They also evaluated the subjects' social networks by measuring the number of contacts the subjects had with people from different categories, such as children, grandchildren, relatives, friends, acquaintances and neighbours. In addition, they measured social support through investigating whether the participant, the spouse, relatives or friends were responsible for the housework, cooking, shopping and repairs in the house (Avlund et al, 1999).

Social Network Analysis (Antonucci and Akiyama 1987, cited in Cruice, Worrall, Hickson and Murison, 2003) is another approach to measuring and representing social participation in a tangible manner. This form of analysis was applied by Cruice et al (2003) by recording the number and types of social relationships engaged in by the person with aphasia. Social network analysis is thus similar to Avlund et al's (1999) approach.

Graney (1975), however, adopted a more structured approach to measuring social participation. Nine questions were asked, covering the areas of media use, interpersonal interaction and participation in voluntary associations. The exact facets that were examined were watching television, listening to the radio, reading, visiting

neighbours, visiting friends and relatives, using the telephone, attending religious services, voluntary association attendance and voluntary association membership (Graney, 1975). Therefore, by combining the specificity of Graney's (1975) method with the ecological perspective of Avlund et al (1999) and Cruice et al (2003), social participation can be described and quantified.

Social participation and communication are inextricably linked and the social impact of aphasia is therefore persistent, long-term and pervasive. Many people affected by aphasia experience residual communicative difficulties after the majority of their linguistic problems has improved. It has been documented that these persisting functional difficulties impact significantly on daily life, causing social isolation, loneliness, a loss of autonomy, restricted activities, role changes and stigmatisation (Simmons-Mackie, 2001). In a longitudinal study of 21 pairs of people with aphasia and their caregivers, Hinckley and Packard (2001) found the long-term effects of chronic aphasia to include depression, social isolation, decreased productivity and changes within family roles and functions.

In terms of productivity post-stroke, aphasia has devastating effects on vocational and leisure activities, as certain hobbies and interests may have to be discontinued or suitably adapted (Parr et al, 1998). The person with aphasia may thus have an increased amount of leisure time without having the means to use it effectively. Consequently, the full psychosocial consequences are realised and the person's poor sense of self is reinforced (Code et al, 1999). It is known that those with chronic aphasia face the difficult tasks of reconceptualising themselves, their friendships and relationships, and their daily activities (Brumfitt 1993, cited in Hinckley and Packard, 2001; Holland and Benson 1993, cited in Hinckley and Packard, 2001). The person may find it difficult to let go of his/her premorbid self-image and accept the new, impaired image (Parr et al, 1998).

The inability to play an active and productive role may result in low self-esteem. This decreased self-confidence contributes to the person's feelings of depression, negatively influencing interpersonal relationships and leading to further withdrawal and isolation (Code et al, 1999; Lubinski, 2001). Furthermore, the person with aphasia may be unable to meet the demands of everyday communication, leading to a

sense of vulnerability and powerlessness within even common and familiar environments (Parr et al, 1998). Depression may persist after rehabilitation as the person begins to understand the reality of the situation. Depression is therefore a very common post-stroke emotion that may contribute to and compound the individual's experiences of loneliness and isolation (Code et al, 1999).

The complex process of social isolation may be bi-directional i.e. the person with aphasia withdraws and his or her friends and relatives withdraw. The person's withdrawal may be as an indirect result of physical symptoms and disease management, such as frequent therapy sessions and doctors' appointments (Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek and Wiener, 1984). It may also stem from the person's discomfort and insecurity surrounding the aphasia (Lafond et al, 1993). Speech errors, such as inappropriate substitutions, can cause members of the person's society to query his or her intelligence. People with aphasia thus feel frustrated and separated. Some adults with aphasia avoid opportunities for conversation for fear of making an error or misinterpreting their conversational partner (Lafond et al, 1993). They may also feel it is easier to avoid communication than to deal with frustration and failure (Lubinski, 2001).

In addition, many people with aphasia have experienced a loss of friends and visitors poststroke (Lafond et al, 1993). The withdrawal of the person's friends and relatives may be based on their discomfort with the person's impairment and a fear of not knowing how to interact with him/her (Strauss et al, 1984). Meaningful interactions rely on social acceptance, as well as on the individual being recognised as a viable conversational partner (Lubinski, 2001). The person with aphasia needs to remain a valued individual within the communicative contexts of relationships and the social environment (Lyon and Shadden, 2001). Due to difficulties with interaction, the person with aphasia is likely to experiences changes within his/her relationships. A loss of communicative abilities could reduce the part the person with aphasia can play in a two-way relationship, commonly causing a breakdown of a friendship or a marriage (Parr et al, 2003). The breakdown of relationships after a stroke is therefore common, adding stress to an already difficult situation (LaPointe, 1999).

In conjunction with personal and relationship-based difficulties experienced by the person with aphasia, are difficulties reintegrating within the social context of his or her family. The position that "An individual's aphasia is a family problem" (Davis, 1983, p.290) complements the family systems model. According to this model, all parts of the family system are interlinked and the family unit is understood as a whole that affects and is affected by the environment. The family is constituted of subsystems and boundaries that influence how and why the unit of its functioning may change. The equilibrium of the family is adjusted according to environmental inputs and demands and is manipulated by social feedback and societal norms (Hanson and Lynch, 2004).

Reintegration is a gradual process, requiring the person and the rest of the family to become accustomed to the changes that have taken place (Lafond et al, 1993). Hanson and Lynch (2004) explain that social changes and family changes are interrelated. In addition, the interactions that occur within the family system are a function of intricate relationships between members of the unit (Hanson and Lynch, 2004). Aphasia alters the interactions that occur and thus has the potential to affect family relationships. The family may feel as though the person with aphasia is intimidating, whereas the person with aphasia may be ashamed and suffer from low self-esteem. As a result of reduced confidence in his or her abilities, and expectations of failure, the person with aphasia may avoid the discomfort and instead withdraw from social interaction (Lafond et al, 1993).

Although those around them may attempt to behave as though nothing has changed, the person with aphasia experiences exclusion from family discussions and decisions. Many people with aphasia therefore live behind a façade, not only within the broader society, but within the family environment as well (Lafond et al, 1993). In his book 'Portrait of Aphasia', David Knox reported his wife's claim that her inability to participate in a normal conversation led to her social isolation and the feeling of being an outsider (David Knox, cited in Lafond et al, 1993, p.216).

The overwhelming nature of the aphasia has further allowed it to have indirect effects on the family. The families of people with aphasia experience social changes which may not be due entirely to the severity of the person's motor and language deficits, but rather as a result of social stigmatisation (Lafond et al, 1993). Much research has been dedicated to investigating the effects of a stroke on the person's family and spouse. Christensen and Anderson (1989) conducted a survey of spouses of stroke patients with aphasia and those without aphasia. They found that a stroke with aphasia has a greater negative impact on the spouse than a stroke without aphasia, thus supporting previous studies. Some of the problems recounted by spouses of people with aphasia were role changes and alterations in social activities and involvement, together with difficulty adjusting to the overall results of their partner's stroke (Christensen and Anderson, 1989).

The person with aphasia's broader society is the next level within the ecological model to be affected by the aphasia. Strauss et al (1984) were accurate in stating that a chronic disease such as stroke affects not only the individual, but has implications for the person's family and greater society. The physical, communicative and psychological effects of a stroke are thus far-reaching and alter the person with aphasia's social role (Code et al, 1999; Parr et al, 1998). Aphasia can have a negative impact on a person's ability to fulfil his/her social roles and participate in social activities and interactions, such as dinner parties and religious services (Parr et al, 1998).

Studies related to social participation after a stroke support the theory that stroke-based impairments lead to negative changes on an individual basis, as well as within the person's family and society or community. Moreover, studies have shown that language and communication skills allow one to participate successfully in social activities and therefore experience a satisfactory quality of life and a positive self-image.

Mayo, Wood-Dauphinee, Cote, Durcan, and Carlton (2002) undertook to investigate the activity, participation and quality of life in people who were six months post-stroke and living at home within their communities. Overall, they found that almost half of the studied stroke population lacked meaningful activity and that, without

intervention, this placed them at risk for depression, social isolation and worsening of function, health and quality of life. In addition, 39% of their subjects reported limitations in functional activities, 54% reported limitations with high-level activities of daily living and 65% reported restrictions in their reintegration into community activities (Mayo et al, 2002).

In a related study by Cruice et al (2003), it was found that individuals with higher levels of functioning and better communication abilities presented with fewer social functioning limitations, higher quality of life, higher emotional health and higher personal, relational and self-acceptance well-being. This research provides evidence for the fact that communication and communication disability at the level of activity are strongly related to social activities, social networks, social support and positive relationships with others. In addition, language, together with social activities, was found to contribute to personal growth and development, and self-acceptance. Cruice et al (2003) concluded that, although functional communication ability and overall language abilities are predictive in people with aphasia, assessment still needs to occur at the levels of impairment, activity and participation.

Despite the findings that have shown a significant impact on social participation following stroke, there has been comparatively little development in terms of therapeutic approaches that focus on psychosocial difficulties in a context beyond the individual and family levels (Pound et al, 2002). Fox, Poulsen, Bawden and Packard (2004) found that there are few existing interventions within the hospital and rehabilitation setting that address the complex needs of the person with aphasia as well as the needs of the caregivers. This gap in intervention is significant, as the families' needs that were unmet during the early stages of rehabilitation were found to persist. In addition, Fox et al (2004) reported that new needs, specifically in the areas of communication and role changes, emerged as families dealt with the long-term consequences of the aphasia.

The assessment of social participation in people with aphasia is therefore a core issue for clinical intervention. Although social participation has been recognised as a major component in intervention, there is a lack of unified theory, as well as holes in the existing models that form the basis of current tools for the assessment of social

participation. Wade and de Jong (2000) reviewed the recent advances that have occurred within rehabilitation and described that a significant change that has taken place is in the approach adopted towards clients. The psychosocial and sociocultural approaches have evolved, while the predominantly medical one has lessened. Moreover, rehabilitative therapy has begun to follow a more functional approach, as opposed to a theory based and impairment orientated approach (Wade and de Jong, 2000).

Within their study on post-stroke functional status, Schuling, De Haan, Limburg and Groenier (1993, p.1173) stated that "a wide range of possibilities lies between death and complete recovery". They defined functional status as the person's ability to care for his/herself and perform certain basic roles and tasks. Therefore, most 'activities of daily living' scales do not consider the person's ability to complete complex tasks, such as recreation, hobbies and housekeeping, and interact socially. However, these psychosocial abilities should be given more attention, as they can affect the person's quality of life (Schuling et al, 1993). Lai et al (2002) found evidence to support the increased focus on abilities beyond activities of daily living. They reported that people who were perceived to be functionally independent three months after their strokes, were still experiencing social isolation.

A new and extended approach to aphasia is the Life Participation Approach to Aphasia (LPPA) which aims to achieve the individual with aphasia's immediate and longer term life goals (Chapey, Duchan, Elman, Garcia, Kagan, Lyon and Simmons-Mackie, 2001). The ultimate life goal is re-engagement in life by encouraging and strengthening daily participation in activities of the individual's choice. The LPAA encourages clinicians to focus on the dual function of communication, namely to transmit and receive messages, and to establish and maintain social connections (Chapey et al, 2001). Within this social approach, the person with aphasia plays an active and participatory role in their intervention. The aim is therefore for those people with aphasia to be members of a communicating society and to participate in personally relevant activities (Simmons-Mackie, 2001).

In order to intervene within the social context, the person with aphasia's authentic life experiences must be understood. Pound et al (2002) stated that the challenge to uncovering the real-life issues facing those with aphasia and their families, is being able to shift away from the therapist's perceptions of what the issues may be and move towards listening to those using the services. van Bennekom, Jelles, Lankhorst and Bouter (1995) found that many commonly used assessment scales, such as the Functional Independence Measure and the Barthel Index, do not consider the patients' opinions on their perceived difficulties.

In a review by Lyden and Lau (1991), it was reported that stroke assessment scales are based on the examination of physical deficits, activities of daily living or on overall evaluation of functional outcome. Once again, all these measures are based on the opinions and impressions of the person rating the scale e.g. the health care professional (Lyden and Lau, 1991). Buck, Jacoby, Massey and Ford (2000) updated the study done by De Haan, Horn, Limburg, Van Der Meulen and Bossuyt (1993) and confirmed that none of the stroke-specific measures were developed through patient-centred methods.

Yet, the affected individuals' subjective opinions are an important criteria against which functional assessment tools should be compared in order to understand the impact of the disability on the life of the person who has had the stroke (Granger, Cotter, Hamilton, and Fiedler, 1993). Furthermore, van Bennekom et al (1995) and Wade and de Jong (2000) believe that clinical assessment in rehabilitation should address the perceived problems of the patient and not only the objective disabilities. It is thus valuable to gain insight into the participation of patients after rehabilitation and understand what it is that health care professionals are failing to assess in present outcome measures (Granger et al, 1993). Consequently, a psychological approach needs to be adopted and incorporated into neurological intervention (Wade and de Jong, 2000).

Therefore, improved quality of life measures are required that are valid, reliable, responsive and comprehensive. Such tools can be developed by using qualitative research with stroke patients to establish the full impact of a stroke on quality of life and to confirm the content and response categories of any new measures (Buck et al,

2000). Hobart, Williams, Moran and Thompson (2002) acknowledged that there is a shift towards incorporating patients' perspectives in healthcare evaluations. However, the scales that have emerged to fit these criteria, assess the patients' physical health. The next step is surely to develop such measures within rehabilitative medicine to obtain the patients' views on their actual functioning and not merely their illness (Hobart et al, 2002).

Without the input of the relevant patient group, the reliability and validity of quality of life measures is questionable (Buck et al, 2000). Furthermore, the validity of any scale relies upon the measure's ability to accurately describe the underlying phenomenon or disease (Lyden and Lau, 1991). Therefore, the areas of assessment should be defined through patient-centred methods. Duncan and colleagues (date of publication not provided, cited in Buck et al, 2000) in the USA identified eight key areas through the patients' perspectives: strength, hand function, activities of daily living, mobility, communication, memory, emotion and social participation. Similarly, Williams et al (date of publication not provided, cited in Buck et al, 2000) found twelve key areas reported by patients: mobility, energy, upper-extremity function, work/productivity, mood, self-care, social roles, family roles, vision, language, thinking and personality. It is important to note that communication and language, together with social participation and social roles, emerged as key areas in both studies.

Holland's (1998) perspective supports the key areas identified from a client perspective, and is in agreement with the LPPA devised by Chapey et al (2001). She feels that the central roles of language and cognitive deficits must be accounted for within the social realm. In addition, the functional outcomes of aphasia need to be placed within the context of activity and participation restrictions in order to be fully understood. Holland (1998) therefore suggested that outcome measures need to progress from scales consisting of an inventory of aphasia-induced impairments, to the assessment of how patients live with impairments and how they manage with daily activities and social participation in spite of them. In addition, scales should include items that estimate the effects of aphasia on daily life (Holland, 1998).

Despite the amount of research conducted about the symptoms, characteristics and effects of aphasia, Pound et al (2002) feel that people with aphasia are persistently viewed as cases and are defined in terms of their impairments. Although the concept of aphasia is thought to be shifting and incorporating an increasing focus on the psychosocial consequences (Pound et al, 2002), this shift remains incomplete. Further research is required to develop theories of social participation within the field of aphasia, as well as to refine assessment tools. In addition, the person-centred, ecological perspective needs to be practically translated into intervention methods.

Although international findings contribute to a sound knowledge base, social participation is strongly related to one's family and community environment. The World Health Organisation (1998) defined quality of life as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (Buck et al, 2000). It has been illustrated through a review of the literature that quality of life is strongly related to social participation. From a South African perspective, it is therefore felt insufficient to merely adopt models of social assessment and intervention from the United States and the United Kingdom. South Africa is a unique and eclectic context that requires research grounded within its own ecological system.

In accordance with the above discussion, a need was recognised to contribute to the transition of the perspective adopted by the clinician within aphasiology. Hinckley and Packard (2001) emphasised the value of assessing and addressing the needs of adults living with aphasia, as well as those of their spouses and families. Therefore, the current research endeavoured to employ a methodology different from those used previously in aphasia research in the form of a family-centred, open assessment. As a whole, this research project was developed to investigate social participation from the stance of people with aphasia and their spouses, as well as from a professional perspective, within individual South African ecologies.

CHAPTER 2

METHODOLOGY

2.1) AIMS OF THE STUDY

The overall goal of this study was to determine aspects of change with regard to the social participation of people with aphasia.

2.1.1) Sub-aims:

The first sub-aim was to determine the perceptions of the people with aphasia with regard to changes that occurred after the stroke in terms of their participation in social activities. The second sub-aim was to determine the perceptions of the spouses with regard to changes that occurred within the family unit. The third sub-aim was to evaluate the current social participation of people with aphasia using a family-centred, open assessment.

2.2) RESEARCH DESIGN

The present study took the form of non-experimental, cross-sectional, multiple single case studies (Pedhazur and Schmelkin, 1991). Cross-sectional research studies subjects within the same time period, who may be at different stages or levels of involvement in terms of their disorder (Drummond, 1996). The cross-sectional nature was selected in accordance with the time constraints of the study that prohibited a longitudinal design (Silverman, 1993). Although the researcher acknowledges the limitations of cross-sectional research, the data that were collected were not dependent too much on time issues.

The heterogeneous nature of aphasia poses challenges to group designs in research, an issue that is addressed by Lyden and Lau (1991) who stated that stroke is difficult to research due to the high level of variance in clinical presentation. Furthermore, it is difficult to measure recovery from stroke in a purely quantitative manner. This difficulty is due to the fact that traditional neurological examination is designed to describe single patients accurately and not a group of patients in a large scale clinical investigation (Lyden and Lau, 1991).

The advantage of a case study design is that description provides material for the establishment of a professional knowledge base (Drummond, 1996). The primary purpose of case studies is to allow the researcher either to describe the natural course of a disorder or to develop an intervention to treat a specific client's problem (Kratochwill and Levin, 1992). Doehring (1988) supported this opinion and stated that the case study is the classic method for obtaining detailed information about individuals with communication disorders. According to Sorin-Peters (2004), qualitative case study research facilitates the study of complex communication within a context, thereby producing a holistic and thorough description of communication. In addition, this methodological practice can address the psychosocial consequences of aphasia. Overall, qualitative case studies have the potential to make great contributions to the knowledge base and practice of speech-language pathology with adults with aphasia as well as their families (Sorin-Peters, 2004).

A further advantage of a case study design is that there is no restriction on the amount and type of information that can be obtained during the research process (Drummond, 1996). In addition, case studies can be used for the purposes of furthering research, studying new techniques and unusual scenarios, and can be used to test theories (Doehring, 1988).

According to Krotochwill and Levin (1992), single-case research is a specialised research application within many areas, including communication disorders. Doehring (1988) explained, however, that a case study does not imply a single subject, but can take the form of a series of individuals with similar disorders. According to Yin (1994), the cases within a multiple case study design are selected on an individual basis and the researcher is not obligated to follow a sampling logic. Therefore, the case study design is applicable in relation to the heterogeneity of the population from which the participants were drawn. In addition, case studies draw on multiple perspectives, through either single or multiple data collection methods (Lewis, 2003). The present study was designed to include numerous viewpoints and also to use various forms of data collection. Thus the parallel case study was deemed to be an appropriate design.

The primary and inherent disadvantage of case study designs is that generalisation of the results is limited by the small, and thus unrepresentative, sample (Doehring, 1988). In terms of case study research, it is correct to assume that case studies are an unsuitable base for classic generalisation (Stake 1976, cited in Lincoln and Guba, 1985). Yet, according to Lincoln and Guba (1985), it is not necessarily correct to assume that if knowledge is not generalisable, that it is specific only to the sample of the study. Stake (1976, cited in Lincoln and Guba, 1985) explained that one should consider the perspective of the user of the generalisation. Often, case studies are the method of choice, as they are epistemologically compatible with the reader's experiences and therefore become a natural basis of generalisation for that person (Stake 1976, cited in Lincoln and Guba, 1985). Consequently, a distinction can be made between scientific and naturalistic generalisation (Stake 1976, cited in Lincoln and Guba, 1985). In addition Yin (1994) suggests that case study findings should be generalised to theory rather than from one case to another.

Thus, although the case studies constituting this research do not form a sufficient sample for scientific generalisation, they may form a basis for naturalistic generalisation. This generalisation may occur particularly from the perspective of those professionals familiar with the emergent findings about social participation post-stroke. Furthermore, the findings may be generalised to existing theory pertaining to the social participation of adults with aphasia, such as the social approach advocated by Simmons-Mackie (2001), among others.

A case study design facilitates the combination of qualitative and quantitative measures (Drummond, 1996). Overall, combining qualitative and quantitative methods was more appropriate to generating answers to the research questions posed (Wahrborg, 1991). From a quantitative perspective, most scales include limited variables and therefore have the benefits of simplicity and utility for both the clinician and the client. However, this simplicity may result in the measures being less complete and less sensitive. Consequently, a purely empirical approach to research might limit the knowledge that one obtains about psychosocial and emotional consequences of stroke and aphasia (Lyden and Lau, 1991). Ross and Wertz (2003) suggested that respondents be provided with an opportunity to supplement

standardised tools with personally relevant items. It was thus deemed necessary to supplement the selected scale through the interviews and observations.

Quantitative and qualitative data alike can vary in terms of validity, reliability and generalisability (Silverman, 1993). The value of qualitative data, is that certain attributes or events are better described through words than through numbers (Silverman, 1993), such as the personal experiences of people with aphasia. In addition, the investigation of real-life behaviours and experiences is the basis of a non-traditional research approach. A qualitative approach complements the scientific orientations to research and is an appropriate adjunct to the quantitative assessment of aphasia (Tompkins and Lustig, 2001).

Nevertheless, when conducting research within the social world, it must be understood that the researcher – as well as the research itself – are part of the environment, community or social structure under investigation (Lyden and Lau, 1991). The validity of qualitative data is therefore a function of the relationship and interaction between the observer and the observed (Silverman, 1993). As a result, steps must be taken to ensure that validity is not compromised. One example of this assurance is to employ independent raters of the data, as occurred in the present study.

In summary, the selected methodology was thoroughly reviewed and multiple case studies combining qualitative and quantitative measures were found to be a design appropriate to the characteristics of aphasia and the nature of the present research.

2.3) PARTICIPANTS

A sample of ten subjects or less was deemed to be acceptable (Shearer, 1982) due to the limited availability of suitable participants. The study was piloted on one person with aphasia. The main study involved four people with aphasia and their spouses.

Participants were selected according to the following criteria:

2.3.1) Inclusionary Criteria:

2.3.1.1) All participants and their spouses were required to be first language English speaking. This criterion was necessary for the reliability and validity of the scales being administered. The Functional Assessment of Communication Skills for Adults (FACS) was standardised with an English speaking population and is administered in English. Furthermore, interviews were conducted with the participant and his or her spouse and their interactions were observed. It was thus necessary for the researcher to fully understand the language in which the participants communicated

2.3.1.2) Participants were required to have received speech therapy during rehabilitation or on an individual or group basis as an outpatient. Whether the participant received therapy, and the extent thereof, could have acted as an extraneous variable. According to Good and Couch (1994), speech-language therapy after a stroke is effective in a wide range of domains, many of which could affect social participation.

2.3.1.3) Participants were required to have no history of substance abuse, no previous head injury, no neurological disease or damage, and no concomitant neurological pathologies, such as Alzheimer's disease. These factors could have acted as extraneous variables by having caused previous neurological and/or communicative impairments unrelated to the stroke (LaPointe, 1999; Snell, 1997) that could have affected premorbid social participation.

2.3.1.4) Participants were required to be married and have a child/children. The methodology required the spouses' perspective on their social participation as well as the social participation of the person with aphasia. It was necessary for the participant to have a child/children, as certain observations occurred within the social context of the participant's family. In addition, having a family and children suggested a minimum level of involvement in social activities.

2.3.1.5) Participants were required to have suffered a left hemisphere stroke resulting in expressive or Broca's aphasia. Broca's aphasia is characterised by articulation difficulties, limited vocabulary and agrammatism. Auditory comprehension and reading comprehension are usually intact (Goodglass and Kaplan 1983, cited in Chapey and Hallowell, 2001), but writing is usually impaired at least to the extent that speech is effected (Chapey and Hallowell, 2001). Primary deficits lie usually within the areas of language formulation and production, leading this type of aphasia to be known also as 'expressive aphasia'. In summary, Broca's aphasia is the most classic presentation of non-fluent aphasia (Chapey and Hallowell, 2001).

The participants' medical, rehabilitation or speech therapy records were relied upon to provide information about the type of aphasia with which they presented. It was also confirmed during the initial interviews that the participants were presenting with Broca's aphasia.

2.3.1.6) This study excluded patients whose stroke was very mild and did not result in communication difficulties, as well as those whose stroke was so severe as to lead to global aphasia or critical health status.

2.3.1.7) Participants were required to have sufficient sensory capacity to participate in the study (vision and hearing). He or she needed to be able to participate in the interview, but also in social activities. Loss of vision or sight could not only hinder the collection of data, but also act as an extraneous variable in terms of the patient's impairments. Information

regarding the participants' sensory status was obtained through patient records, the participants' speech therapists and their spouses.

2.3.1.8) Participants were required to be alert, orientated and able to attend for sufficient periods of time to complete the interview. Pedersen, Jorgensen, Nakayama, Raaschou and Olsen (1996) found that impaired orientation can influence basic activities of daily living and higher-level activities of daily living, as well as social activities. This study measured social participation, not the effects of altered alertness, orientation and attention. Any deficits in these areas would thus have acted as extraneous variables. Information pertaining to the participants' alertness, orientation and attention was obtained from their speech therapists and spouses. In addition, the participants were closely observed during the first meeting with the researcher in order to determine whether they were able to focus and attend for sufficient periods of time to take part in the study. Orientation was assessed through case history questions and deficits would have immediately become apparent during the interview.

2.3.2) Sampling:

Participants were obtained via private rehabilitation centres. The head of a unit was approached regarding the study. In addition, participants were located through individual speech-language pathologists and support or treatment groups. The centres, speech-language pathologists and groups were approached, and the purpose of the research explained to them.

The inclusionary criteria for participants were forwarded to the relevant personnel at the rehabilitation centres, speech-language pathologists and support groups in order to determine that the participants suggested by the referral sources met the inclusionary criteria.

2.3.3) Additional Variables:

Additional factors may have existed that influenced the results of the individual case studies. Such variables included the participants' age, gender, level of education, time post stroke and severity of aphasia. Although these variables would affect social participation, they were not deemed to be exclusionary criteria.

2.3.3.1) Age

Although much research in aphasia takes cognisance of age because of the effects of aging on language and other functions, age was not controlled for in this study. Kolata (1991, cited in Chapey, 1994) found that there was no valid reason to assume that age independently led to decline and loss of intellectual and cognitive abilities. Furthermore, the majority of people over 85 years are still able to care for themselves and the elderly are more active and independent than ever before (Frady et al 1985, cited in Chapey, 1994). Allison (1991) and Kolata (1991, cited in Chapey, 1994). concluded that a decline in mental functioning in the elderly was usually associated with concomitant factors such as amnesia, Alzheimer's disease, vitamin deficiencies or substance abuse.

Co-occurring neurological impairments or conditions were controlled for and a certain level of independence was stipulated by requiring the participants to be living at home. In addition, the multiple case study design allows for variability among the participants and it was therefore acceptable for the participants to differ in their ages. Consequently, it was deemed unnecessary for age to be a separate inclusionary criterion. However, through the interviews it was determined whether age was having a marked effect on social participation that would impinge on the results. If this were the case, the participant would have been excluded from the study.

2.3.3.2) Education

The level of education of the participants was not controlled for in this study. Social interaction is necessary in the majority of life contexts and it was thus felt that differing levels of education across the participants would enrich the findings as opposed to having a negative impact on the results. As this study adopted a multiple case study design, the level of education of each participant was viewed as an individual factor specific to each case.

2.3.3.3) Gender

It was not felt necessary to control for gender, as this study was not attempting to obtain gender specific findings. It was felt that any gender-based issues that arose would be specific to the discussion of the individual cases.

2.3.3.4) Time post-stroke

As heterogeneity is permissible in the multiple case study design, the amount of time since the participants' strokes was not limited. Nevertheless, this variable was inherently limited in certain respects, as the participants were require to be living at home. Sufficient time had thus lapsed since the stroke for the participants not to be in an acute hospital setting and to no longer be undergoing inpatient rehabilitation (if they had done so).

2.3.3.5) Severity of aphasia

Although, the severity of the participants' aphasia was not formally assessed, certain restrictions were placed on the severity of the participants' condition. People who had suffered strokes of such a mild nature so as to induce no impairments were not included. Similarly, those whose stroke resulted in a critical medical condition or global aphasia were not included. These restrictions were felt to be sufficient, as the case study design facilitated a fair amount of variability across the participants.

Despite the effects that these variables could have on social participation, the parallel multiple case study design allows for individual variability or heterogeneity, as well as lenience in inclusionary criteria. However, these variables were taken into account in the analysis of the data.

2.3.4) Participant Description:

Four people with aphasia were involved in this study. Biographical information as well as information regarding their previous and present occupations and living circumstances, is documented in table 1.

Table 1: Demographic data pertaining to the participants

PARTICIPANT	AGE	GENDER	TIME SINCE STROKE ON ASSESSMENT	REHABILITA-TION CENTRE LENGTH OF STAY	OCCUPATION AND CURRENT JOB STATUS	DOMESTIC SITUATION
MB	78	M	18 months	2 weeks	Primary school teacher, retired since stroke	Living with wife
CS	66	M	30 months	None	Works at car dealership as before the stroke	Living with wife and domestic worker
RS	52	F	8 months	6-7 weeks	Previously a housewife/home-maker, currently no occupation	Living with husband, daughters and a full-time domestic worker
PM	52	M	10 months	2 weeks	Primary school teacher, retired since stroke	Living with wife and 4 children

Four spouses of people with aphasia were involved in this study. Biographical information as well as information regarding their previous and present occupations, is documented in table 2.

Table 2: Demographic data pertaining to the spouses of the participants with aphasia

SUBJECT	AGE	GENDER	OCCUPATION; CURRENT JOB STATUS
MB's spouse (MB-S)	69	F	Runs a small business from home
CS's spouse (CS-S)	62	F	Assists husband with car business
RS's spouse (RS-S)	54	M	Runs a factory (engineer)
PM's spouse (PM-S)	41	F	Teacher

2.4) PROCEDURE

2.4.1) Ethical Clearance:

Ethical consent was obtained for the study from The Committee for Research on Human Subjects (Medical), protocol number M040328. (See Appendix F)

2.4.2) Participant Contact:

As a result of the communication difficulties experienced by the participants with aphasia, the majority of contact occurred with their spouses. Participants' spouses were contacted telephonically to invite them and their partners with aphasia to take part in the study. They were then faxed the information sheet and consent forms in order to review these before agreeing to participate. Participants' spouses were then contacted again telephonically in order to set up appointments.

2.4.3) Participant Records:

Participant records were accessed at their respective rehabilitation centres, Speech-Language therapists or groups if and when this was necessary. The majority of the necessary information was obtained directly from the participants and their spouses.

2.4.4) Method:

The methodology involved the selection of measures to comprise a test battery. There are many challenges to assessing social participation, as the effects of impairments on functional outcomes seem to be underestimated by the item weightings on certain stroke scales, such as the Barthel Index and the Sickness Impact Profile (De Haan et al, 1993).

A quantitative scale used commonly as an outcome measure within stroke research, is the Functional Independence Measure (FIM). However, speech-language pathologists in general view the FIM as a very broad evaluation of communication (Holland, 1998). In addition, speech-language pathologists do not rely on measures of functional recovery as indicators of the person's communicative abilities (Carlomagno, Pandolfi, Labruna, Colombo and Razzano, 2001). A more abstract point made by Holland (1998), is that the FIM rates the person in terms his/her independence, but that communication is never a completely independent activity in pathological and non-pathological conditions alike. The main reported disadvantage of the FIM is its lack of sensitivity to cognitive-communicative and swallowing impairments (Holland, 1998).

As with many other outcome measures, the FIM emphasises primarily physical activities of daily living (ASHA, 2004). As the present study was not assessing physical functioning, available stroke scales or outcome measures were not felt to be appropriate for the purposes of this research. It is for this reason that the test battery was developed.

2.4.4.1) Development of the Test Battery

In order to strengthen the research design and optimise the validity and reliability of the results, triangulation was implemented. Triangulation was employed to endeavour to facilitate the use of various methods and data sources to enhance the researcher's understanding and the explanations of the results (Maggs-Rapport, 2000; Ritchie, 2003). The current study made use of both methodological triangulation and data triangulation. The methodology was triangulated by using the FACS, interviews with the participants and their souses, and a series of multiple observations of the participants in their social settings. The data was triangulated as it was obtained from more than one data source – the patient, the spouse and additional family members, as well as an additional speech-language pathologist where necessary (Maggs-Rapport, 2000; Ritchie, 2003).

The primary caution with regard to triangulation is that there is a possibility that each method is flawed, leading to incorrect inferences that seem to correlate (Maggs-Rapport, 2000). The second caution is that it is difficult to prove that the validity of one set of results is greater than another if multiple methods are used and produce multiple findings. These issues can be avoided by evaluating the methodological triangulation within the research design before beginning (Maggs-Rapport, 2000). The battery of selected measures was therefore piloted before beginning the research in order to evaluate whether components should have been excluded or altered. The pilot study will be discussed in a later section.

In the section that follows, the measures utilised for the purposes of the present study are defined and described. In addition, a rationale for their selection is provided.

1. **<u>The Functional Assessment of Communication Skills for Adults (FACS) (Frattali, Thompson, Holland, Wohl and Ferket, 1995):</u>** (See Appendix A)

   Although the focus of the present study is on social participation, it was felt that a functional language assessment should be included in the test battery to provide quantitative information about the participants' communication abilities. Wade (1992) feels that many measures of language are time consuming and complex, with too much emphasis on differentiating between various types of aphasia. The FACS, however, was based on the World Health Organisation's classification of Impairment, Disability and Handicap and aims to assess how speech, language, hearing and/or cognitive deficits influence the performance of activities of daily living. This quantitative measure was therefore deemed appropriate for the present study, both in terms of time restrictions and in terms of the information it could provide in supplementing the qualitative measures implemented.

   The FACS comprises four domains: social communication; communication of basic needs; reading, writing and number concepts; and daily planning. Each domain's items are rated according to two scales. The first is a 7-point Scale of Communicative Independence. A 7-point scale was selected in order to increase the sensitivity of the scale to gradual increments in communicative functioning. A 7-point scale is also psychometrically consistent with other measures of functional communication within multidisciplinary rehabilitation. The second scale is a 5-point Scale of Qualitative Dimensions of Communication, assessing the nature of the functional communication deficit (Frattali et al, 1995).

   In terms of the psychometric properties of the FACS, high inter-rater reliability is illustrated by a mean correlation coefficient of 0.82 for domain scores and 0.9 for the overall scores. The FACS also differentiates behavioural characteristics of the impairment groups of stroke and traumatic brain injury and is thus relatively sensitive (Fratalli et al, 1995). Aside from the strong psychometric characteristics of the FACS, additional advantages of selecting this measure were apparent. Firstly, training is not required in order to administer the FACS. Secondly, information for the scoring of the FACS may be obtained from other sources and the participants' spouses and could thus be consulted for the completion of this measure. Lastly, the FACS can be scored when the clinician is not with the

participant (Frattali et al, 1995). This thus reduced the amount of time required from the participant and was an advantage of this measure.

On reviewing the FACS manual, the FACS was scored by the researcher. It was ensured that sufficient time was spent with the participants to become familiar with their communication. Frattali et al (1995) recommend a minimum of three contacts with the person with aphasia. The researcher therefore spent a total of three, hour-long interactions with each participant. However, employing a second rater is known to improve the reliability of the results (Drummond, 1996). Therefore, a Speech-Language Pathologist who worked regularly with two of the four participants acted as a second rater for the FACS of those two participants. Consequently, 50% of the FACS profiles were reviewed by an external party.

2. **A semi-structured interview with the person with aphasia and with his/her spouse:**

The interview with the person with aphasia investigated general activities and social participation before and after the stroke. It then focused on the similarities and differences found between these two areas of functioning. The guideline used for the interview is in Appendix B. The interview with the person with aphasia's spouse included areas pertaining both to the general activities and social functioning of the spouse pre- and poststroke, and of the person with aphasia pre- and poststroke. The guideline used for the interview is in Appendix B. Although the interviews may appear structured, they were merely frameworks to direct the interviews. The researcher followed the direction of the person with aphasia and his/her spouse and phrased each question in an open-ended manner.

Overall, interviews involve a complex interaction between individuals and may be affected by the characteristics of those involved (Hult, 1996). A disadvantage of interviews is the effect of the interviewer on the respondents (Dingwall, 1997). The interviewer may have beliefs about the respondents that lead them to form expectations as to the answers that should be elicited. Similarly, the respondents may present with beliefs or attitudes that affect their behaviour and responses. Furthermore, the respondents' reactions and behaviours may be affected by interview situation (Hyman, Cobb, Feldman, Hart and Stember, 1970). These

effects were attempted to be countered by the informality of the interviews, as well as by the inclusion of the less invasive qualitative method of participant observation (Dingwall, 1997).

The advantage of interviews is that they allow for unanticipated information to be shared by the participants (Whyte, 1984). In addition, they allow for the observation of significant non-verbal behaviours (Hult, 1996) and assist in the interpretation of observed behaviours (Whyte, 1984).

Each participant was interviewed together with his/her spouse at a location and time convenient to them both. MB, CS and RS were seen at their homes and PM was seen on the premises of the support group he attended during the week. MB and PM were seen during the week in the mid-afternoon. CS was seen during the week in the late afternoon, as he was still working. RS was seen on the weekend in the afternoon, as her husband worked during the week.

One of the primary cautions when conducting research with participants who have aphasia, is that impaired speech restricts their answers. This increased the demands on the researcher and great attention was paid to the manner in which questions and instructions were presented and explained (Wahrborg, 1991). In addition, the person with aphasia's spouse provided assistance with rephrasing questions and extracting answers. As a result, the person with aphasia's spouse may have provided information pertaining to his/her interview while assisting the person with aphasia. Furthermore, the researcher is a Speech-Language Pathologist who has worked with people with aphasia. She thus has experience in supporting the conversation of people with aphasia and assisting them in the use of various modes of expression.

The semi-structured style of the interviews facilitated an informal and open approach. Although the researcher initially planned to conduct the interviews separately, the two interviews were conducted simultaneously. The reasons for this change in protocol are detailed in the discussion of the pilot study. By combining the interviews, the time required from the participants and their spouses was reduced and the threat of participant fatigue was diminished. The

interviews took approximately one hour to complete, but this time frame varied slightly according to the amount of information provided by the participants and their spouses, and the amount of assistance required by the person with aphasia.

3. **Multiple observations:**

The behaviours observed were defined in advance and observations were carefully recorded to ensure that an observational methodology was not mistaken for casual observations (Doehring, 1988). The guidelines used for the observations were drawn from Avlund et al (1999) and Graney (1975) and focussed on interpersonal interactions, social activities, social networks and supports, and the use of common media such as newspapers (See Appendix C).

Observations within a natural context can provide information about the effects of different contexts on the person, in terms of his or her communication disorder (Doehring, 1988). The primary advantage of observational methodology is that the setting in which the patient is studied is authentic, not a contrived experimental environment (Doehring, 1988; Dingwall, 1997). In addition, observations are valuable in terms of linking the interview responses to a particular context and obtaining unspoken information (Whyte, 1984). In summary, the observations provided the researcher with information that was ecologically valid (Galanti, 1999).

The main disadvantage of observations is that behaviour in one setting cannot be easily generalised to another situation (Doehring, 1988) and the researcher has no control over the environment in which the observation occurs. In addition, the participants may behave in an unnatural manner as a result of being observed (Hult, 1996). Consequently, the participants were observed in more than one context and on numerous occasions. The effects of observer bias are also reduced by conducting multiple observations (Doehring, 1988). Nevertheless, observations in general do not produce quantitative data and may thus be regarded as an unscientific method of data collection (Hult, 1996). It is thus essential to link interviews and observations in order to validate the data obtained (Whyte, 1984).

MB was observed in his home environment, shopping and having coffee with his wife, and attending his support group. CS was observed in his home environment with his wife, on a separate occasion at home with his grandchildren, and attending his support group. RS was observed at home with her family and her domestic worker/full-time helper. She could not be observed in a different environment, as it was difficult for her to leave the house and she did not enjoy doing so. In addition, she received all her therapy at home and did not attend any support groups. PM was observed with his daughter, with his wife and attending his support group. However, these observations all occurred on the premises of the support group for the convenience of the participant and his family.

2.4.4.2) Reliability measures

a. ASHA FACS

A second Speech-Language Pathologist completed the FACS for two of the four participants. There were minor discrepancies between the researcher and the second rater on certain scores of communicative independence. However, the difference between the scores allocated was a maximum of 1 point on the 7-point scale. The differences thus had a minor impact on the overall results. Discrepancies occurred on 3 of the 43 items for MB and 1 of the 43 items for CS. The two raters therefore agreed on 93% of the FACS item independence scores for MB and 98% of the FACS item independence scores for CS. There were no discrepancies related to the scores allocated to the qualitative dimensions of communication on the 5-point scale. The inter-judge agreement was thus 100% for this element of the FACS. Inter-judge reliability is considered to be high if the judges agree on a minimum of 90% of their observations or judgements (Doehring, 1988; Shearer, 1982). The inter-rater or inter-judge reliability for 50% of the participants' FACS was thus of an acceptable standard.

b. Interviews and Observations

The interviews were recorded on audiotape as well as transcribed, and extensive notes were made during the observations. The inclusion of a second Speech-Language Pathologist in the observations would have reduced researcher bias and incorporated an additional perspective (Doehring, 1988). An additional observer further contributes to the reliability of the observations by allowing their repeatability to be evaluated (Silverman, 1993). However, it was not possible for a second rater to be involved in the observations for reasons that will be discussed in the pilot study. Instead, observed behaviours were documented with the findings of the interviews and reviewed as a whole by the second Speech-Language Pathologist who listened to the recordings of the interviews.

Two of the four participants' recordings and notes were analysed by the researcher, together with a second rater, who was a Speech-Language Pathologist. The inclusion of an additional professional in the interpretation the interviews and observations aimed to control for researcher bias and improve inter-judge reliability (Doehring, 1988; Shearer, 1982). The second rater reviewed the data on completion of the data collection. She was instructed to listen to the recordings and read the documented responses and observations. She was asked to provide her objective professional opinion on the data.

Following that feedback, the researcher discussed her interpretations and inferences with the second rater and asked her to voice her agreement or disagreement. Areas of discrepancy were discussed in greater detail until a resolution was reached. There were no incidences of differences remaining unresolved, as the researcher and second rater concurred on the majority of their analyses. The interpretations and inferences within the discussion of the results are a combination of the perspective of the researcher and that of the second Speech-Language Pathologist.

2.4.4.3) Pilot study

The principal objective of conducting a pilot study is to review the initial research design in order to identify inadequacies and to modify the design based on these initial findings (Yin, 1994). The participant for the pilot study was selected in accordance with the inclusionary criteria. The aims, procedures and findings of this study, together with the resultant modifications to the research design, are detailed below.

The first goal of the pilot study was to establish the time the protocol would take to administer. This was established by timing the pilot session to assess whether it was a reasonable amount of time to expect from the participant. In addition, the pilot participant was monitored throughout the session for signs of fatigue or decreased alertness, attention or concentration. The protocol was found to take a reasonable amount of time, but the FACS could be partially completed without the participant and thus did not require his/her time. The interview would evidently vary in the time it took, based on the severity of the person's aphasia and the amount of input they wished to give. Based on this experience, it was noted that sections of the FACS could be completed based on notes taken during the interview. The time required from the participant was thus further reduced and the repetition of questions pertaining to communication could be avoided. In addition, the researcher acknowledged that the times set aside for the interviews would need to be flexible and that the interview may have had to be conducted on two separate occasions.

The second goal of the pilot study was to establish the appropriateness of the protocol. This aim was carried out by assessing whether the interview questions were relevant and whether the necessary information could be obtained through this particular protocol. It was found that the interview for the person with aphasia and the interview for the spouse were repetitive and that often the person with aphasia and his/her spouse would answer together. Furthermore, while assisting the person with aphasia to respond, the spouse would often provide additional information and indirectly answer his/her own interview questions. The researcher thus decided to conduct the interviews simultaneously.

In addition, it became evident that it would not be possible to include a second rater in the observations. The pilot participant displayed a measure of anxiety in sharing her emotions and experiences with the researcher and it was felt that a second external observer could cause the participants to feel uneasy or uncomfortable. It is known that there are interviewer and observer effects and it was felt that the inclusion of a second rater could heighten these extraneous influences and have a negative impact on the results of the study. It was therefore decided that the observed behaviours would be recorded in writing along with the interviews and be analysed together with the interviews by the selected second rater.

The third aim of the pilot study was to practice the administration of the protocol. The entire protocol was therefore completed with the pilot subject. Through this exercise, the researcher became familiar with the protocol, allowing the sessions with the participants to flow smoothly and comfortably.

The fourth aim of the pilot study was to obtain valuable input from the pilot participant. As the entire protocol was completed with the pilot participant, a vast amount of data was obtained. This participant contributed valuable information and insights that served to add depth to the study and either converge with or diverge from themes identified across the participants.

The final aim of the pilot study was to work on adapting the interview to the needs of a participant with aphasia. The researcher was able to assess how and when to adapt questions to accommodate the expressive language difficulties of the participants. It was established that additional time would be required for the participants to answer questions and that the spouses participants would play a vital role in assisting with the interview process. However, it was noted that the spouses may find it easier in the interview context to speak on behalf of the participants with aphasia. The researcher therefore had to ensure that adequate time was allocated, that the participants with aphasia were always addressed directly and that respect for the participants' competence was clearly demonstrated.

It is therefore evident that the pilot study was a valuable preliminary exercise and contributed significantly to refining the research design.

2.4.5) Considerations:

If, through the research, people were identified who were in need of further rehabilitation, referral options were made available. If required, participants were provided with a list of possible clinicians and rehabilitation centres that would be willing to provide treatment. The options excluded the researcher unless, in the unlikely event, there were no viable alternatives.

2.5) DATA ANALYSIS

Data analysis was both qualitative and quantitative, according to the measures implemented in the study.

2.5.1) Analysis of the FACS

The FACS was quantitatively analysed in accordance with the administration manual. Individual domain items were rated on the 7-point scale in terms of the participants' independence. The domain mean scores were then calculated, leading to an overall communication independence mean score. In addition, each domain was rated on a 5-point scale in terms of the participants' adequacy, appropriateness, promptness and communication-sharing (where applicable). Based on these scores, an overall qualitative dimensions mean score was calculated. The raw data set for each participant is tabulated within his/her results.

2.5.2) Analysis of the interviews and observations

The interviews and the observations were analysed qualitatively through content analysis. According to Lolas (1986), the term 'content analysis' can include various forms of analysing verbal reports, specifically within naturalistic research. Lolas (1986) regards content analysis as a systematic method of transforming verbal data into symbolic representations of the communications that occurred. Content analysis is therefore a means for expanding on data descriptions and making inferences. Overall, Lolas (1986) regards content analysis as the integration of a sensitive, compassionate element with a scientific element, thus fusing a clinical with an experimental approach. Furthermore, Lolas (1986) believed that content analysis could lead to revelations about humans and their communication system. This method of data analysis was thus highly applicable to the aims of the current research project.

The selected form of content analysis was coding, which is the process of disbanding and reconstructing the data. Specifically, open coding is a form of thematic analysis and was used to identify themes and concepts within the data (Ezzy, 2002). Stewart (1998) explains that open coding can be used to develop core themes that make coherent the data collected on the observed aspects of social life. In addition, thematic analysis has been applied to transcriptions of semi-structured interviews within the field of health care and rehabilitation (Crisp 2000, cited in Ezzy, 2002). The widespread use of coding was confirmed by Jones (1985), who suggested that many qualitative researchers relied on coding to order, structure and finally analyse their data. Overall, content analysis is applied when a mass of qualitative, contextual data requires focussed analysis (Stewart, 1998). Evidently, open coding was appropriate to the methods of data collection applied in the current research, as well as to the overriding qualitative nature of the study. Moreover, coding was selected, as it is a relatively uncomplicated and natural process (Ezzy, 2002) that could be performed by the researcher and second rater without additional training or assistance.

If performed carefully, coding can result in the researcher revealing new insights within the data that are beyond the content and expectations of the pre-existing theory. However, it is easily possible for qualitative data to be subject to inconsistent and haphazard analysis. In addition, Lolas (1986) cautions that communications can have multiple meanings and may convey meanings beyond that directly observed or translated by the researcher. Lolas (1986) therefore acknowledges that the reliability and validity of content analysis has been questioned, yet feels that it remains a beneficial form of analysis within the social and behavioural sciences. It is consequently imperative for data to be systematically and meticulously analysed if it is to lead to valid interpretations (Ezzy, 2002). Furthermore, the validity of the content analysis of a given data set can be confirmed by the amalgamated analysis of the same data (Lolas, 1986), hence the inclusion of a second rater in the present study.

A specific form of open coding, known as inductive coding, was applied. Inductive coding is used when themes are not determined prior to the data collection. The point at which themes or categories are identified distinguishes between coding and other methods of content analysis wherein the categories are selected prior to data collection (Ezzy, 2002). The researcher therefore followed the steps suggested by Jones (1985) by listening to the tapes of the interviews and reading the interview and observation transcripts before coding the data and developing themes and categories. Following the exploration of the data and the identification of themes, codes were allocated to the established feelings, meanings and actions. Within the process of thematic analysis, themes were identified and used to develop a systematic account of what was observed and recorded during both the interviews and the observations (Ezzy, 2002).

Once the researcher had experimented with these codes, they were compared and contrasted and placed into sub-categories. Finally, the codes were collated and integrated into inclusive codes, the properties of which were documented and described (Ezzy, 2002). Therefore, the copious data obtained via the interviews and observations was reduced using the technique of thematic summaries (Spencer, Ritchie and O'Connor, 2003).

2.5.3) Development of social network analyses

In addition to the coding, further qualitative analysis was conducted in the form of social network mapping. A social network diagram is part of the Communicative Profiling System (Simmons-Mackie and Damico 1996, cited in Simmons-Mackie, 2001) and represents people with whom the person with aphasia regularly interacted/s. Each participant underwent a social network analysis based on the information provided in the interviews, as suggested by Lubinski (2001).

Social network diagrams can be used to visually represent changes in a person's social participation. Simmons-Mackie (2001) suggests that social network analysis be used within intervention to document the person with aphasia's accomplishments in life participation. It was decided for the purposes of this research, to use network analysis as a means of illustrating the changes that occurred in social participation after the person's stroke. Therefore, social network diagrams were devised for each participant to represent his/her social participation pre- and post-stroke.

CHAPTER 3

RESULTS

The results of the study are presented in two sections. The first section is a presentation of the participants' social participation measures on a case-by-case basis. The second section presents the themes deduced through content analysis, followed by a summary of the results. The participants are identified by their initials, for example CB, and the spouses are identified by a suffixed –s, for example CB-S

In considering the meaning of the quantitative scores provided by the ASHA FACS, the concept of functional communication must be understood. Functional communication has been defined as the 'ability to receive a message or to convey a message, regardless of mode, to communicate effectively and independently in a given environment' (ASHA 1990, cited in Lubinski, 2001). Within the FACS, the scores representing the participants' communicative independence are based on the frequency with which assistance and/or prompting is required. The scores representing the qualitative dimensions of communication (excluding communication sharing) represent the frequency with which the dimension is demonstrated during natural communication. The rating of communication sharing depends on the extent to which a burden is placed on the communication partner.

Overall the results of the FACS were reflective of the participants' communicative abilities as perceived by the researcher during the interviews and observed interactions. In addition, they were largely representative of the comparative levels of social participation across the participants, specifically in distinguishing the most active from the least active participant. However, in terms of the two participants in the middle of the spectrum, the FACS scores did not accurately distinguish their levels of participation.

This lack of sensitivity may be due to the fact that, although the FACS is scored in a naturalistic situation, it does not account for family and community based factors. Furthermore, the scores appropriate within one context may be inappropriate within another context. It is noted that the FACS is scored over the course of a minimum of

three interactions, yet, this still may not include the full range of communicative contexts in which the person is involved. Moreover, it does not consider unexpected or unplanned circumstances and situations. Lyon (2000) explains that functional communication within real-life settings is not wholly based on the person's level of communicative independence. It is related to the person's broad social or life environment. In addition, the ability to cope well in real-life situations is not restored by the remediation of functional deficits. The restoration of purpose, meaning and social relations is required (Lyon, 2000).

The FACS raw scores for each participant are tabulated and interpreted within the individual case reports. The results of the interviews and observations are presented in an integrated manner, as the interactions that occurred and the behaviours that were observed could not be separated.

The interviews provided valuable data on the perceptions of the person with aphasia and of his/her spouse in relation to changes that have occurred in social participation on an individual and family level. In addition, information was obtained pertaining to the self-esteem and life satisfaction since the stroke of the person with aphasia and his/her spouse. Finally, the participants and their spouses identified factors that they felt had produced the changes in their life participation. The observations provided insight into the actual participation of the people with aphasia in social and general life activities. They allowed the researcher to witness strategies and coping mechanisms implemented by the people with aphasia and facilitated a thorough assessment of their social participation in authentic situations.

Finally, the social network analyses are presented as network diagrams before and after the participant's stroke. In the social network analyses, certain shapes are representative of certain network components, for example sons and daughters are represented by triangles. These shapes are consistent throughout the participants' results. In addition, a reduction in the size of a certain element from the pre-stroke to the post-stroke network is indicative of a reduction in the frequency of, or number of contacts within that particular element. Finally, if an element from the pre-stroke network is absent in the post-stroke network, the contact between the person with aphasia and that network component has ceased. In each case, definite reductions in social participation were illustrated by the altered structure of the participant's post-stroke social network in comparison to the pre-stroke network.

SECTION A: INDIVIDUAL PARTICIPANT RESULTS

The results of each participant are presented separately in this section. The results are presented as a summary of the findings of the FACS, followed by a summary of the observations and interviews, and finally, a social network analysis is presented. As multiple, parallel single case studies were conducted, it was felt necessary to present the results on a case-by-case basis before combining and integrating the results. The individual case presentations include raw data and provide the background against which the results were interpreted.

3.1.) Participant 1 (MB)

3.1.1) ASHA FACS

Table 3.1: FACS raw scores for participant 1

COMMUNICATION INDEPENDENCE SCORES

Assessment Domain	Total Of Items Scored	Total Items Rated	Domain Mean Score
Social Communication	128	21	6.1
Communication of Basic Needs	39	6	6.5
Reading, Writing, Number Concepts	37	8	4.6
Daily Planning	24	4	6
Total Domain Mean Score			23.2
Total Number of Domains Rated			4
Overall Communication Independence Mean Score			**5.8**

QUALITATIVE DIMENSIONS OF COMMUNICATION SCORES

	COMMUNICATION DIMENSIONS			
Assessment Domain	Adequacy	Appropri-ateness	Prompt-ness	Communicati on-Sharing
Social Communication	3	2	2	2
Communication of Basic Needs	4	4	3	2
Reading, Writing, Number Concepts	2	3	2	
Daily Planning	4	4	3	
Total Dimension Score	13	13	10	4
Total Number of Domains Rated	4	4	4	2
Dimension Score	3.25	3.25	2.5	2

Total Dimension Mean Score	11
Total Dimensions Rated	4
Overall Qualitative Dimensions Mean Score	**2.75**

MB's overall FACS scores indicated that, although he was relatively independent (obtaining a mean score of 5.8 with the maximum being 7), the qualitative aspects of his communication were lacking (obtaining a mean score of 2.75 with the maximum being 5). The impact of his poor qualitative score was that those outside of his immediate environment may have been unfamiliar with his communicative style and may thus have found him difficult to understand. In addition, although he achieved good scores in the domains of social communication, communication of needs, and daily planning, he achieved a low score in the qualitative dimension of communication sharing. Translated into real life situations these scores indicated that, despite his actual functional abilities, MB was limited in his social interactions and his conversational partner would need to carry the majority of the burden of the interaction.

3.1.2) Interviews and observations

MB is 78 years of age and lives in a flat with his wife. He suffered a stroke on 5 March 2003 and received treatment in a rehabilitation hospital for 2 weeks. He did not attend individual therapy but attended stroke support and activity groups twice per week. MB was a primary school teacher and worked up until the time of his stroke. Thus, MB was working up to the age of 75 years and his age clearly had little or no impact on his life participation. MB has three sons, two of whom do not live in South Africa, and ten grandchildren.

From a family perspective, MB's aphasia had limited his interaction with his wife, children and grandchildren. He reportedly reduced the length and frequency of his conversations with his wife and with his son living in South Africa. MB and MB-S also explained that MB found it very difficult to interact with his grandchildren in South Africa, as they did not understand his communicative impairment, causing him to feel embarrassed. It was particularly difficult for MB to communicate with his family overseas, as he did not use the telephone and could not read or write emails. MB and MB-S explained that MB had actively chosen to avoid using the phone. Due to the difficulty he experienced in expressing himself, he would not answer the telephone and would not make any telephone calls. MB's primary source of social support was his wife.

It emerged in the interview that MB's involvement in his community, particularly in his place of prayer, had markedly decreased since the stroke and that his general socialisation had also been reduced. MB rarely paid visits or received visitors and felt that his friendships had dwindled due to the awkwardness of his communicative impairment. He felt that his lack of expressive language restricted his ability to participate and to interact with friends and colleagues. Similarly, MB's desire to form new relationships was reportedly limited to supportive situations, such as the stroke groups, where others also experience communicative difficulties. Within the group situation, MB was observed to greet fellow members but did not often initiate conversation. He responded when approached by the facilitator or by another member, but his responses were brief and he avoided being called upon. In the one-on-one situation of the interview, MB offered information and occasionally initiated conversational topics, but when he felt as though he was taking too long or experiencing too much difficulty, he withdrew and allowed his wife to speak on his behalf.

MB was reportedly an avid reader, and his written language impairment had thus left a void that he felt affected his life satisfaction. For example, he was unable to read the newspaper to follow current affairs. Furthermore, MB was no longer able to teach, which he described as a passion throughout his life. Since his stroke, MB had not replaced lost hobbies and/or activities with any new activities aside from the stroke support and activity groups. He thus felt that his life was distinctly emptier than it had been prior to his stroke. At the time of the research, he watched TV and played games on the computer when at home. In terms of activities outside of the home, MB was unable to drive and was therefore heavily dependent on his wife. MB reported that his wife took him to movies and to the theatre, but that he fatigued easily. He was, however, able to walk to his place of prayer as he lived within close proximity.

During the interview MB expressed that he saw little point in discussing the changes in his life, as the stroke had occurred and he was forced deal with the consequences regardless of how he felt. In terms of general abilities, MB reported that he experienced slight memory problems and that his numerical abilities had been

affected, preventing him from making any monetary transactions. Overall, he felt that his abilities were largely intact aside from his expressive language.

MB-S is MB's wife and is 69 years of age. She runs a small family business from home. MB-S reportedly tried to maintain certain hobbies and activities outside of the home, but did not feel comfortable leaving MB alone for long periods of time. Due to this concern, MB-S sometimes took MB with her to go shopping or run errands. However, she also felt that she needed some time alone and for that reason she occasionally went out without him. Furthermore, MB-S used the time when MB was at his support groups to have time for herself and to run household errands. She had maintained her involvement in her religious women's committee for meetings and fundraising. In addition, MB-S reported that she had maintained friendships and tried to meet friends for tea.

MB-S reported that she occasionally travelled overseas to visit her children, but MB remained in South Africa at an old aged home while she was away. She did not feel that she could cope with taking him on such a journey. In addition, MB-S reported that she did not invite people for dinner unless her son was able to attend. This was due to the fact that MB had difficulty making conversation and she felt uncomfortable leaving her guests while she was in the kitchen. As a result, MB-S limited the number of social invitations that she accepted, as these invitations would require reciprocation.

On one occasion when the researcher accompanied MB-S and MB shopping, it was observed that MB participated as little as possible and that MB-S took charge and directed MB's activities. However, when they sat to have coffee, MB was able to greet the waiter and place his order. He also engaged in conversation with MB-S and the researcher. Furthermore, when a salesman approached him, MB responded and participated in a reciprocal conversation with an unknown partner. According to both MB and MB-S, it was a rare occurrence for MB to converse with a stranger.

During the interview, MB-S expressed that she had tried to maintain her life as much as possible as it was prior to MB's stroke. However, she felt that she had to bear all the responsibilities and make all the decisions and this left her feeling frustrated. MB-

S felt that, although her social participation had decreased, her life satisfaction was different and not necessarily better or worse. MB-S felt that one learnt to cope with challenges through facing them, thereby becoming a stronger person. In terms of MB's life participation and satisfaction, MB-S felt he had lost interest in many activities due to the increased effort that was required since the stroke. She thus perceived MB's general involvement, and consequently his life satisfaction, as being significantly reduced since the onset of his aphasia.

3.1.3) Social Network Diagrams

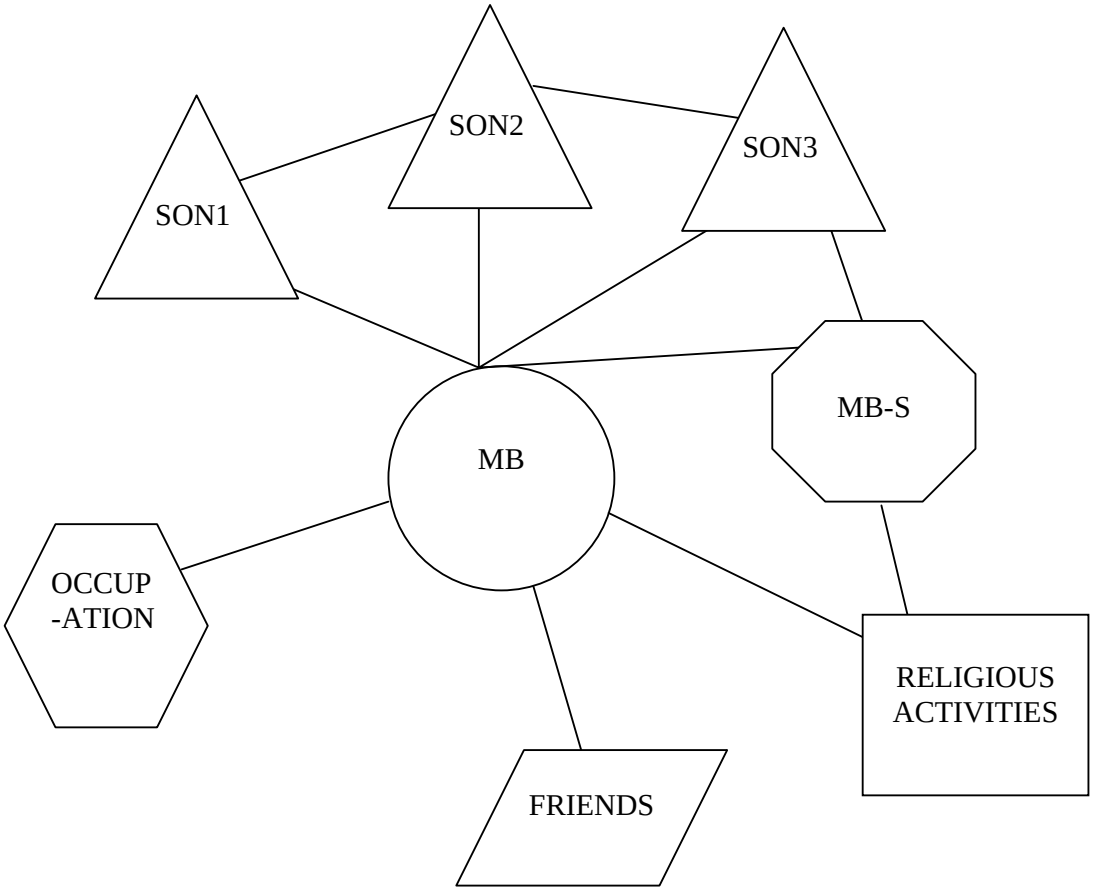

Figure 3.1.1: Pre-stroke social network of participant 1

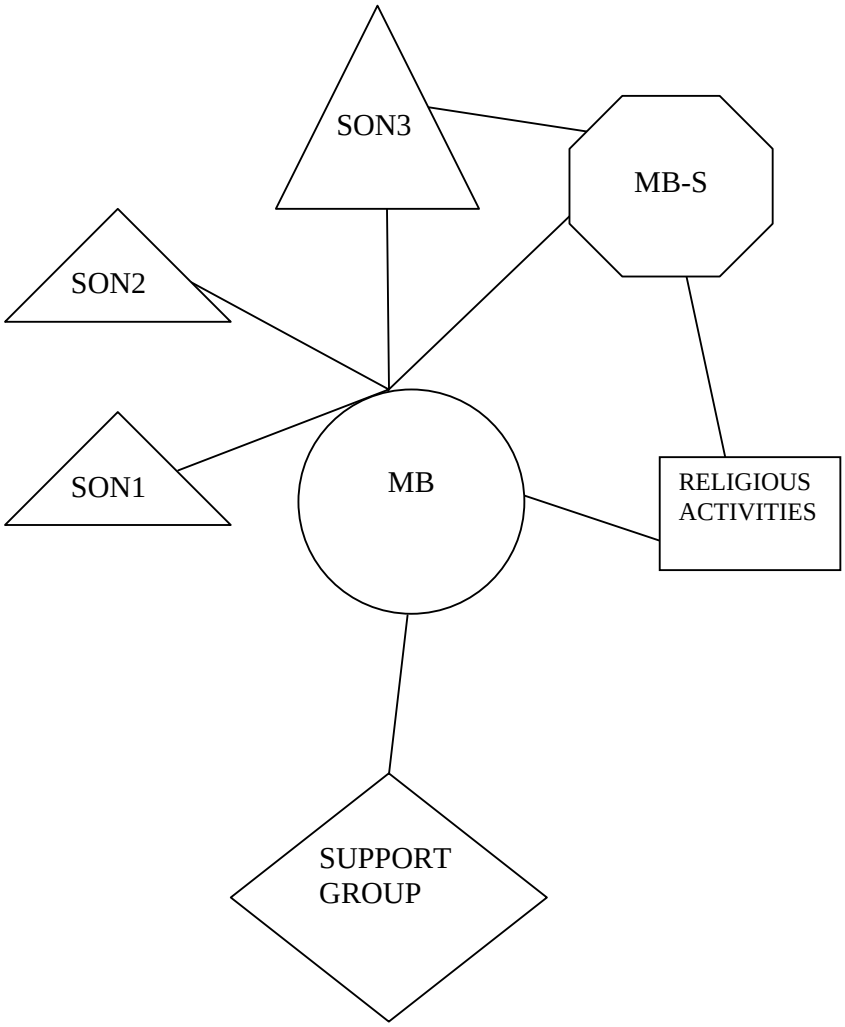

Figure 3.1.2: Post-stroke social network of participant 1

Description of networks

There was a clear reduction in MB's social contacts and activities since the onset of his stroke. The number of contacts within his social network had decreased and the frequency of interaction with the remaining contacts had diminished. The triangles representing son1, son2 and son3 include MB's sons, their wives and their children. Due to MB's difficulties using the telephone and email, the quality and quantity of direct communications between MB and his children and grandchildren living overseas had become increasingly limited. The element of the pre-stroke network representing MB's occupation includes MB's pupils, their parents and other members of staff. As MB was teaching until the time of his stroke, the absence of this social element left a significant gap in his network. In addition, MB had lost contact with

his friends as a result of his difficulty in maintaining his communicative role within the relationship. Again, the loss of his friends left a considerable void in his social network.

However, MB was a member of two post-stroke support groups and had thus replaced certain lost activities and contacts with the activities and members of the groups. Consequently, a new element had been added to MB's social network. Jordan and Keiser (1996) explain that the person with aphasia's number of social contacts may remain unchanged after a stroke due to the addition of contacts such as support groups, rehabilitation professionals and helpers. However, MB was not receiving individual therapy or support and did not engage with any professional or volunteer helpers. Therefore, the support groups replaced only one of his lost network components. Although, MB's involvement in religious activities had decreased, it was an area wherein both he and MB-S still participated and was a positive factor within his network. Thus, MB had maintained a level of involvement in his religious activities despite a change in the quality and quantity of interactions he experienced within this context.

The single element of MB's social network that remained unchanged was his wife. Although MB's interactions with MB-S had been affected by the aphasia, she formed his primary social support and compensated for a loss of conversation by introducing new activities and adopting a different interaction style. Hence, the quality of their interactions had been altered and adjusted to accommodate the aphasia and the size of her representation in the network had remained stable.

Overall, the changes in MB's social relations and activities that were described during the interviews have been illustrated by his social network analysis. As a result of the communication barriers imposed by the aphasia, clear voids occurred after the stroke and remained unfilled, while other contacts became degraded. The single new contact established was a supportive aid required after the stroke and was therefore selected for a purpose as opposed to being engaged in for pleasure. Nevertheless, the support group provided a meaningful new context for interaction and for the establishment of new relationships to reduce the sense of emptiness left by the absence of MB's teaching and of his friends.

3.2) Participant 2 (CS)

3.2.1) ASHA FACS

Table 3.2: FACS raw scores for participant 2

COMMUNICATION INDEPENDENCE SCORES

Assessment Domain	Total Of Items Scored	Total Items Rated	Domain Mean Score
Social Communication	144	21	6.9
Communication of Basic Needs	49	7	7
Reading, Writing, Number Concepts	43	8	5.4
Daily Planning	28	4	7
Total Domain Mean Score			26.3
Total Number of Domains Rated			4
Overall Communication Independence Mean Score			**6.6**

QUALITATIVE DIMENSIONS OF COMMUNICATION SCORES

	COMMUNICATION DIMENSIONS			
Assessment Domain	**Adequacy**	**Appropri-ateness**	**Prompt-ness**	**Communication-Sharing**
Social Communication	4	4	4	4
Communication of Basic Needs	4	4	4	4
Reading, Writing, Number Concepts	3	3	3	
Daily Planning	5	5	4	
Total Dimension Score	16	16	15	8
Total Number of Domains Rated	4	4	4	2
Dimension Score	4	4	3.75	4

Total Dimension Mean Score	15.75
Total Dimensions Rated	4
Overall Qualitative Dimensions Mean Score	**3.9**

CS's overall FACS scores indicate that he is highly independent (obtaining a mean score of 6.6 with the maximum being 7). In addition, the qualitative aspects of his communication are of a relatively high standard (obtaining a mean score of 3.9 with the maximum being 5). The positive impact of his high independence and qualitative scores is that CS coped well in one-on-one as well as group situations. Nevertheless, CS's weakest scores relate to the area of reading, writing and number concepts and the effects of these deficits are not realistically reflected in the overall mean score. The high independence mean score is deceptive in that it masks this single area of weakness that prevented him from reaching maximum independence, despite his good functional communication.

3.2.2) Interviews and observations

CS is a 66-year-old male who lives at home with his wife. He suffered a stroke on 7 March 2002 and attended private speech therapy after being discharged from hospital. At the time of the research he was attending a stroke support and activity group. CS also underwent certain alternative forms of healing, such as acupuncture. It must be noted that CS had a premorbid stutter. He was not excluded from the study on the basis of this speech impediment, as he reported that the stutter improved over the course of his life and had no impact on his socialisation. CS did, however, report that the stutter had worsened slightly after the stroke. Nevertheless, no stutter in CS's speech was evident to the researcher and the aphasia was his only apparent communication impairment.

CS has one son and one daughter who lives in America. He has three grandchildren and spent a great amount of time with the grandchildren that live in South Africa. Since the stroke, CS experienced difficulty writing and typing and preferred to speak to his daughter in America on the phone than via email. He said that he had difficulty constructing grammatically complete sentences and that typing comprehensive emails required too much time and effort.

During the observed interactions between CS and his grandson, it was evident that CS was honest about his aphasia and could laugh together with his grandson at the changes in his communication and temperament since the stroke. This honesty was illustrated when CS's grandson was describing an incident during which CS had lost

his temper with a waiter. CS did not deny the incident, but concurred with his grandson that he would not have previously behaved in that manner. CS-S was also honest and forthcoming about her husband's deficits. She did not interrupt or speak on his behalf, but allowed him the time to be an equal conversational partner. CS felt that his family overcame his difficulties effectively by being open and using humour. For example, CS's grandson reported that he helped "grandpa" and taught him new words.

CS maintained his occupation and worked full time in the same job he occupied prior to the stroke. He dealt only with three or four people at work with whom he was familiar and who were understanding and supportive of his impairments. This situation prevented him from having to deal with customers and communicate with unfamiliar people.

CS said that he did not use the phone, aside from with his family, and would not answer if it rang at home. However, when an observation session had to be rescheduled, CS answered his cellular phone and was able to have a fluent conversation with the researcher. CS also reported that he read a great deal in the past but that his reading had been affected by the stroke. He took longer to comprehend and thus read less. CS was thus not able to read the newspaper well but followed current affairs through radio and television.

In terms of activities outside the home, CS was still able to drive and his hobbies included cycling and gym. Although he reported that he cycled less since his stroke, CS was preparing for the 94.7 Cycle Challenge at the time of his participation in this study. His sustained active role within the community was thus illustrated. In addition, CS had remained involved in his religious community and institution.

In general, CS had maintained social relations since the stroke and appeared willing and able to initiate new relationships. CS felt that his friends understood his communication impairment and that they were able to deal with it using humour and a relaxed approach. CS, however, reported that his socialisation had decreased since the stroke. He felt that this was due to his aphasia as well as to natural factors, such as time constraints and the aging of his friends.

In addition to his home environment, CS was observed at his support group. In this group situation he contributed to group conversations and assisted other members to contribute. Within a group conversation and in a one-on-one situation, CS was sensitive to subtle cues and facial expressions. He used humour, followed the entire conversation, and reinforced and linked other members' contributions. CS initiated discussions and played a reciprocal role in terms of receiving and providing support. He understood and used social language well and his pragmatic skills compensated when his linguistic skills were lacking.

Overall, CS felt that the stroke had had a small impact on his general life satisfaction but that his relationships had been affected. He described in particular the frustration of being unable to discuss matters or problems with his wife. In addition, he felt that his temperament had been affected by the stroke, as he had always been a calm person but had become short-tempered.

CS-S provided CS with extensive social support in terms of running household affairs and assisting in his business. She felt that her activities and community involvement had remained the same and that their religious institution had provided extensive support since CS's stroke. In terms of her social participation, she was able to spend time with her friends alone during the day while CS was at work. She reported that it was initially very stressful to go out and leave CS alone at home and that she had been lonely during this time. However, she reported feeling far more comfortable at the time of the research and they had both gradually returned to a routine. She said that at that stage she would be able to travel overseas alone and not be concerned about CS. CS-S was very involved with her grandchildren and they spent much time at her and CS's home. She reported that her level of involvement with them had not changed and she was still able to help with their general activities.

CS-S reported one of the greatest changes being that she was required to assume a more dominant role in running the finances and other household issues, such as insurance, and that she was unable to discuss these issues with CS. In terms of CS's participation and the changes within his life, she agreed with his responses during the interview.

3.2.3) Social Network Diagrams

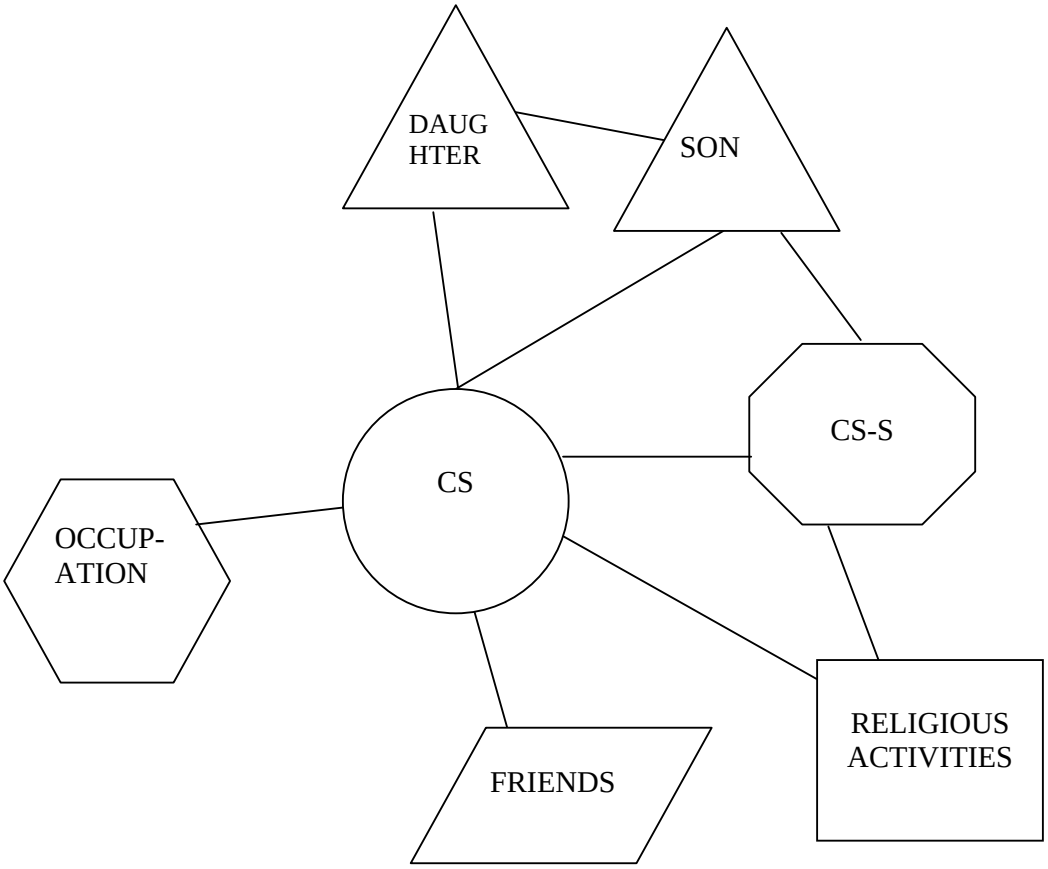

Figure 3.2.1: Pre-stroke social network of participant 2

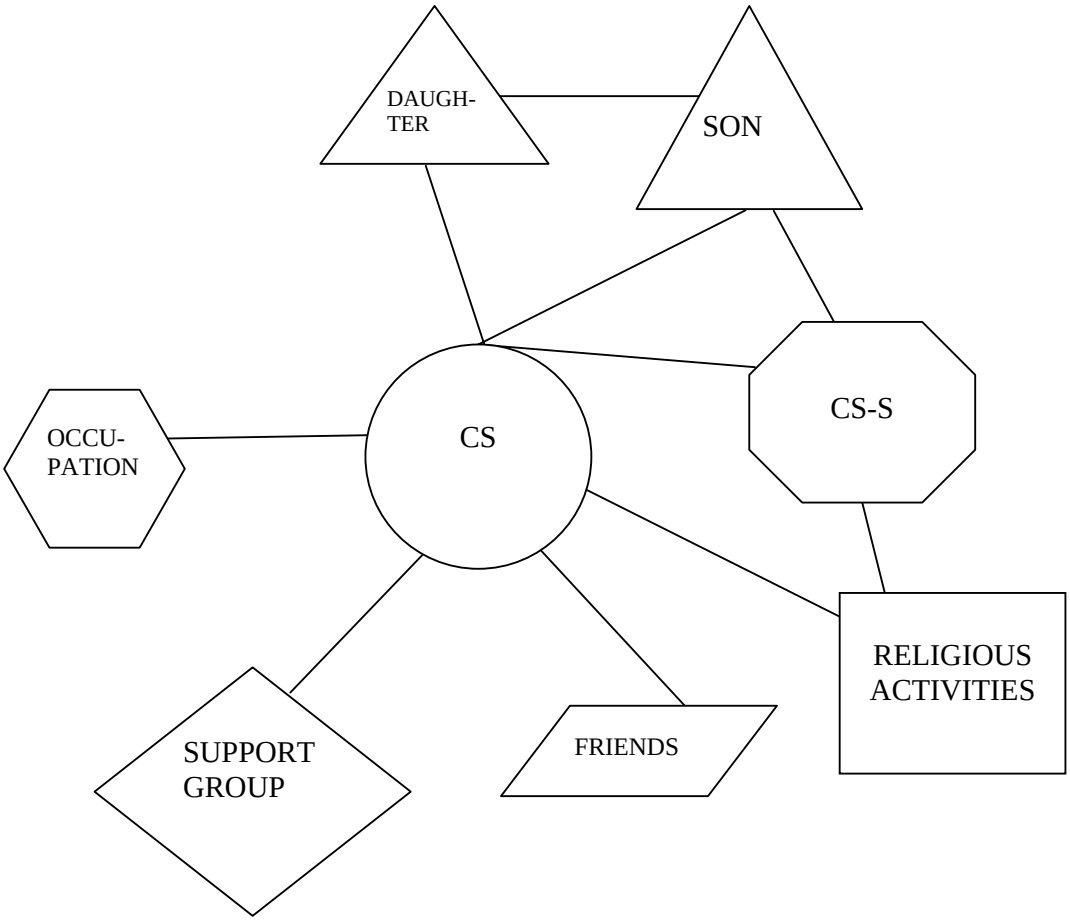

Figure 3.2.2: Post-stroke social network of participant 2

Description of networks

When comparing CS's post-stroke network to his pre-stroke network, it is evident that CS's social contacts remained the same after his stroke. Furthermore, the stroke group formed an additional component of the network, thus expanding on the pre-stroke network. However, the frequency and quality of CS's interactions with certain contacts was affected by the stroke.

The triangle representing CS's daughter, includes her husband and children living overseas. The triangle representing CS's son, includes his wife and children living in South Africa. In the post-stroke network, there is an evident reduction in the direct communication between CS and his daughter and her family living overseas. It is also illustrated that CS communicated directly with fewer colleagues and clients since

the onset of his aphasia. Similarly, CS had less frequent social contact with his friends.

However, CS was a member of a post-stroke support group and had thus replaced certain lost activities and contacts with the activities and members of the group. In addition, CS's level of involvement in his religious activities had been sustained since the stroke. This is a very positive factor within his network, as the religious context reportedly provided extensive support for both him and CS-S. Furthermore, the religious activities provided a common environment wherein CS and CS-S participated together.

CS-S had remained a constant element within CS's social network. Although the quality of their interactions was reported to have been altered by the aphasia, CS-S was CS's primary social support. She adapted her interaction style and appeared to regard him as an equal conversational partner, but with specific needs. CS-S was thus a vital element of his network.

Overall, the changes in CS's social relations and activities that were described during the interviews have been illustrated by the social network analysis. Although CS's general social participation had diminished since his stroke, no blatant voids had been left in his social network or his life. Nevertheless, CS established new contacts in the form of the support group and appeared to both enjoy and benefit from the opportunities for interaction that it provided.

3.3) Participant 3 (RS)

3.3.1) ASHA FACS

Table 3.3: FACS raw scores for participant 3

COMMUNICATION INDEPENDENCE SCORES

Assessment Domain	Total Of Items Scored	Total Items Rated	Domain Mean Score
Social Communication	55	19	2.9
Communication of Basic Needs	22	6	3.7
Reading, Writing, Number Concepts	21	9	2.3
Daily Planning	19	4	4.75
Total Domain Mean Score			13.65
Total Number of Domains Rated			4
Overall Communication Independence Mean Score			**3.4**

QUALITATIVE DIMENSIONS OF COMMUNICATION SCORES

	COMMUNICATION DIMENSIONS			
Assessment Domain	**Adequacy**	**Appropri-ateness**	**Prompt-ness**	**Communication-Sharing**
Social Communication	3	2	1	1
Communication of Basic Needs	3	2	1	1
Reading, Writing, Number Concepts	2	2	1	
Daily Planning	3	2	1	
Total Dimension Score	11	8	4	2
Total Number of Domains Rated	4	4	4	2
Dimension Score	2.75	2	1	1

Total Dimension Mean Score	6.75
Total Dimensions Rated	4
Overall Qualitative Dimensions Mean Score	**1.7**

RS's overall FACS scores indicated that her communicative independence was relatively weak (obtaining a mean score of 3.4 with the maximum being 7) and the qualitative aspects of her communication were poor (obtaining a mean score of 1.7 with the maximum being 5). RS's functional communication was thus impaired in all areas, resulting in a low level of communicative competence within her family environment as well as with unfamiliar people and within activities outside of the home. Translated into real life situation, these scores indicated that RS was limited in her social interactions as a result of the inadequacy of the quantity and quality of her expressive language skills. In RS's case, the overall FACS score is heavily skewed towards the low scores she obtained on the items necessitating expressive language. As a result, her functional receptive and cognitive competencies are masked by the FACS scores and she is shown to be generally inadequate in many areas of communication.

3.3.2) Interviews and observations

RS experienced significant communication impairments and her husband (RS-S) and her daughter therefore played particularly pivotal roles in the interviews.

RS is a 52-year-old female who suffered a stroke in February 2004 and spent 6 weeks undergoing rehabilitation. She lives at home with her husband and two daughters and has a full-time domestic worker/helper. At the time of the research, one of RS's daughters was living overseas. It was therefore extremely difficult for RS to communicate with her on the telephone and through email, as both her expressive language, and her reading and writing, were impaired by the stroke. However, RS was helped and encouraged by her family to speak to her daughter overseas on the telephone.

RS did not work prior to the stroke, but was active in looking after her home and family. She fulfilled all the domestic activities and took care of the garden herself. Prior to the stroke, RS was not involved in the community in terms of committees or religious institutions. She did, however, entertain regularly and go out for meals and for entertainment, such as movies and theatre. RS had two very close friends whom she saw often prior to the stroke. It was reported that she saw them less often since the stroke, as she was unable to drive and they thus had to visit her at home. Her

husband reported that she had not been a particularly sociable person before the stroke and had not enjoyed being in groups or crowds of people. He explained that she preferred one-on-one interactions. However, RS-S reported that RS was a language oriented person who spoke German and Afrikaans (in addition to English) fluently prior to the stroke. At the time of the research it was reported that RS could still understand both German and Afrikaans, but her expression in these languages was affected together with her English.

Major changes had occurred in terms of RS's life satisfaction. RS-S reported that she experienced great frustration at not being able to take care of her home and garden as before. She required the help of a full-time domestic worker and could not cook, clean or garden as a result of the physical impact of the stroke. In addition, much of RS's time was still dedicated to home-based rehabilitation when she participated in this research. She received physiotherapy three times per week, occupational therapy twice per week and speech-language therapy twice per week. At the time of the research RS was gradually becoming independent in her activities of daily living. Thus, social participation was not a priority or focus of her treatment at that stage.

RS-S is 54 years of age and runs a factory a fair distance from the family's home. RS-S reported that he and his wife were home oriented people before the stroke, but that they had always enjoyed going out for meals and going shopping together. RS-S explained that he and RS loved to travel but felt that it would be more difficult as a result of the stroke. He said he would like to be able to still take RS to a movie or travel together, but that such activities were directly dependent on factors outside of his control, such as accessibility and facilities for persons with disabilities. RS and RS-S had been to a movie since the stroke, but the movie theatre was not wheelchair friendly and they found public bathrooms to be a problem. Therefore, in terms of activities outside the home, RS-S reported that the physical limitations caused by the stroke played the greatest role in restricting their participation. In terms of his personal activities and life satisfaction, RS-S felt that it was difficult to make decisions without being able to discuss issues with his wife.

As RS-S did not work close to home, having his daughters at home had been an extremely positive factor. At the time of the interview, one daughter was overseas. However, the younger daughter attended lectures at night and was therefore at home during the day while RS-S was at work. RS-S said that he used to feel guilty about leaving RS alone at home in case something happened. In addition, RS-S felt that he had less personal time to relax, as he was now busy on weekends with household jobs and gardening. Yet, he expressed that he was becoming more accustomed to the situation and RS was becoming more independent in terms of her self-care. Although RS's physical limitations appeared to have had the greatest impact on her daily functioning, her limited verbal communication was problematic, as RS-S reported that RS had previously fallen at home and been unable to call for help.

RS used writing, vocalisations and gesture to help her communicate. Her daughter strongly encouraged her to speak and to use gesture. RS's family reported that her use of nonverbal communication was improving and she was able to dial and partially write a telephone number during the interview. However, RS's ability to participate in conversations with her family and with unfamiliar people was restricted by her lack of fluent speech. Therefore, RS-S was required to interpret RS's nonverbal communication and attempt to complete her verbalisations in order to understand what she wanted or needed. This led to a simple task, such as making her a sandwich, becoming a complicated and lengthy activity. Nevertheless, both RS-S and their daughter actively included RS in all conversations by using direct yes/no questions or by phrasing their conversational turns in a manner that did not require a complex reply from RS.

In terms of the physical family environment, the house had two levels and a downstairs room had been converted into a bedroom for RS. RS-S explained that it was extremely difficult to get RS up the stairs, but that it was also difficult not being able to share a bedroom anymore.

As RS's daughter was at home during the interview, she provided some information and insight from her perspective. RS's daughter felt that her life had also changed dramatically as she was required to assume her mother's duties and additional responsibilities in the house. She felt strongly, however, that it was important for her

mother to resume previous activities. She had thus begun re-orientating RS within the home and had begun cooking with RS. RS's daughter also reported that it was easier when her sister was at home, but that the family coped by following a set daily routine.

3.3.3) Social Network Diagrams

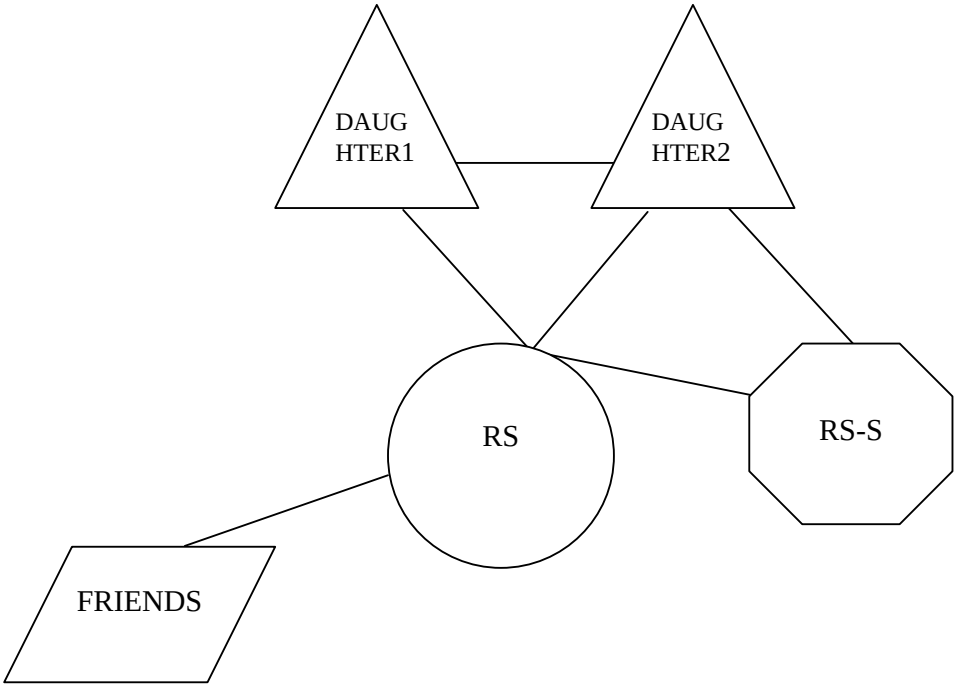

Figure 3.3.1: Pre-stroke social network of participant 3

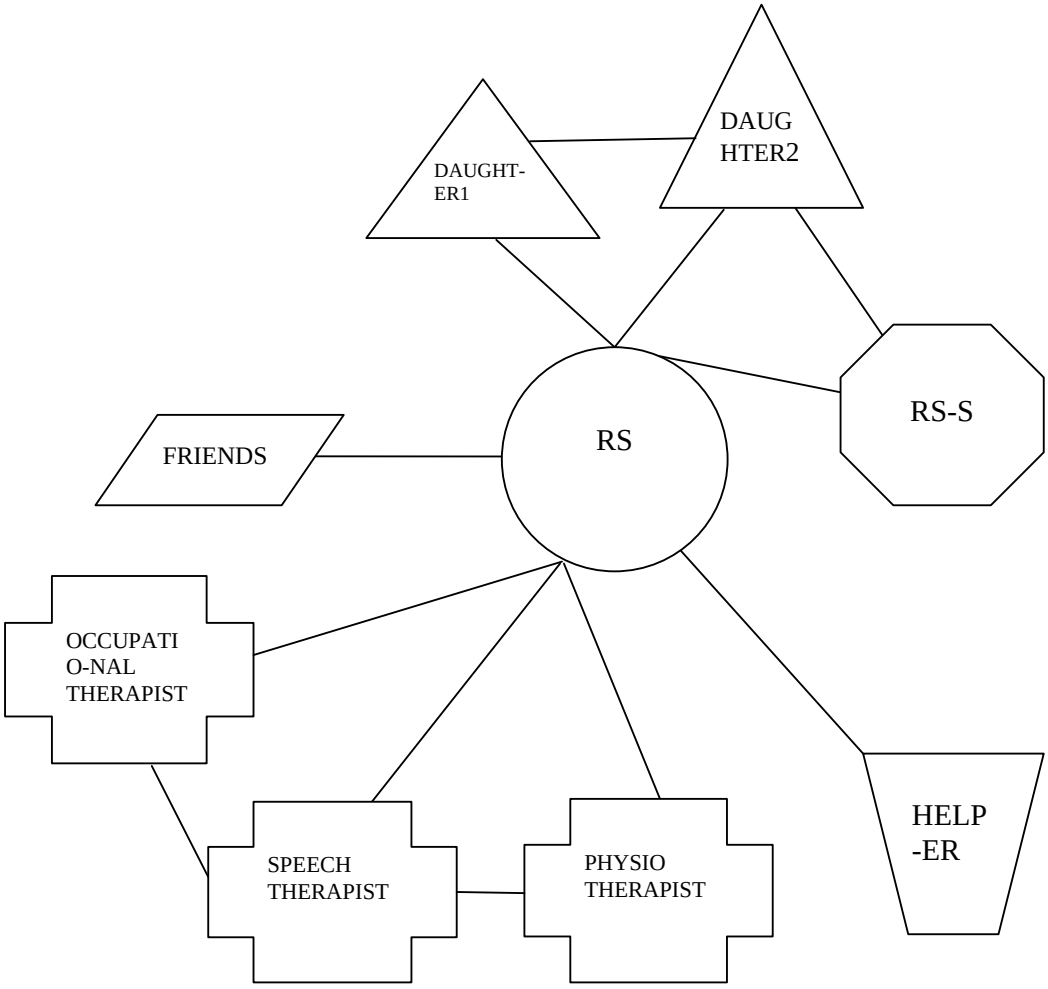

Figure 3.3.2: Post-stroke social network of participant 3

Description of networks

When visually comparing RS's pre-stroke and post-stroke social networks, it appears as if the number of social contacts increased after the stroke. However, a closer analysis of the network is required in order to understand the apparent increase. Daughter1 had been living overseas since shortly after RS's stroke. As a result of RS's difficulties expressing herself over the telephone and her difficulties reading and writing emails, the quantity and quality of direct communication between RS and her daughter had decreased. In addition, the frequency of contact between RS and her two close friends had been reduced. This was related to her lack of mobility and inability to drive, as the friends were required to visit her at home if they were to see her.

At the time of the research, RS was receiving speech therapy, physiotherapy and occupational therapy at home numerous times per week. Therefore, the additional contacts in the network took the form of therapeutic and support services only necessary due to the stroke. These contacts, namely the speech therapist, physiotherapist and occupational therapist, are not sustainable contacts from a long-term perspective. Lubinski (2001) discusses the phenomenon of a naturally increased social network during rehabilitation. She explains that members of the rehabilitation therapy team provide the person with opportunities for communication, as well as providing support. This was clearly the case with RS at the time of the research. However, therapy is not an indefinite process and RS was not receptive to becoming a member of a support group. Therefore, the reduction in social contact with friends was not substituted by genuinely new or functional social connections, such as fellow support group members.

Furthermore, as RS could no longer fulfil all the household duties, the family's domestic worker was employed full-time as opposed to the part-time hours she had kept prior to RS's stroke. RS thus spent a great deal of time with her during the day, especially when no other family members were present. Although RS's social contact with her domestic helper was restricted to the home and family environment, this relationship is viewed by Jordan and Kaiser (1996) as a replacement for the loss of contact with friends or colleagues.

As RS was not working prior to her stroke, an absence was not created by the loss of contact with colleagues or clients. From the interviews it became evident that RS placed more value on her abilities to care for her home and her family than she did on socialisation. Her social activities involved predominantly her husband and she was not fond of crowds, resulting in her pre-stroke network being relatively small. Although her contact with certain network components was reduced by the aphasia and physical effects of the stroke, no voids had been created. Therefore, the changes in RS's social participation are not well illustrated by a comparison of her pre-stroke and post-stroke social networks.

3.4) Participant 4 (PM):

3.4.1) ASHA FACS

Table 3.4: FACS raw scores for participant 4

COMMUNICATION INDEPENDENCE SCORES

Assessment Domain	Total Of Items Scored	Total Items Rated	Domain Mean Score
Social Communication	78	19	4.1
Communication of Basic Needs	31	6	5.2
Reading, Writing, Number Concepts	36	10	3.6
Daily Planning	21	3	7
Total Domain Mean Score			19.9
Total Number of Domains Rated			4
Overall Communication Independence Mean Score			**4.9**

QUALITATIVE DIMENSIONS OF COMMUNICATION SCORES

	COMMUNICATION DIMENSIONS			
Assessment Domain	**Adequacy**	**Appropri-ateness**	**Prompt-ness**	**Communication-Sharing**
Social Communication	3	2	2	2
Communication of Basic Needs	3	2	2	2
Reading, Writing, Number Concepts	3	2	2	
Daily Planning	3	2	2	
Total Dimension Score	12	8	8	4
Total Number of Domains Rated	4	4	4	2
Dimension Score	3	2	2	2

Total Dimension Mean Score	9
Total Dimensions Rated	4
Overall Qualitative Dimensions Mean Score	**2.25**

PM's overall FACS scores indicated that his functional communication abilities are average, both in terms of independence (obtaining a mean score of 4.9 with the maximum being 7), and in terms of qualitative aspects (obtaining a mean score of 2.25 with the maximum being 5). PM's lowest independence score was within the domain of reading, writing and number concepts and his highest independence score was in the domain of daily planning. These scores create a paradoxical situation, as PM had the ability to plan and structure his life in a highly competent manner, yet he was unable to perform daily transactions involving written language or numbers. In terms of the qualitative dimensions of PM's communication, he was able to convey the main meaning of his message about half of the time, yet had difficulty doing so under the right circumstances and without significant delay. In addition, his conversational partner was required to play a dominant role in the interaction and thus carry the majority of the burden. Translated into real life situation, these scores reflect PM's potential for becoming a functional communicator, while clearly highlighting the negative impact of his expressive language impairments.

3.4.2) Interviews and observations

PM is a 52-year-old male who suffered a stroke on 20 February 2004 and received rehabilitation for approximately two weeks. At the time of the research, he was attending an activity and support group. PM lives at home with his wife and four children. PM's wife reported that PM was premorbidly bilingual and that both his languages were affected equally by the stroke.

Prior to his stroke PM was a primary school teacher, who had been very involved in school activities, such as sports and attending courses. He enjoyed watching and playing soccer and listening to music and the radio. PM was also extensively involved in his religious establishment, attending services and assisting the pastors. He had been in the process of completing a course to become a church counsellor. Since the stroke, PM had ceased the majority of these activities. He was no longer able to teach or play soccer and was unable to complete his counselling course. In addition, PM had regarded himself as a 'handy man' and felt as if he could not contribute within the home environment after the stroke. This change in role had taken a negative toll on his self-esteem and life satisfaction.

In terms of PM's activities since the stroke, he attended the support and activity group, attended religious services and was considering a temporary job in computing or accounting. Although PM-S described PM as a quiet person, PM explained that he enjoyed attending the group as he became lonely and worried if he was at home alone. In addition, PM reported that he did not mind going to public places, such as shopping malls, but that walking was difficult. He said he occasionally accompanied his wife at her request.

On an interpersonal level, PM maintained friendships, but only saw his friends if they visited him at home. PM-S reported that PM was able to speak to his friends and relatives on the phone but experienced difficulty speaking to strangers. In addition, PM did not enjoy spending time with people outside the home, as he found it stressful due to his speech impairments. PM-S reported that PM did not demonstrate a desire to form new friendships or relationships independent of her and found it difficult to interact with unfamiliar people. This difficulty was apparent during the interview, as PM allowed his wife to play a dominant role.

However, on observation, PM appeared comfortable at his treatment and support group and interacted with the other members as well as with the staff. In this environment he was able to communicate effectively and independently without PM-S. Yet, it should be noted that the staff at the support group were familiar with interacting with people with communication difficulties, and many of the other members experienced similar problems. In addition, PM refrained from engaging in group conversations and spoke mainly when approached directly.

As a result of the stroke, PM experienced difficulty with reading and writing. These difficulties prevented him from reading as many books as he did prior to the stroke. He read the newspaper but explained that it required increased time and effort. PM was able to speak in full sentences, but felt that his speech fluctuated and was better at home than it was at the support group. PM, however, felt that his speech had improved and that walking was his biggest challenge.

PM-S is a teacher. She teaches at a primary school and is very involved in school activities and committees, such as the school governing body and the school choir. PM-S reported, however, that she had reduced the amount of time that she spent at school, for example by attending alternate school meetings. In addition, she was previously very involved in the church choir, but had only attended practice once a week since MB's stroke, instead of three times per week. PM-S also reported that the visiting that she and PM did had decreased and that she went shopping alone unless it was for a specific purpose, such as going to the bank. In terms of maintaining her community involvement, PM-S attended meetings for a women's religious group one Sunday per month.

PM-S reported that she had a strong personality and a coping attitude, but was initially very disturbed by PM's stroke. She felt that her life satisfaction had been specifically disrupted immediately after PM's stroke. In terms of the changes that had occurred in her life, PM-S felt that PM did not want to enter into discussions and did not always understand her during conversations. As a result, she had to make decisions alone and assume responsibility for the whole family, as well as all household and financial affairs.

Although PM said that walking was his biggest challenge, PM-S felt that his speech and the use of his right arm were the biggest problems to overcome. She sensed PM to be depressed, as he had not been able to return to work. In addition, PM-S perceived PM to be emotionally volatile and dissatisfied with his life at the time of the interview, as too many changes had occurred since the stroke. PM-S felt that a major change had occurred in PM's level of involvement and interaction with his younger children. For example, his oldest daughter or PM-S would attend school parents' meetings for the younger children. During the discussion, PM concurred with the above opinions and admitted to feeling depressed.

In terms of quality of life as a married couple, PM-S reported that she missed being able to walk with PM through shopping malls and shop together. Nevertheless, she emphasised that the stroke had strengthened their marriage and proven their love and dedication to each other. She felt that through looking after PM, she had grown closer to him and that her feelings for him had strengthened.

3.4.3) Social Network Diagrams

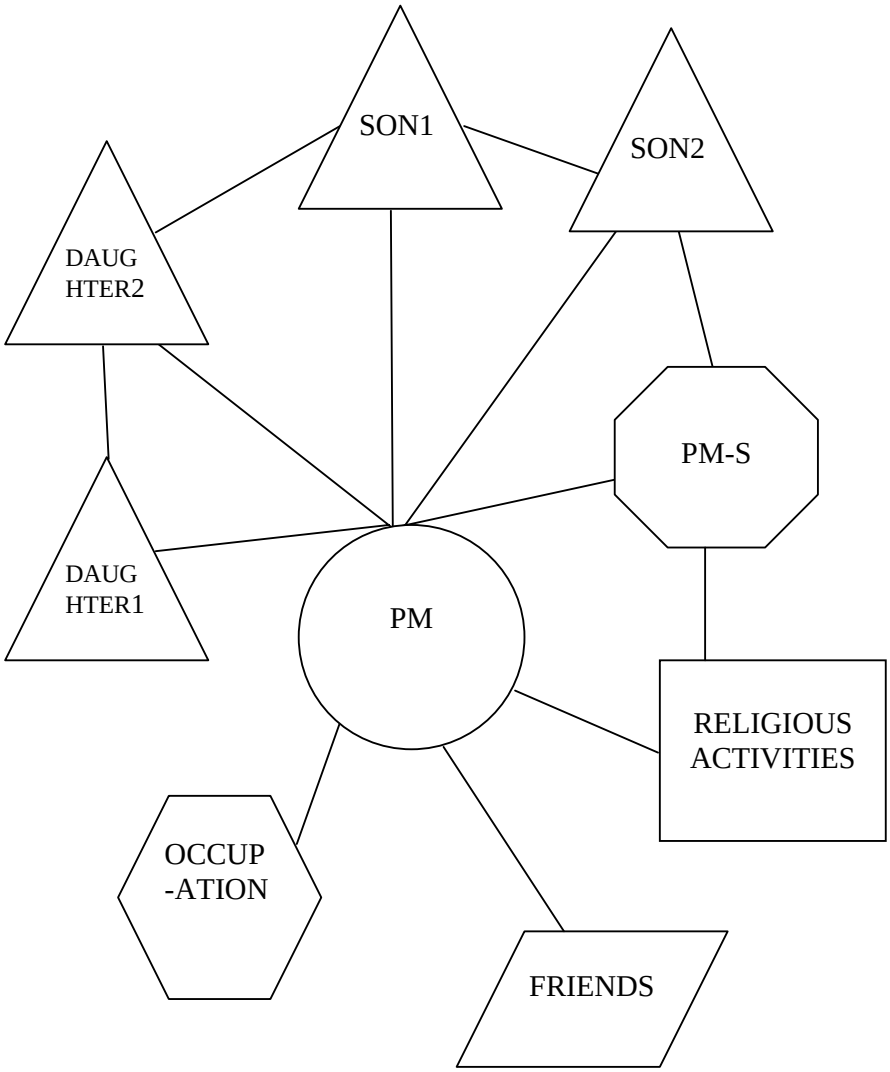

Figure 3.4.1: Pre-stroke social network of participant 4

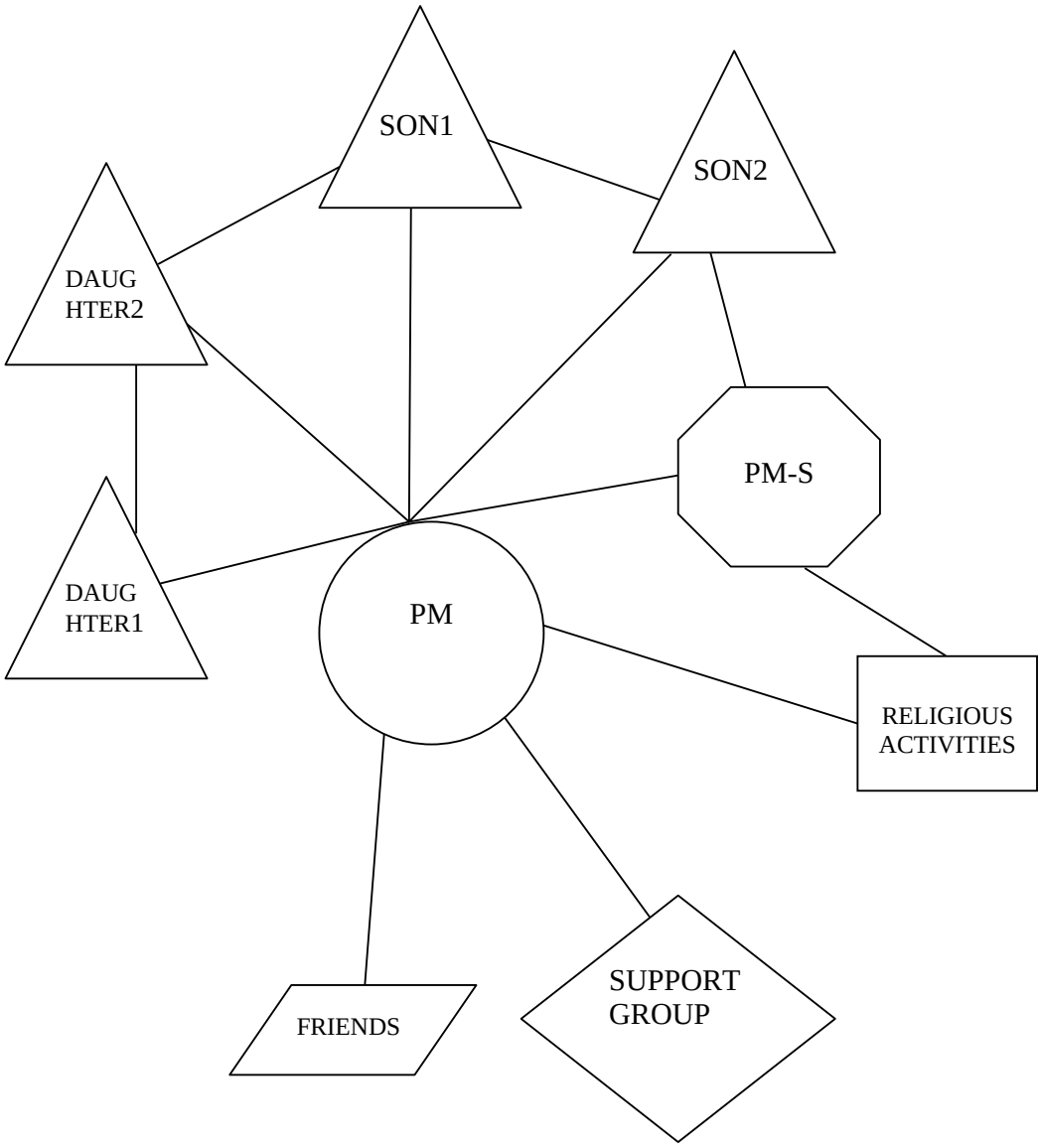

Figure 3.4.2: Post-stroke social network of participant 4

Description of networks

When comparing PM's pre-stroke and post-stroke networks, little major change is evident. It is clear that PM's family remained constant components within the network. This was due to the fact that all PM's children were still living at home, allowing the maintenance of his direct interactions with them. In addition, PM-S remained a stable contact and primary source of social support. However, the manner and style of PM's relations with his family reportedly changed since the onset of the aphasia. As a result of his aphasia, PM was less able to engage in conversations with

his wife and children and was less able to be involved in the children's school activities.

The element representing PM's occupation in the pre-stroke network includes the pupils, parents and fellow staff members. All social contact related to his job ceased after his stroke. However, two teachers with whom PM was friendly continued to visit him at home. They are therefore included in the 'friends' icon as opposed to the 'occupation' icon. The absence of work-related interactions left an obvious void in PM's life and reportedly contributed to his feeling depressed.

An additional major change within PM's network was the reduced frequency of contact with his friends, which was related to his inability to drive and his being wheelchair-bound. Although lessened, PM had maintained a level of participation within his religious environment. This continued participation was a very positive factor within his network, as the religious context reportedly provided extensive support for both him and PM-S. In addition, the religious activities provided a common environment wherein PM and PM-S participated together. In addition, PM was a member of a post-stroke/head injury support group and thus replaced certain lost activities and contacts with the activities and members of the group. This should be regarded as a positive and meaningful addition to his social network, as it provided him with the opportunity for social interaction and with the possibility of new social relationships.

Overall, PM managed to sustain a relatively rich and full life, despite obvious changes in his physical and communicative capacities for social participation. Owing to a strong family unit, gaps that formed within PM's social network were being compensated for by a combination of individual, familial and community support strategies.

SECTION B: CONTENT ANALYSIS

A content analysis was conducted from the data obtained. The themes that emerged with regard to the social participation changes and perceptions are described in this section, and tables of examples are used to complement the text. The themes that emerged are described in four sections. The first set of themes is related to the participants with aphasia and the second to the spouses. Following that, individual differences are discussed. The first set of differences is related to the participants with aphasia and the second to the spouses.

It is difficult to classify aphasia as a disability, as it is intangible to the impartial observer. Moreover, aphasia does not fit the pattern of a standard illness with a set recovery period. In addition, the nature of aphasia is unpredictable and generally poorly understood. (Parr et al, 1998). Despite the fact that the symptoms and nature of aphasia can differ both inter- and intrapersonally (Parr et al, 1998) there are certain consequences that appear to be common among the participants in this study. Through the open coding of the results, it is evident that the information and opinions obtained from the participants and their spouses concurred more than it diverged.

3.5) Themes that emerged across the adults with aphasia

The International classification of impairments, disabilities and handicaps was revised in 1999 to form the ICIDH-2 (Wade and de Jong, 2000). The ICIDH-2 defines impairment, activity and participation as follows: Impairment is defined as: "Abnormalities or changes in the structure or function of the whole body". Activity is defined as: "Abnormalities, changes, or restrictions in the interaction between a person and his or her environment or physical context (that is, changes in the quality or quantity of behaviour)". Participation is defined as: "changes, limitations, or abnormalities in the position of the person in their social context" (Wade and de Jong, 2000, p.1386). The ICIDH-2 model has been used as a background against which the themes are discussed. Also evident is the interaction of the levels of activity and participation with each other and with the level of impairment, as postulated by Larson, Kirschner, Bode, Heinemann, Clorefene and Goodmann (2003).

3.5.1) An overall decrease in socialisation

This theme clearly demonstrates the effects of underlying impairments and activity limitations on the area of participation. Each participant reported an overall decline in social participation since the onset of the aphasia. Reduced contact with friends was described by the participants, but in particular by those participants who were confined to wheelchairs and/or unable to drive. The participants attributed the loss of contact with friends to being largely homebound and not being able to converse successfully. The participants felt that their expressive language difficulties led to their friends feeling uncomfortable and thus placed strain on their relationships. These findings are in accordance with the literature. LaPointe (1999) documented that many people with aphasia and their significant others felt unwelcome to visit friends and family, were excluded from previously enjoyed activities, felt a lack of support and were ignored or abandoned by friends.

Lyon (2000) suggests that people with communicative impairments can resume their pre-stroke activities if the necessary modifications are made. He implies that the only change is in the person's level of ability to perform these activities. However, the current research found that certain participants ceased activities rather than performing them at a lower level. Perhaps this reluctance to resume prior activities was related to the increased amount of effort that was required, as well as feelings of inadequacy and low self-esteem.

3.5.2) The negative effect of communicative impairments on daily activities

As a result of their verbal deficits, no participant was willing to answer the phone at home and only two of the participants would use the telephone to communicate with other family members. This posed a challenge for those participants whose children live overseas. Compounding this issue is the fact that every participant reported difficulties with reading and writing. Consequently, email was not a viable alternative to the telephone for long-distance communication. In addition, three of the participants reported finding it difficult to read and understand the newspaper and thus watched TV in order to follow current affairs. These reading impairments affected three of the participants' involvement in their religious activities. All four participants also presented with decreased numeric abilities that negatively affected their independence. They were unable to make monetary transactions and were thus

excluded from activities such as shopping or being involved in the household finances. Once again, the participants' underlying communicative impairments, restricted their daily activities and thus compromised their ability to engage in their social environments.

3.5.3) Adjusting to altered roles within the family environment

Each participant expressed decreased self-esteem due to a reduced or absent ability to contribute to household finances and activities. In addition, they were limited in their abilities to help their spouses make decisions. For the two male participants who were no longer able to work, their role as the primary breadwinner was usurped and the effects of this reversal were stressful for both them and their wives. The importance of the spouse as a primary caregiver and source of social and emotional support was demonstrated by each participant. In addition, all participants and their families emphasised the importance of implementing a routine that assisted them to cope with the life changes induced by the stroke. Fisher and Sullivan (2001) support this theme of change and adjustment by stating that, after a stroke, daily activities such as looking after oneself, work and recreation are often irreversibly altered by the multitude of resultant impairments.

3.5.4) The role of physical impairments

This theme illustrates the pivotal impact of the first ICIDH defined level affected by the stroke i.e. bodily structure and function. The physical restrictions imposed by the stroke negatively affected the activity of walking in three of the four participants. Of these three, two were reliant on a wheelchair. Walking thus posed a major obstacle for these participants, as many social places (such as shopping centres and movies) are not wheelchair friendly or do not have accessible bathrooms. Furthermore, certain outings required extensive assistance from the participants' spouses, resulting in them being extremely effortful as well as time-consuming for both parties. Consequently, the participants were severely limited in terms of the social activities and environments in which they could engage outside of the home. Again it is illustrated how the levels of activity and participation constantly interact with each other and with the level of impairment (Larson et al, 2003).

3.5.5) The role of religion

The role of religious institutions and figures as forms of social and emotional support was emphasised by all the participants aside from RS. Furthermore, the religious context provided an opportunity for joint involvement of the person with aphasia and his/her spouse. Despite their impairments, the participants with aphasia maintained their connection with this specific area of social contact to a greater or lesser extent.

3.5.6) The value of support groups

Three of the four participants attended groups at least once per week that provided support as well as group treatment activities. They all reported these groups to be a valuable source of peer and professional support, information and socialisation. LaPointe (1997) supports the roles of the group context as described by the participants. He further explains that members of treatment/support groups learn to improve their self-monitoring skills in a natural communication environment (LaPointe, 1997). Simmons-Mackie (2000) therefore advocates group therapy as a vital component of the social approach as it provides a valuable environment for conversational intervention.

Table 3.5 Examples from themes that emerged across the adults with aphasia

THEMES ACROSS THE ADULTS WITH APHASIA	**EXAMPLE**
1. An overall decrease in socialisation	"Its lonely at home by myself".
2. The negative effect of communicative impairments on daily activities	"I can't count money, can't go to shop".
3. Adjusting to roles within the family environment	"used to fix things in house".
4. The role of physical impairments	"We love to travel but it will be difficult now". "Difficult to go out, no driving".
5. The role of religion	"They have been very nice to us during this time. It's comforting to know they are there and they think of us".
6.The value of support groups	"We all went through the same thing".

3.6) Themes that emerged across the spouses

3.6.1) The restructuring of their lives according to the needs of those with aphasia

Each spouse explained how he/she had reconstructed his/her life around the needs and care of the adult with aphasia. They expressed feelings of anxiety and guilt at leaving the person with aphasia alone at home, yet were frustrated by a reduction in the amount of personal time available to them. Three of the spouses used the time when the adult with aphasia was at a treatment/support group to run household errands, meet friends or merely to have time alone. Nevertheless, the spouses of those with aphasia actively reduced the amount of time spent on themselves and spent outside of the home.

This theme is supported by vast amounts of literature pertaining to the burden of care placed on the spouse of someone who has suffered a stroke, particularly a stroke resulting in aphasia. Christensen and Anderson (1989) found that a stroke with aphasia has a greater negative impact on the spouse than a stroke without aphasia. Also documented were the difficulties faced by the spouses of people with aphasia, including social, emotional and role changes. Such challenges were evident in the lives of those involved in the current study and were described particularly by the participants' spouses.

Through the discussion of this theme, it has been illustrated that the spouse, in addition to the person with aphasia, is at risk of becoming socially isolated. Grant, Weaver, Elliot, Bartolucci and Newman Giger (2004) therefore suggest that intervention is required for family caregivers in order to facilitate their social interactions and reduce their burden of care.

3.6.2) Burden of care

In each case, the person with aphasia's spouse was required to assume additional responsibilities with which he/she was unfamiliar. The wives of MB, CS and PM were required to take responsibility for all financial affairs and make important decisions alone. In addition, the spouses of MB and PM were presented with the burden of being the primary breadwinners. It is interesting to note that this issue of additional responsibilities applied to RS as well, despite the fact that the participant's

husband was already the primary breadwinner. RS-S found it stressful to have to assume household duties such as gardening. Once again, the burden and responsibility of being the person with aphasia's primary caregiver, was highlighted. This theme is supported by literature that describes the stress and emotional difficulty of adjusting to role changes within a family (Christensen and Anderson, 1989). In addition to the assumption of unfamiliar roles, it is frequently expected that the person with aphasia's family will compensate for his/her decreased social interaction. This pressure further increases the burden of care (Simmons-Mackie, 2000).

3.6.3) The value of support groups

This was a common theme between the participants with aphasia and their spouses. The spouses felt that the support groups were a positive context in which the people with aphasia could gain insight into their impairments, as well as professional input and general encouragement. They perceived it as healthy for the participants with aphasia to interact with others faced with similar challenges. In addition, the support groups provided time alone for the spouses. The support groups thus served a dual purpose by providing the adult with aphasia with meaningful activity and socialisation, while providing the spouses/caregivers with much-needed time. They were able to use this time to run errands, socialise with friends or have restful time alone.

Table 3.6. Examples from themes that emerged across the spouses

THEMES ACROSS THE SPOUSES	EXAMPLE
1. The restructuring of their lives according to the needs of those with aphasia	"I used to feel guilty about leaving her alone in case of something like a fall". "I take him there, then to the group…very busy".
2. Burden of care	"I had to take over the finances, insurance…can't have discussions".
3. Value of support groups	"I try to meet a friend for tea".

3.7) Individual differences that emerged across the adults with aphasia

3.7.1) Different attitudes towards the aphasia

Alaszewski, Alaszewski and Potter (2004) explain that a person's reaction to his/her perceived losses and impairments depends on his/her life context and everyday routine. Although, individuals post-stroke all attempt to make sense of what has happened and return normality to their lives, their strategies may differ (Alaszewski et al, 2004). Of the four participants, CS demonstrated a markedly different and more positive attitude. CS was able to use humour to deal with his speech-language impairments in a socially appropriate and effective manner. He had thus sustained more relationships than the other participants. Furthermore, CS used his honesty and humour to give himself the confidence to initiate conversations and form new relationships with the other members of his support group. He did explain, however, that he lacked confidence with unfamiliar people and limited his interactions to those with whom he felt comfortable. The fact that he was less impaired relative to the majority of the other group members, raised his self-esteem enough for him to assume a dominant role.

3.7.2) Different levels of independence

Again, the impact of this difference was illustrated by CS. CS was the only participant who was able to drive after his stroke, which allowed him to sustain better social participation. He was able to move with ease between work, his support group, his home, the gym and his cycling club. He did not have to rely on his wife, thus reducing their interdependence and indirectly reducing her burden of care.

Table 3.7 Examples from differences that emerged across the adults with aphasia

DIFFERENCES ACROSS THE ADULTS WITH APHASIA	**EXAMPLE**
1. Different attitudes towards the aphasia	"What else can we do?". "You have to laugh about it sometimes". "I'm worried".
2. Different levels of independence	"Difficult to go out, no driving".

3.8) Individual differences that emerged across the spouses

3.8.1) Differences in the perceptions of the life changes induced by the stroke and resultant aphasia of their spouses

According to Bauer and Kulke (2004), families have different approaches in adapting to aphasia, a variance that emerged clearly within the present research. PM-S was the only spouse to give positive feedback on the life changes that occurred since her husband's stroke. The other spouses did not give definitively negative feedback, but expressed a pragmatic attitude of having to tackle the altered situation and deal with it in the best way for them, their spouse with aphasia and their families. Nevertheless, the spouses of MB, CS and PM all expressed sadness at certain changes that had occurred within their marriages. In support of their perceptions, Christensen and Anderson (1989) suggested a distinctly negative impact of aphasia on the marriages of the participants within their study. In contrast, while PM-S expressed sadness and loss, she felt that PM's stroke had strengthened their marriage and brought them closer as a couple.

In terms of interaction style, CS-S also exuded an attitude different from those of the other spouses. She did not interrupt CS or speak on his behalf. She regarded him as an equal conversational partner under most circumstances and this attitude was also thought to contribute to CS's positive self-esteem and self-confidence.

Table 3.8 Examples from differences that emerged across the spouses

DIFFERENCES ACROSS THE SPOUSES	EXAMPLE
1. Differences in the perceptions of the life changes induced by the stroke and resultant aphasia of their spouses	"It happened, so it happened". "You just have to accept it, hope it will improve". "We love each other, its stronger now". "The grandchildren laugh and teach him new words, then he laughs…it makes a huge difference".

In summary, the content analysis provided a broad overview of the individual experiences of the participants and their spouses, as well as of the phenomena observed by the researcher. When comparing the multiple case studies and regarding the collective results, it became evident that the individual families involved shared many common experiences and opinions. The common themes generally originated from external factors on an activity level, such as public access for and acceptance of persons with impairments of any nature. Although all the themes represented changes that had occurred within the lives of the participants and their spouses, they did not all portray negative sentiments.

In particular, the themes pertaining to religious support and support groups illustrated certain positive sequalae. Religious involvement was maintained to a greater or lesser degree by all those participants to whom it was important, and they were able to participate in this environment together with their spouses. The support groups also served a dual positive role in providing the people with aphasia with an arena for information sharing and social interaction, while providing the spouses with time to spend alone, with friends or fulfilling household responsibilities. However, had the stroke not occurred, the need for support groups would not have arisen and the participants and their spouses would more than likely have continued their religious involvement. Therefore, although certain changes were regarded as positive, they were only perceived as such in light of the person's stroke and its resultant impairments.

The negative themes of a decrease in socialisation, problems with daily activities and adjustment to altered family roles all related to the communicative deficits experienced by the participants with aphasia. However, an additional negative theme stemmed from the physical impact of the stroke and drew attention to the effect of societal barriers, such as poor wheelchair access in public places.

The differences that arose among the participants with aphasia and their spouses originated mainly from personal factors such as attitude and character. Yet, despite individual variation, the single case studies concurred more than they diverged, thereby confirming previous research and existing theory discussed in chapter 1. The value of the themes, however, lies in the fact that they represent a person- and family-centred perspective and thereby build on the knowledge provided by the generic stroke scales utilised in pervious research within aphasia and social participation. Consequently, the data obtained from the current study has the potential to not only broaden the clinical perspective, but to contribute to the further development of social participation models and theories.

CHAPTER 4

DISCUSSION AND CONCLUSIONS

The four families who participated in this study were clearly changed by aphasia. The results were not unexpected because there is a large body of research that has demonstrated the effects of aphasia on psychosocial aspects of life. The main findings of the current study concur with previous reports of a decrease in socialisation, changes in daily activities and altered family function for both the participants with aphasia and their spouses. However, previous research has been conducted from a different perspective, using different methods. In this discussion of the results of the current study, the participants are discussed together, while relevant information pertaining to individual cases is included. Information obtained via the interviews and behaviours observed has been interpreted and incorporated with relevant literature. Current social models and approaches to intervention are reviewed, while professional role expansion and the needs of the South African context are also considered. Furthermore, the concept of resilience and implications for future research are discussed.

On completing the current study, an appraisal of the methodology was conducted. The protocol comprised the ASHA FACS, semi-structured interviews and observations, aiming to combine a quantitative outcome measure with qualitative person-centred measures. Although it was expected that the interviews and observations would provide the most authentic and valuable information, the FACS was included to triangulate the qualitative measures with a standardised adult assessment measure of functional communication. As discussed in chapter 3, the FACS lacked adequate sensitivity and did not contribute information additional to that obtained through the interviews and observations.

The use of semi-structured interviews and observations resulted in remarkable amounts of information and facilitated the gaining of a person- and family-centred perspective. The interviews were conducted successfully by combining the interview of the adult with aphasia with the interview of his/her spouse. In addition, the participants indicated that they were comfortable to discuss their life difficulties

related to aphasia with the researcher, as she was a Speech-Language Pathologist and was thus perceived as empathetic to their circumstances. The observations also produced valuable data and enriched the information obtained during the interviews. Although the observer effect is difficult to escape (Dingwall, 1997), it was fruitful to observe the participants within authentic life situations and a true reflection of communication skills and social performance was thought to have been obtained.

The social network diagrams provided a graphic representation of the results. By comparing the pre- and post-stroke diagrams, the manner in which the participants' social contacts had changed was clearly illustrated, while the components that had remained constant were highlighted. Overall, the participants underwent many similar changes in their social lives that were reflected in the social network analyses and in the content analysis. The content analysis through open coding produced common themes, as well as differences among the participants with aphasia and their spouses. It became evident that, no matter where in the world one lives, one's experiences of aphasia are universal.

An internationally pertinent issue that arose in the current research is the fact that the world is truly becoming a global community. Many families are divided across countries and continents, while technology facilitates easy and efficient means of long-term communication. That is, unless one has aphasia. Three of the four participants had children living overseas and were unable to successfully communicate via the telephone or via email. Evidently, the demands on communication are becoming more complex in the modern world and the exact developments that are meant to simplify life, pose great challenges for many people with communicative impairments.

Despite many commonalities, however, individual variation was present among the case studies and certain interesting issues arose. Avlund et al (1999) caution that social participation may not be desirable for those who find it problematic or stressful. A low level of participation may thus be voluntary, and not an impairment, in certain individuals. This point is particularly relevant in the case of RS. Prior to the aphasia, she did not engage extensively in social activities outside of her home and she interacted primarily with her family and two close friends. It cannot therefore be expected for her to enjoy socialising with the added complication of a communicative disorder.

Moreover, RS had suffered her stroke the most recently of the four participants, with the length of time post-stroke among the participants ranging from 8 months to 30 months. At the time of the research RS was receiving speech therapy, occupational therapy and physiotherapy at her home numerous times per week. These treatments consumed much of her energy and time. Although, RS was not a particularly socially active or involved person prior to the stroke, her situation at the time of the research did not facilitate the initiation of new activities or the maintenance of prior activities.

Further individual deviations occurred as a result of other variables not accounted for in the present research. One such factor was gender and the case studies consisted of 3 males and 1 female. As the only female participant, RS's identity had been based on her abilities to run her home, cook, care for her family and tend to her garden. Therefore, the biggest life changes stemmed from her role as homemaker. In the case of RS, her family system was her primary context for social interaction and thus the environment in which she shaped her societal role. Consequently, her reduced ability to fulfil the role of homemaker, negatively impacted on her self-esteem and sense of purpose as described by Code et al (1999) and Parr et al (1998). These feelings of inadequacy caused RS to feel depressed. Code et al (1999) explained that the type and severity of the depression is strongly linked to the value and emphasis the person places on language and communication within their familial and societal roles. RS clearly constructed her positive sense of self according to her role within her family.

In the cases of the male participants, the effects of changes in gender roles were strongly conveyed during the interviews and contributed to themes such as altered family roles and burden of care. As MB and PM could no longer work, they experienced self-esteem issues, while MB-S and PM-S experienced significantly increased responsibilities.

Siminski (2003) states that socially-determined norms of participation exist that differ according to the person's life phase. The extraneous factor of age did not appear to have a direct effect on the social participation of the participants, but did impact slightly on the structure of their social support systems. As variability was permitted across the single case studies, the participants ranged in age from 52 to 78 years of age. As the oldest participants, MB and CS no longer had children living at home and had grandchildren who extended their family systems. RS and PM, however, still had children living at home. This provided additional support for the participant with aphasia, as well as his/her spouse. MB and CS's children were able to provide support, but not continuously and not always within the immediate home environment. Therefore, the support provided by children living in the home, was more constant and was perceived as very valuable.

Further differences were related to the level of severity of the participants' aphasia. No formalised aphasia test was implemented to establish the exact severity of their Broca's aphasia. The level of severity of the aphasia was controlled for on either extreme of the scale by excluding those people not presenting with any difficulties as well as those people with global aphasia or a critical state of health. CS presented with the least severe impairments across the four participants and was the only one of the participants to have returned to work after the stroke. However, Hinckley (2002) states that the severity of the aphasia does not necessarily predict life participation. Furthermore, she suggests that return to work and successful community reintegration can be achieved regardless of the extent of the communication impairment. The present study cannot confirm or question Hinckley's theory. The qualitative case study design allows for trends and disparities to be deduced and provides no predictive basis.

An additional difference possibly related to the severity of the aphasia was the level of confidence and self-esteem of the participants. CS was more self-assured within individual and group interactions and was less anxious to speak in front of others. However, it is difficult to separate the effects of personality and attitude, from the effects of the severity of the aphasia. It is therefore not possible to draw direct inferences based on CS's behaviour.

The final extraneous variable not accounted for was the participants' levels of education, as it was felt that variation would enrich the data collected. Each of the four participants had completed school and MB and PM had received university degrees. The level of education of the participants played no noticeable role in the results of the study.

Despite reduced control of inclusionary criteria, and the resultant variability across the case studies, the overall results of the current research echo those of previous studies. One such example is the Framingham Study, which found stroke survivors to socialise less, have fewer hobbies and interests, be less able to use public transport, be less able to complete household tasks and be less likely to be involved in vocational pursuits (date not provided, cited in LaPointe, 1999). Furthermore, many people with aphasia and their significant others have reported feeling unwelcome to visit friends and family, being excluded from previously enjoyed activities, feeling a lack of support and being ignored or abandoned by friends (LaPointe, 1999). These perceptions are evidently shared by the people with aphasia and their spouses involved in the current study.

Moreover, the present research demonstrated the pervasiveness of the sequalae of aphasia. Lubinski (2001) said that, although the individual who experienced the stroke is the most affected, all those who try to communicate with the person with aphasia will be faced with difficulties. The truth of this statement has been confirmed by the experiences of all four participants with aphasia and their spouses.

The results of the present research further confirmed previous research by demonstrating the negative impact of communicative impairments on social participation and therefore on overall quality of life. Social relationships and participation were found by Worrall and Holland (2003) to be strongly related to quality of life, together with functional communication, emotional distress, involvement in activities and environmental aspects. In addition, one of the primary findings of Carod-Artal, Egido, Gonzalez and Seijas (2000), was that although patients were independent in activities of daily living, they were not functioning at the level they enjoyed prior to the stroke. This consequently resulted in a perception of diminished quality of life. Most of the participants in the current research were independent in their activities of daily living, with the least independent participant requiring minimal assistance. Nevertheless, each participant reported changes in his/her social participation, and as a result, in his/her perceived quality of life.

Although previous research has shown social participation to be a major problem, it has generated insufficient information from the client and family. In addition, no observations by professionals were included. Distinguishing the current research from other works in the field is the fact that the methodology was triangulated to generate a great amount of qualitative, person and family-centred data. Although interviews and observations carry the inherent dangers of researcher bias, triangulation was implemented in the data collection and a second rater analysed the data generated by each component of the protocol in order to combat these known risks. Furthermore, all elements of the protocol can be applied in a clinical capacity for assessment purposes or for monitoring and measuring changes related to intervention.

Much previous research has therefore neglected to portray the person with aphasia within the family unit and consider his/her social participation from an ecological perspective. Many models exist that represent the isolated constructs of communication, quality of life and family systems, yet a unified model has not yet been developed that integrates these inextricable concepts. Although some researchers are attempting such developments, there remains a clear need for models and assessment and intervention frameworks that consider the person's life factors.

The ICIDH-2 is formally recognising the psychosocial consequences of living with a disability by including cognitive and communicative impairments as influential factors regarding restrictions on the levels of activity and participation (Hinckley and Packard, 2001). The participation dimension of the ICIDH-2 classification is concerned with social issues and is highly dependent on the interaction between the person and the environment or context (Worrall, 2000). The level of activity involves the person's ability to initiate a social contact, whereas participation involves the person's participation in friendships and other interpersonal relationships (Worrall, 2000).

Cruice et al (2003) proposed a model that views the ICIDH-2 levels specifically in relation to communication. Their model evaluates impairment, activity, participation and quality of life as separate components, representing communication within quality of life and psychosocial well-being for people with aphasia. Quality of life is viewed as comprising a social component and was evaluated in terms of its association with emotional health, language, vision and hearing impairments, communicative ability and activity, social network relationships and social activities. Communication comprised language impairment, functional communication ability and activity and social participation (Cruice et al, 2003).

Although the social dimension is considered by Cruice et al's (2003) model, it is embedded within the constructs of quality of life and communication. It is thus proposed by the researcher that social participation be defined as an independent entity as opposed to being entrenched in other constructs. Stemming from that definition, the links between social participation and other areas and levels of functioning can be described. Therefore, perhaps novel models should comprise intertwined links of equal value, instead of hierarchical levels with sublevels and subcomponents.

Whichever model is adopted, clinicians need to ensure that therapy is meaningful and is making a notable difference to the client. Fratalli (1997, cited in Simmons-Mackie, 2000) suggests that intervention be judged against two criteria. The first criterion is the improvement of the person's capacity to engage in activities that reflect physical, psychological and social well-being. The second criterion is the satisfaction of the client with the outcomes and his/her level of functioning. These criteria are in accordance with the World Health Organisation, who state that the ultimate outcomes of rehabilitation are related to the person's level of life participation, such as perceived life satisfaction, a return to employment and integration into the community (Hinckley, 2002). Similarly, Fritz and Penn (1992) state that a patient's socialisation is a measure of therapeutic success, while Chong (1995) feels that one of the primary aims of rehabilitation is to return patients to their chosen environment.

It is therefore clear that the reintegration into his/her society of the person with aphasia, should be a key long-term aim of intervention. Clinicians should carefully consider the links between treatment and the goals of rehabilitation (Simmons-Mackie, 2001) and adopt an approach that targets psychosocial well-being and communication simultaneously (Simmons-Mackie 1998, cited in LaPointe, 1999). One such approach is the social approach supported by the present research.

The social model is consciously inclusive of the person's immediate and broader contexts and thus adopts an ecological perspective. This model regards disability as resulting from the failure of the person with aphasia's social and physical environment to account for his/her needs, as opposed to resulting from the patient's functional limitations (Pound et al, 2002). Thus, therapeutic objectives linked to this model include the identification and breaking down of barriers to the person's social participation. In addition, intervention attempts to expand and enhance the person's participation in society (Ross and Wertz, 2003).

In the search for new models and therapy frameworks, the strengths and weaknesses of traditional forms of intervention need to be understood. Lyon (2000) reviewed studies completed by Simmons (1993) and Simmons-Mackie and Damico (1997) and concluded that clinically trained communication strategies were not being carried-over into authentic situations. He subsequently suggested that clinicians expand their focus and include other variables in treatment, while basing it in meaningful contexts, if they hope to induce lasting change.

In addition, Lafond et al (1993) explain how many health care professionals understand the threat of social isolation due to communication difficulties and thus ensure that such experiences do not occur during therapy. Consequently, they are not preparing the person with aphasia for the reality of independent functioning. A supportive and un-invasive therapeutic environment is unrealistic and is not reflective of the patient's authentic socialisation contexts.

All the participants limited the number and type of their conversational partners. The social models thus have a role in supporting and facilitating communication with real-life partners. Simmons-Mackie (2000) explains that the person with aphasia's social network can be expanded by identifying people with whom ongoing relationships can be established and cultivated. Conversational training for these specific people allows pre-selected partners to provide sufficient support and thus facilitate successful interactions (Simmons-Mackie, 2000). The network analyses within the current research illustrated clear changes and reductions in contact that had a negative impact on the participants' social participation. Consequently, an intervention technique such as conversational training may have been effective in countering both the restrictions induced by the aphasia and those actively implemented by the participants.

However, therapy cannot be restricted to a structured one-to-one situation. It may not necessarily be sufficient to bring in other communication partners for training. The clinician needs to step into the client's environment in order to complete holistic and reintegrative rehabilitation. The social model does not, however, suggest that impairment-based therapy be eliminated. It rather proposes that traditional intervention be expanded to incorporate the person's communication and social goals. Therefore, by placing importance on social and psychological recovery, in addition to

linguistic recovery, therapists may be able to better improve the person with aphasia's quality of life (Simmons-Mackie, 2000).

The present research points to the validity of a shift in approach from the traditional aphasia therapy in which communication partners are brought into therapy to train them in methods of communicating with people with aphasia. The strength of the methodology employed lies in the results that encourage the clinician to step into the client's environment.

An intervention programme embedded in the social model is the Life Participation Approach to Aphasia (Chapey et al, 2001). The LPPA aims to enable the person to live successfully and satisfyingly with the aphasia. In order to achieve this goal, the LPAA's objectives include the enhancement of natural communication, the increasing of successful participation in natural events, the provision of support systems within the person's community, the increasing of communicative confidence and a positive self-image, and the promotion of advocacy and social action (Simmons-Mackie, 2001). Therefore, this approach begins by targeting the level of impairment on a one-to-one basis and expands upwards through the ICIDH-2 levels, while expanding outwards into the person's ecological contexts such as family and community.

The social approach ultimately aims to include people with aphasia in communicating societies by making adaptations, not only involving the person with aphasia, but also his/her society. Byng et al (in press, cited in Pound et al, 2002) developed six interconnected goals for aphasia, one of these being the identification and dismantling of internal and external barriers to social participation. A broad perspective must be adopted, as the needs of the person with aphasia will differ according to his/her context (Simmons-Mackie, 2001). However, one cannot aim to dismantle barriers from a distance. Rather, one needs to get involved and 'get one's hands dirty'. The observational component of the current research's methodology allowed the researcher to move into every-day, naturalistic environments with the participants, thus initiating the identification of internal and external social barriers as described by Byng et al (in press, cited in Pound et al, 2002). Such observations may thus prove valuable in propelling intervention out of the traditional therapy setting and into the client's ecology.

If a social approach is to be adopted in its entirety, clinicians need to advocate for social changes to occur. One arena for such changes is the creation and provision of community resources and services. In addition, a range of activities should be available from which the person with aphasia can select the most personally suitable (Simmons-Mackie, 2000). The choice could include individual therapy, group therapy, supported conversation, recreational activities, counselling, self-help groups, work training and advocacy groups (Elman 1998, cited in Simmons-Mackie, 2000). Thus, there is a clear need for the professional role of the Speech-Language Pathologist to be expanded beyond the traditional boundaries (Simmons-Mackie, 2000). In addition, there is a definite calling for other professionals to be involved in the social aspects of rehabilitation of people with aphasia.

Hirsch and Holland (2000) emphasise that all those involved in rehabilitation, should be concerned about the extent to which their patients can resume their participation in society. Specifically in individuals with communications impairments, reintegration into a social context is the greatest obstacle. Perhaps a model of intervention such as the LPPA could be adopted by a range of rehabilitation professionals in order to expand on the traditional view of post-stroke rehabilitation. Although traditional therapy has its merits, professionals should be raising their social awareness and becoming cognisant of the long-term, real-life needs of their clients. Thus, it is through constant learning from other professionals, as well as from the clients and their families, that all professionals will be able to work within a holistic framework to improve life satisfaction post-stroke.

An implication of the current research project is therefore the possibility for an exploration of the roles of all professionals involved in post-stroke rehabilitation. Social participation encompasses such a broad range of skills and contextual factors that it may be difficult to define precisely whose responsibility it is within the professional team. Consequently, perhaps professional roles should be expanded and their boundaries should be more flexible when the time arrives to reintegrate the person into their home, family and society. Ultimately each member of the family unit, not the person with aphasia alone, requires intervention and support.

It has therefore been illustrated that aphasia affects the lives of many people, both directly and indirectly. There is a need to extend clinical practice to account for social changes and to therefore include a social worker in the management of aphasia. Programmes such as Living with Aphasia use social workers to intervene with the person with aphasia's primary caregiver (e.g. the spouse), while the Speech-Language Pathologist works with the person with aphasia. This intervention protocol aims to assess not only communication within the home, but also within other social systems engaged in by the person on a daily basis (Lyon, 2000).

The overall objective of Living with Aphasia is not to restore life to the situation that existed prior to the stroke, but to alter the daily routine of the person with aphasia and his/her spouse so that it is comfortable and purposeful, with both parties assuming certain responsibilities. It is also hoped that the person with aphasia will be able to enjoy meaningful communication and participate in activities of his/her choice outside of the home (Lyon, 2000). The participants involved in the present research all expressed feeling limited in terms of their activities outside of the home. It appeared as though they could not choose desirable activities, but rather had to let the appropriate or manageable activities choose them. The present research involved four families from various South African ecologies, yet the outcomes showed marked similarities in their experiences. Despite the obvious need for socially embedded assessment and intervention, there are few, if any, social programmes such as the LPPA and Living with Aphasia, in place within the South African context.

The current study points to a need in South African aphasiology practice that is not necessarily being fulfilled. Thus, perhaps the positive qualities of the social models and programmes could be emulated and adapted for application within the South African context. Although a social approach may be adopted by individual clinicians, programmes are required that extend to a community level, engaging society as a whole. In addition, an extension of the rehabilitation team is required. In South Africa, where the needs outweigh the resources, role expansion and role sharing may facilitate broader service provision and hence greater social reintegration. Finally, the activation of a greater number of community services, such as the support groups attended by three of the participants, would allow intervention to reach further without becoming too sparse.

Clearly the potential exists for the generation of more positive and proactive social interventions. However, despite extensive research into the negative life changes induced by aphasia, there is little study on the positive factors that protect individuals from the effects of aphasia. In addition to all those people who suffered extensive impairments, it is likely that there are many adults with aphasia who have not endured the same psychosocial difficulties or have possessed the resilience to overcome them. Shouldn't we then be questioning what protective factors exist and how we can learn from those who have overcome aphasia to lead personally meaningful and successful lives?

Within the current research, CS demonstrated certain personality traits and attitudes that allowed him to be the most socially successful of the four participants. He approached his difficulties with humour and portrayed himself as a naturally confident person. In addition, he viewed life positively and made appropriate adaptations to his social networks without placing extensive limits on his participation. Thus, perhaps it is this form of a balance that is needed – acknowledging and compensating for one's weak areas, while capitalising on one's strengths. Yet, in addition to individual factors, CS received extensive social support in many areas of his daily life, including his occupation, his friends, his religious environment and his family environment. CS-S acknowledged CS as an able communicator and portrayed an attitude of acceptance. Furthermore, CS was a member of a support group in which he felt comfortable and confident. He therefore also achieved a balance in terms of relying on existing supports such as his wife and religion, while actively sourcing additional community services such as his support group.

In contrast to CS, MB was evidently uncomfortable with his communication deficits. Moreover, it appeared as if MB-S felt more affected by the stigma of the stroke and the aphasia than MB. She appeared to construct their lives so as to limit the need for MB to communicate. Although this may have seemed like an effective coping strategy to MB-S, it further limited MB's opportunities for social interaction and possibly contributed to his withdrawn nature. Although accepting aphasia and its ramifications is evidently difficult, Parr et al (1998) feel that a person needs to learn to live with aphasia, instead of feeling ashamed or making excuses for themselves. In

MB's case, both he and his wife were experiencing difficulty striking the balance between controlling for MB's deficits, while still welcoming opportunities for interaction and social participation. As a unit they were therefore not displaying resilience, despite having a similar family and religious environment to CS.

In terms of the other two participants, PM also capitalised on certain positive factors, such as a strong religious base and a secure and supportive family environment. PM-S displayed a similar attitude of acceptance to CS-S and exuded a great amount of love for her husband in spite of his difficulties. In the case of RS, the family unit was relatively small and religion was not an important factor within their lives. These factors limited the social support available to them and, at the time of the research, they were not making use of community-based services such as support groups.

Therefore, within this current research, factors emerged that appeared to contribute to the resilience of certain participants and allowed them to more successfully overcome particular consequences of the aphasia. However, far more research is evidently required into factors that allow people with aphasia to overcome their difficulties at each ecological level, until ultimately they have re-immersed themselves in their societies. Although such factors are most likely of a very personal nature, perhaps certain common characteristics and/or tactics will be identified that could increase our clinical understanding of how to achieve our clients' long-term life goals.

Siminski (2003) states that observed patterns of disability are inconsistent with the medical model, as it does not account for social factors. As a result, the social model of rehabilitation has been receiving increased attention. The greatest pressure for an increased focus on the social model of intervention stems not from professionals, however, but from those with aphasia and their families (Parr et al 1997, cited in Simmons-Mackie, 2000). People with aphasia and their families are still reporting experiences of social discrimination, social isolation, exclusion from vocational, educational and leisure activities, and limited community supports and benefits. Clearly their needs are not being fully met (Parr et al 1997, cited in Simmons-Mackie, 2000).

Aphasia changes lives. The human need for and tendency towards social participation is not unique to a particular context or nationality. Although the nature and style of social participation may be influenced by one's culture and environment, it appears to be a valuable aspect of universal daily life. It is undeniable that aphasia impacts heavily on a person's social activities and involvement within his/her family and community. Although the role of ecology is gaining attention, much persistence, advocacy and the refinement of an acute social awareness are required to complete the paradigm shift from a medical to a social approach. Moreover, within the social approach, additional definitions and models are required that embody the construct of social participation.

Parr et al (1998, p.134) stated: "Language is what makes the world as it is". However, those persons with language impairments such as aphasia should suffer no further discrimination. They are equal members of this world and should be provided with every viable assistance and opportunity to regain their positions within society. Nevertheless, an intricate relationship exists between communication and socialisation. As Speech-Language Pathologists, we therefore need to assume an active role in the development and use of innovative definitions and models of social participation. Furthermore, we need to contribute to the expansion of professional roles and the diversification of the rehabilitation team. Perhaps then we will be one step closer to truly meeting the needs of those with aphasia and their families.

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