

**RATING THE ICF DOMAINS FOR REHABILITATION FOR ADULTS WITH
APHASIA: COMPARING THREE PERSPECTIVES**

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ABSTRACT

Aphasia has an impact on people's ability to communicate effectively and may therefore affect participation in all aspects of life. The International Classification of Functioning, Disability and Health (ICF) provides a holistic view of the functioning of a person with disabilities in context, since it allows for a description not only of the impairment at the level of body structures and functioning, but also of the way a person takes part in activities of daily life and participates in various areas. The domains of activities and participation have been suggested to be useful starting points for identifying rehabilitation priorities. This quantitative descriptive study aimed to describe and compare the perspectives of adults with aphasia, their significant others and their speech-language pathologists (SLPs) regarding the importance of the 9 ICF activities and participation domains for the rehabilitation of the adult with aphasia. A total of 15 adults with aphasia, 15 respective significant others and 15 SLPs were asked to rate the importance of these domains of the ICF for the rehabilitation of the adult with aphasia on a 3-point scale. The Talking MatsTM framework was used as a visual communication support to facilitate the participation of the adults with aphasia. Results indicated that many of the ICF domains were regarded as important by adults with aphasia, their significant others and SLPs. The domain *Communication* received the most positive ratings in terms of importance. Adults with aphasia rated domains important to work on in rehabilitation more frequently than significant others and SLPs. Statistically significant differences were only noted for 3 of the 9 domains: *Work and Education*, *Leisure* and *Self Care*. The findings of this study suggest that various team members (including the adult with aphasia) view the ICF activities and participation domains as important for rehabilitation. Furthermore, Talking MatsTM can be used as a clinical tool to allow adults with aphasia to identify the ICF domains which they would regard as important to work on in rehabilitation; their priorities can be compared to those of other team members.

OPSOMMING

Afasie het 'n impak op mense se vermoë om effektief te kommunikeer en kan daarom deelname aan alle aspekte van die lewe beïnvloed. Die *International Classification of Functioning, Disability and Health (ICF)* verskaf 'n holistiese raamwerk van die funksionering van 'n persoon met gestremdheid in konteks, aangesien dit 'n beskrywing toelaat, nie net van die gebrek op die vlak van liggaamstruktuur en funksionering nie, maar ook van die manier waarop die persoon deelneem aan aktiwiteite van daaglikse lewe en in verskillende areas. Die aktiwiteite en deelname-domein is voorgestel as nuttige vertrekpunte vir die identifisering van om rehabilitasieprioriteite. Hierdie kwantitatiewe beskrywende studie het gepoog om die perspektief van volwassenes met afasie, hul betekenisvolle ander en hul spraak-taal patoloë (STPë) te beskryf en te vergelyk aangaande die belangrikheid van die 9 *ICF* aktiwiteite en deelname-areas vir die rehabilitasie van die volwassene met afasie. 'n Totaal van 15 volwassenes met afasie, 15 betekenisvolle ander en 15 STPë is gevra om die belangrikheid van die aktiwiteite en deelname areas van die *ICF* vir die rehabilitasie van die volwassene met afasie op 'n 3-punt skaal te evalueer. Die *Talking Mats*TM raamwerk is gebruik as 'n visuele kommunikasiesteunmiddel om die deelname van die volwassene met afasie te fasiliteer. Resultate dui aan dat baie van die *ICF* areas as belangrik beskou is deur die volwassene met afasie, hul betekenisvolle ander en STPë. Die area *Kommunikasie* het die mees positiewe beoordeling in terme van belangrikheid ontvang. Volwassenes met afasie het areas meer dikwels as belangrik om in rehabilitasie aan te werk beoordeel as betekenisvolle ander en STPë. Statisties beduidende verskille is net vir 3 van die 9 areas waargeneem: *Werk en Opleiding*, *Vrye Tyd* en *Selfversorging*. Die bevindinge van hierdie studie dui aan dat verskillende spanlede (insluitend die volwassene met afasie) die *ICF* aktiwiteite en deelname areas as belangrik beskou vir rehabilitasie. Verder kan *Talking Mats*TM as 'n kliniese hulpmiddel gebruik word om volwassenes met afasie toe te laat om *ICF* areas wat hulle as belangrik beskou om in rehabilitasie aan te werk te identifiseer, en hulle prioriteite kan met dié van ander spanlede vergelyk word.

TABLE OF CONTENTS

	Page
CHAPTER 1: Introduction and problem statement	1
1.1 Introduction	1
1.2 Problem statement	1
1.3 Terminology	4
1.4 Abbreviations	5
1.5 Outline of chapters	6
1.6 Summary	6
CHAPTER 2: Literature review	8
2.1 Introduction	8
2.2 The ICF framework	8
2.3 Aphasia rehabilitation and the ICF	11
2.4 Talking mats™ for adults with aphasia	20
2.5 Summary	21
CHAPTER 3: Methodology	22
3.1 Introduction	22
3.2 Aims	22
3.3 Research design	23
3.4 Stages of the study	23
3.5 Pilot study	24
3.6 Participants	30
3.7 Materials and equipment	39
3.8 Procedures	42
3.9 Summary	50
CHAPTER 4: Results and discussion	51
4.1 Introduction	51

4.2	Ratings by adults with aphasia	52
4.3	Ratings by significant others	59
4.4	Ratings by SLPs	63
4.5	Comparing the ratings of the domains	68
4.6	Summary	73
	CHAPTER 5: Summary and conclusions	74
5.1	Introduction	74
5.2	Summary	74
5.3	Critical evaluation of the study	75
5.4	Clinical implications	76
5.5	Recommendations for future research	77
5.6	Summary	78
	References	79
	Appendices	90

List of tables

Table 2.1	Studies with ICF and aphasia	16
Table 3.5	Pilot study	26
Table 3.6	Selection criteria for adults with aphasia	31
Table 3.7	Selection criteria of significant others	34
Table 3.8	Selection criteria of SLPs	34
Table 3.9	Descriptive criteria of adults with aphasia	36
Table 3.10	Descriptive criteria of significant others	37
Table 3.11	Descriptive criteria of SLPs	38
Table 3.12	Study aims and type of analysis conducted	47
Tale 4.1	Percentages of ratings and p-values across the domains	68

List of Figures

Figure 2.1	ICF framework	9
Figure 3.1	Stages of the study	24
Figure 4.1	Ratings of the adults with aphasia	52
Figure 4.2	Ratings of the significant others	59
Figure 4.3	Ratings of the SLPs	63

List of Appendices

Appendix A	Script of first meeting	91
Appendix B	Second information letter and consent form for adults with aphasia	93
Appendix C	Second information letter and consent form for significant others	98
Appendix D	Second information letter and consent form for SLPs	102
Appendix E	Observer form	104
Appendix F	SLP brief	105
Appendix G	Ethics approval letter	106
Appendix H	Request to practice owners to recruit participants	107
Appendix I	Initial information letter	111
Appendix J	Biographical questionnaires for adults with aphasia	113
Appendix K	Biographical questionnaires for significant others	116
Appendix L	Biographical questionnaires for SLPs	119
Appendix M	Screening task	121
Appendix N	Yes, Maybe, No Talking Mats™ rating scale	122
Appendix O	ICF domains depicted in PCS symbols	123
Appendix P	Identifying domains rating scales for significant others and SLPs	124
Appendix Q	Domain descriptions	127
Appendix R	Script for Talking Mats™	128
Appendix S	Procedural integrity checklists	129

CHAPTER 1

Introduction and problem statement

1.1 Introduction

This chapter provides an orientation to the study. The problem statement is discussed, outlining the rationale for the study. A chapter outline is provided, as well as a discussion of the terminology and abbreviations used in the study.

1.2 Problem statement

Aphasia is a condition that results from a stroke and affects a person's participation in daily activities and social interactions (Simmons-Mackie & Kagan, 2007; Worrall, McCooey, Davidson, Larkins, & Hickson, 2001). Adults with expressive aphasia may present with reduced or limited verbal output and word retrieval difficulties and therefore experience difficulty in communicating their basic daily needs and engaging in higher-level conversational tasks (Lasker, Hux, Garrett, Moncrief, & Eischeid, 1997). These adults require strategies and support to assist them to participate in daily tasks and social interactions competently.

Speech-language pathologists (SLPs) are the rehabilitation professionals who have expertise in the field of communication difficulties (Finch et al., 2013; Brown, Worrall, Davidson & Howe, 2011) and they may guide and assist the process of selecting and implementing appropriate communication modes for adults with aphasia (Wallace & Purdy, 2013). Communication rehabilitation for adults with aphasia has traditionally focussed on the retraining of skills such as word retrieval and grammar (Simmons-Mackie & Kagan, 2007). However, with the paradigm shift from a medical to a social conceptualization of disability, the importance of functional goals, compensatory strategies and partner and environmental adaptations has increasingly been recognised (Johansson, Carlsson, Ostberg & Sonnander, 2012; Simmons-Mackie & Kagan, 2007; Rautakoski, Korpijaakko-Huuhka, & Klippi, 2008). The importance of focussing on communication functioning in natural contexts has increasingly been recognized (Garrett & Lasker, 2005; Hux, Manasse, Weiss & Beukelman, 2001; van de Sandt-Koenderman, 2008) and SLPs have been encouraged to understand the social environments of adults with aphasia and the way in which they are able

to participate in these environments. Functional goals tend to be targeted specifically once the period of spontaneous neural recovery has passed (six months or more post-stroke) (Allen, Mehta, McClure, & Teasell; 2012; Cherney & Robey; 2001; Howe, Worrall, & Hickson, 2004; Worrall et al., 2011).

This shift to functional goals has necessitated adjustments in rehabilitation service delivery to adults with aphasia and their families. In order to truly achieve positive change in functional situations, persons with aphasia as well as their families and/or significant others need to be actively involved in the rehabilitation process. In this way, adults with aphasia and their significant others may identify problem areas in the home and social environments that could be targeted for improvement in rehabilitation. However, it is often found that, within the rehabilitation setting, rehabilitation professionals focus on discipline-specific priorities which they may feel are necessary for the individual and may not align priorities or goals to assist individuals in the home or other environments (Hersh et al., 2012; Sherratt, et al., 2011; Worrall et al., 2011). It is necessary to establish joint rehabilitation priorities to ensure that all members of a rehabilitation team are working towards the same outcome (Harty, Griesel & van der Merwe, 2011; Simmons-Mackie & Kagan, 2007).

The International Classification of Functioning Disability and Health (ICF) (World Health Organisation [WHO], 2001) is a framework that has been used to approach the assessment and management of disorders and disabilities, including stroke and aphasia. The ICF provides a format to view the participation of adults with aphasia in their daily life areas (Simmons-Mackie & Kagan, 2007; WHO, 2007). The nine activities and participation domains of the ICF framework offer a platform for SLPs and other rehabilitation professionals to assist adults with aphasia in their daily activities and interactions (Simmons-Mackie & Kagan, 2007). The activity and participation domains of the ICF include *Learning and Thinking, Coping, Communication, Mobility, Domestic Life, Work and Education, Relationships, Leisure/spare time* and *Self Care* (World Health Organization [WHO], 2001; Murphy & Boa, 2012). These nine domains consider interaction and participation in daily life activities and therefore the overall functioning and independence of the individual. These domains may address the functional activities that adults with aphasia have difficulty in managing and therefore may provide a point of departure for identifying problem areas, because team members are able to indicate which of the domains present concerns that need

to be addressed in rehabilitation (Bornman and Murphy, 2006; Harty et al., 2011; Worrall et al., 2011).

Including adults with aphasia as active partners in their rehabilitation programme presents certain challenges. Often such adults have very little control over their own lives and activities are often decided for them by others (rehabilitation professionals and/or family members), since the individuals themselves have difficulty expressing their needs. These individuals may not be provided with the choice or freedom to participate in identification of rehabilitation priorities or goal setting (Hersh et al., 2012; Worrall et al., 2011). Communication modes and frameworks need to assist these individuals in various communicative situations and environments, including identification of their needs, which ultimately may lead to selecting priorities for rehabilitation. Because it is difficult for clients to be involved in problem identification when they present with expressive language difficulties, alternative communication modes can be used to assist individuals to communicate and share their needs (Garrett, Beukelman & Low-Morrow, 1989; Johnson, Hough, King, Vos, & Jeffs, 2008; Leach, Cornwell, Fleming, & Haines, 2010; Murphy & Boa, 2012).

The Talking Mats™ visual format is an example of a low-tech framework that has assisted people in communicating their needs (Murphy, Tester, Hubbard, Downs, & MacDonald; 2005; Murphy & Boa, 2012). This framework consists of line drawings with written words that people can identify, select and use to make choices or indicate needs (Bornman & Murphy, 2006; Murphy, 2000). The Talking Mats™ interview allows adults with aphasia to identify and select needs, concerns and preferences (Beringer, Tönsing & Bornman, 2012; Murphy & Boa, 2012). Talking Mats™ has been used successfully in conjunction with the activity and participation domains of the ICF to allow adults with aphasia and other long-term communication difficulties to participate in goal setting. A study conducted by Murphy and Boa (2012) described how people with long term communication difficulties were actively able to participate in goal setting using an adapted version of the ICF within the Talking Mats™ framework. Individuals were able to indicate whether they were ‘managing’ an activity or task within this supportive framework. This framework consists of cards with line drawings and written words that can be used as a reference point for adults with aphasia to identify rehabilitation priorities.

This research study will determine the ICF domains (related to activities and participation) rated as important by adults with aphasia for their rehabilitation, using the Talking MatsTM framework. It will also determine the domains rated as important for them by their significant others and SLPs and compare these ratings across these three perspectives. Since a functional and compensatory approach to rehabilitation becomes especially important after the period of spontaneous neural recovery has passed (six months or more post-stroke), the study will specifically focus on adults in the chronic stage of aphasia.

1.3 Terminology

The following terms are frequently used in the study. The way these terms are defined for the purposes of this study is therefore clarified below.

1.3.1 Augmentative and alternative communication

Augmentative and alternative communication refers to the communication modes and strategies used to enhance the participation of adults with aphasia in communicative settings, particularly when natural speech is not effective or possible (Hux et al., 2001).

1.3.2 Aphasia

Aphasia is a language disorder resulting from damage to the left temporal-frontal areas of the brain (Davis, 2007; Cruice, Hirsch, Worrall, Holland, & Hickson, 2000). It is the disturbance of comprehension or expression of language (Schoeman & Van der Merwe, (2010). Expressive aphasia refers to the impairment of language expression, resulting in difficulty verbalising needs or communicating using natural speech (Hux et al., 2001). Receptive aphasia refers to the impairment of language comprehension, resulting in difficulty to understand auditory information (Hux et al., 2001).

1.3.3 International Classification of Functioning, Disability and Health (ICF)

The ICF is a framework developed by WHO (2001) to assess and manage diseases and disorders. The ICF provides a standardised language and framework for health and health-related domains.

1.3.4 Significant other

For the purpose of this study, ‘significant other’ refers to a family member or close friend of the adult with aphasia. This person had to be someone who knew the adult with aphasia well and who had some input in the rehabilitation process.

1.3.5 Speech-language pathologist

Speech-language pathologists assess, manage and remediate speech, language and swallowing disorders. They offer expertise and knowledge in communication difficulties and assisting people with the most appropriate and effective modes in which to communicate in various social settings to maximise quality of life (ASHA, 2007).

1.3.6 Talking Mats™

Talking Mats™ is a framework developed to assist people with communication difficulties to identify and indicate needs, concerns or rehabilitation goals (Murphy, 2000; Murphy & Boa, 2012). This format has been used with the ICF activities and participation domains to assist adults with aphasia to engage in rehabilitative goal setting (Murphy & Boa, 2012; Harty et al., 2011).

1.3.7 Team

In this study, ‘team’ refers to the adult with aphasia, his/her respective significant other and the SLP.

1.4 Abbreviations

- AAC:** Augmentative and alternative communication
- ICF:** International Classification of Functioning, Health and Disability
- PCS:** Picture communication symbols
- SLP:** Speech-language pathologist
- WAB:** Western aphasia battery

1.5 Outline of chapters

Chapter 1 presents the rationale for the study and the list of terminology, abbreviations that were used and an outline of the chapters.

Chapter 2 contains an overview of the theoretical issues related to the study. This includes aphasia and the ICF. The activities and participation domains of the ICF framework to guide rehabilitation will be discussed. The importance of team collaboration in the identification of rehabilitation priorities will be described with explanations of the importance of using the visual framework (Talking Mats™) to assist adults with aphasia in this process.

Chapter 3 provides a detailed description of the methodology of the study. The aims of the study, research design and stages of the study are outlined. The results of the pilot study are presented in table format. The main study is discussed in terms of the criteria for participant selection, ethical considerations and data collection procedures, followed by a discussion of the equipment and materials. Data analysis, validity and issues relating to reliability are described.

Chapter 4 presents the results of the study and a discussion of these results. The results are presented graphically in graphs and tables in accordance with the aims proposed in the methodology.

Chapter 5 provides a summary of the study. A critical overview highlighting its strengths and limitations is presented. Clinical implications are described and recommendations for future research are suggested.

1.6 Summary

This chapter provided a rationale for the study by, firstly, highlighting the relevance of the activities and participation domains of the ICF in aphasia rehabilitation that have a functional focus. Secondly, the importance of team collaboration in the rehabilitation of adults with aphasia was illustrated, as were the difficulties in involving adults with expressive communication difficulties (such as expressive aphasia) in the identification of rehabilitation priorities. The Talking Mats™ framework was introduced as one method that allows adults

with expressive communication difficulties to express their views on rehabilitation priorities and the importance of comparing their views to those of their SLPs and significant others was explained. The terminology and abbreviations used in this study were explained, and an outline of the chapters was provided.

CHAPTER TWO

Literature review

2.1 Introduction

In this chapter, the International Classification of Health, Disability and Functioning (ICF) framework will be described. The extent to which aphasia affects people's participation in daily life and how the activities and participation domains of the ICF can be used as a framework to guide rehabilitation will be discussed. The importance of team collaboration, (including the adult with aphasia, his/her respective significant other and SLP) in the identification of domains to be addressed in rehabilitation will be described with explanations for the necessity of a framework that can be used by all team members as a common point of departure. Furthermore, The Talking Mats™ framework will be discussed as a useful method to assist adults with aphasia to make their views known.

2.2 The ICF framework

The International Classification of Functioning, Disability and Health (ICF) (World Health Organization [WHO], 2001) and the ICF – Child and Youth version (ICF-CY (WHO, 2007) aim to provide a standardised language and framework to describe health. Since its development in 2001, the ICF has been involved in the classification of functioning and disability of health conditions across many health sectors and by various health disciplines and professionals (Bruyere, Van Looy & Peterson, 2005; Jelsma, 2009). The components within the ICF/ICF-CY relate to various domains of health (WHO, 2001; Simeonsson et al., 2003). These international classifications developed by WHO are based on a biopsychosocial model of disability (Jelsma, 2009; Ustun, Chatterji, Bickenbach, Kostanjsek & Schneider, 2003) and aims to facilitate a multi-dimensional description of health and disability beyond a mere diagnosis (Simeonsson et al., 2003; Jelsma, 2009; WHO, 2001). A biopsychosocial model involves viewing the person holistically and considering how the interaction of the biological issues, psychological and social factors that may have an impact on a person (WHO, 2001). The ICF/ICF-CY was initially implemented to describe health and health-related outcomes of functioning but has further developed to also describe disability, the limitations and barriers that influence disability and the potential abilities and opportunities that may enable and empower individuals to recover and engage in rehabilitation to optimise

their level of functioning in order that they may participate fully in all life areas (Cerniauskaite et al., 2011; Simmons-Mackie & Kagan, 2007; Boles & Lewis, 2003). This framework, outlined in Figure 2.1, describes five components related to functioning, which include the individual's functioning at the levels of the body (body structures and functions), the individual (activities) and society (participation) as well as contextual components (both environmental and personal factors) (WHO, 2001). Therefore the interaction between individuals with this health condition and their context or environment (including the people within this environment) can be identified and understood (Cerniauskaite et al., 2011; Bornman, 2004; Geyh et al., 2004; Raghavendra, Bornman, Granlund & Bjorck-Akesson, 2007). Figure 2.1 below provides an example of the ICF framework.

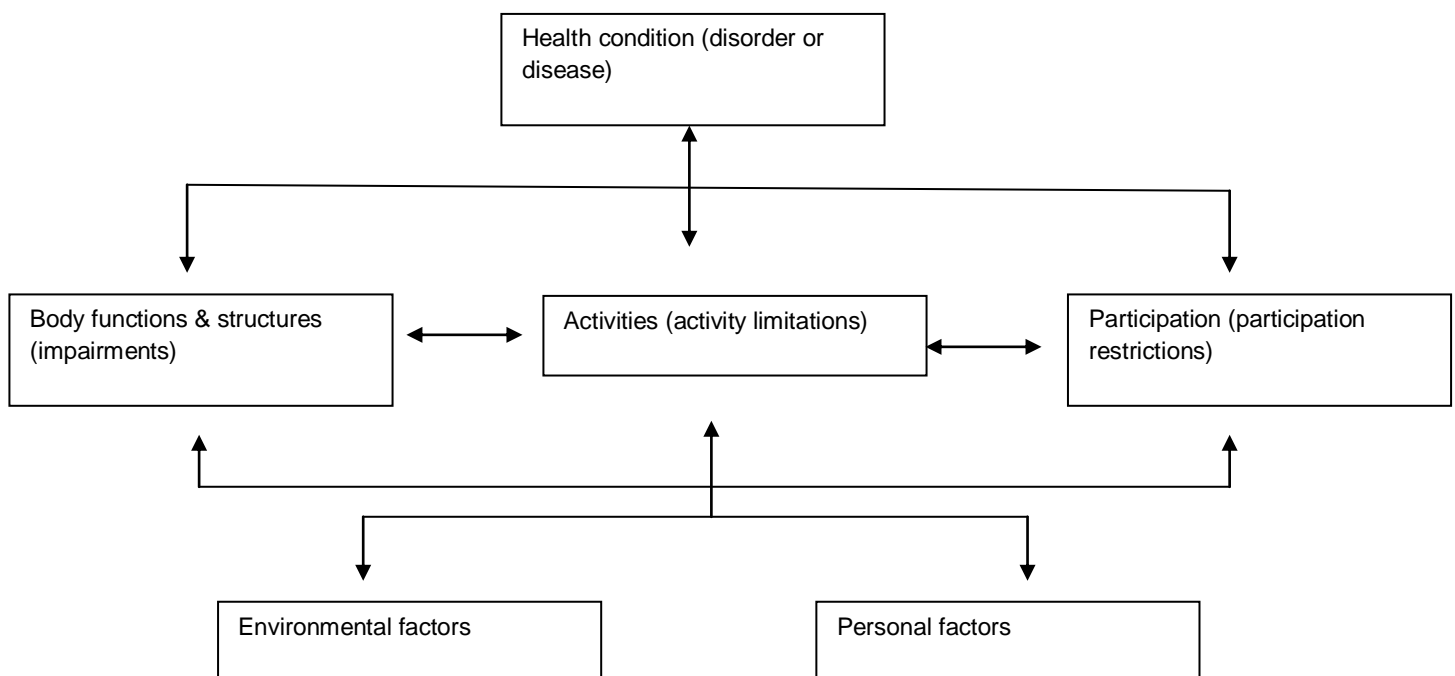


Figure 2.1 The ICF framework (WHO, 2001)

While the ICF is a theoretical framework that aims to provide a holistic view of functioning, it also allows for the detailed description of each of the components related to the functioning of a person with a health condition or a disability within a particular environment. Codes have been developed for four of the five components contained in the ICF/ICF-CY (body structures and functions, activities and participation, environmental factors, personal factors), which allow a detailed description of functioning and environmental factors that may influence functioning. This framework is therefore meant to be a tool for clinical practice that health professionals and patients can refer to in identifying

areas of difficulty and to target these areas in therapy (Cerniauskaite et al., 2011; Coufal & Francois, 2011; Ustun et al., 2003). Furthermore, the framework further intends to provide a ‘common language’ that can be used across disciplines and with family members to encourage functional, integrated and systemic interventions and support (Adolfsson & Björck-Åkesson, 2012; Simeonsson et al., 2003).

Although some studies have pointed to challenges regarding the clinical application of the ICF and ICF-CY (Jeglinsky, Salminen, Brogren Carlberg & Autti-Ramo, 2012; Wiegand, Belting, Fekete, Gutenbrunner & Reinhardt, 2012) these frameworks and taxonomies have been applied and adapted over time in order to assist with the moving from a conceptual framework to clinical practice. Various studies have been conducted in this regard. Studies seem to have focussed mainly on two areas: firstly, the development of code sets and, secondly, the application of the ICF as a tool to facilitate teamwork. Developing code sets entails reducing the high quantity of codes contained in the taxonomy to those that are seen as most important in describing a particular population. These code sets assist with implementation of the ICF in daily practice for describing the functioning of people with various disorders and disabilities, since it reduces the complexity and the time required to consider all codes contained in the taxonomy (Escorpizo & Stucki, 2013; Scherer et al., 2012). Code sets have been developed for many neurological-related disorders, including multiple sclerosis (Paul et al., 2014; Karhula, Kanelisto, Ruutiainen, Hamaianen & Salminen, 2013; Conrad, Coenen, Schmalz, Kesselring & Cieza, 2012; Coenen et al., 2011; Khan & Pallant, 2007), myasthenia gravis (Leonardi et al., 2009), dementia and Alzheimer’s (Scherer et al., 2012; Muo et al., 2005) and stroke (Alguren, Lundgren-Nilsson & Stibrant Sunnerhagen, 2010; Geyh et al., 2004) and those people in the acute stage of rehabilitation (Muller et al., 2011; Grill, Ewert, Chatterji, Kostanjsek, & Stucki, 2005). Code sets have been implemented for populations of people who require AAC, including children (Clark & Price, 2012; Rowland et al., 2012) and adults (Fried-Oken & Granlund, 2012; Murphy & Boa, 2012).

Because the ICF and ICF-CY propose to be a ‘common language’ that can facilitate communication about functioning and disability across disciplines (Simeonsson et al., 2003), studies have addressed the role of the ICF/ICF-CY in team collaboration (Grawburg et al., 2013; McCormack et al., 2010; Pless et al., 2009; Tempest & McIntyre, 2006; Grill et al., 2005; Heerkens, van der Brug, Napel & van Ravensberg, 2003; Simeonsson et al., 2003).

Studies conducted with the ICF-CY and families of children with neurological difficulties demonstrated the advantages of having all team members (including health professionals and family members) to assist with the identification of problems and planning for intervention (Martinuzzi, Carraro & Petacchi, 2013; Bjorck-Akesson, Granlund & Adolfsson, 2012; Self, Coufal & Francois, 2011; Lee, 2011).

Other studies found that the ICF was beneficial in facilitating team collaboration in the rehabilitation of adults, including those with chronic pain (Steiner et al., 2002), with neurological conditions (Rentsch et al., 2003) and also, specifically, post-stroke individuals (Murphy & Boa, 2012; Tempest, Harries, Kilbride, & De Souza, 2012; Tempest & McIntyre, 2006; Visser-Meily et al., 2006, Worrall et al., 2011). Of the studies focusing on adults post-stroke, some concentrated on team collaboration amongst professionals (Tempest et al., 2012; Rentsch et al., 2003), while others concentrated on the input by the family or the adult who had had the stroke (Visser-Meily et al., 2006). No studies have as yet compared the perspectives of all three of these groups using the ICF as a basis.

2.3 Aphasia rehabilitation and the ICF

Aphasia is a result of an acquired neurological disorder, such as a stroke (Kadojic et al., 2012; Simmons-Mackie & Kagan, 2007). Research shows that aphasia is prevalent in patients who have ischemic stroke, most often resulting from a large vessel stroke or a cardio-embolic stroke.

Aphasia results from damage to those areas of the brain that are associated with receptive and/or expressive language functions, namely the left fronto-temporal areas. Aphasia manifests as a communication disability that has an impact on language function, which may severely influence daily living and quality of life (Cruice et al., 2000; Lyon, 2000; Patterson & Chapey, 2008; Verna, Davidson, & Rose, 2009).

The severity of aphasia may vary from mild to severe and both receptive and expressive language abilities may be differently affected. This will influence the communication abilities of individuals in various interactions and conversations (Williamson, Richman & Redmond, 2011; Darrigrand et al., 2010; Hux et al, 2001). Some individuals may recover their language abilities, whereas others may not recover these skills sufficiently,

despite speech-language therapy (Koul & Corwin, 2003). Adults who present with moderate to severe aphasia have difficulty regaining their language abilities for participating in daily conversations and interactions effectively and sufficiently (Darrigrand et al., 2010; Hux et al., 2001; Koul & Corwin, 2003). People with mild aphasia also experience communicative difficulties in various conversational settings; therefore, regardless of the level of severity, aphasia typically reduces people's abilities to function and participate in daily life and communication situations as effectively as they had previously done (Rohde et al., 2012; Darrigrand et al., 2011; Worrall, 2010).

Traditional therapeutic approaches to address communication problems in persons with aphasia have focussed on ameliorating impairments in functioning at the level of body structures and functioning—in line with the medical model of disability (Ross & Wertz, 1999). Such approaches may have included the retraining of grammatical skills and techniques to facilitate word finding (Simmons-Mackie & Kagan, 2007). However, there is a lack of carryover into daily life situations, since the functional limitations in daily life tend to persist (Johansson, Carlsson, Ostberg & Sonnander, 2012; Rautakoski et al., 2008; Simmons-Mackie & Kagan, 2007). The biopsychosocial model of disability acknowledges that a person's functioning results from the interaction between his/her abilities and the environment. When a person's abilities are limited due to changed body functioning, environmental interventions may be more effective than attempts to retrain certain skills (Worrall et al., 2011; Kagan et al., 2008). Therapy approaches for adults with aphasia have therefore become more focussed on compensatory strategies and the employment of various communication modes (rather than speech only) that are effective and that may be used functionally in daily activities and tasks, as well as in social situations (Patterson & Chapey, 2008; Worrall, 2000; Garrett & Lasker, 2005; Fox & Fried-Oken, 1996). Such approaches have included various strategies to improve communication, including partner training (Simmons-Mackie, Raymer, Armstrong, Holland & Cherney, 2010; Kagan, 1998) as well as the use of augmentative and alternative communication methods (Lasker & Bedrosian, 2001; Jacobs, Drew, Ogletree, & Pierce et al., 2004; Beukelman et al., 2007; Holland, 1998). In addition, outcome measures have moved beyond the evaluation of discrete skills to evaluating the individual's participation in daily life (Holland, 1998; Threats & Worrall 2004). This change in the focus of rehabilitation would appear to articulate well with the ICF framework and taxonomy, since it acknowledges the importance of the interaction between person and environment and activities and participation and places and emphasises

participation of people with disabilities in various activities and life events (Worrall et al., 2011; Simmons-Mackie & Kagan, 2007).

A functional approach to rehabilitation has also necessitated change in the manner in which interventions are structured. The move away from discipline-specific goals necessitates increased collaboration amongst professionals, the involvement of significant others and of the adult with aphasia (Worrall et al, 2010; Hersh et al., 2012). Here, too, the ICF as a ‘common language’ would appear useful as a tool to enhance team collaboration.

In the following sections, the roles of SLPs, significant others and adults with aphasia themselves in their rehabilitation are briefly reviewed. Following this, an overview is given of studies that have considered or utilised the ICF for rehabilitation with adults with neurologically-based acquired communication difficulties, and especially adults with aphasia.

The roles of team members are important in rehabilitation. The team members include adults with aphasia, SLPs and significant others (previously discussed in Section 2.1). All team members play relevant roles in rehabilitation (Johansson et al., 2012). SLPs are concentrated on (rather than all rehabilitation professionals) because adults with aphasia require on-going speech-language therapy due to the persisting communication difficulties (Finch et al., 2013; Brown et al., 2011) and the impact these difficulties have on daily interactions and conversations (Simmons-Mackie & Kagan, 2007). Studies have shown that adults with aphasia and SLPs often have differences in terms of priorities and goals (Worrall et al., 2007; Brown et al., 2011). The knowledge and experience that SLPs can provide are not enough to understand the priorities and goals of adults with aphasia. This may be due to a misalignment of perceptions and focus areas between SLPs and adults with aphasia; also, SLPs traditionally tend to lead the goal setting process, particularly when communication difficulties hinder the effective participation of adults with aphasia (Sherratt et al., 2011). SLPs need to ensure client-centred therapy by ensuring that adults with aphasia can identify their priorities by viewing their situations from all perspectives; this includes obtaining input from significant others and the adults with aphasia themselves.

As a result of a sudden loss of abilities, a person with aphasia often experiences extreme changes to his or her life, often coupled with a loss of autonomy with regard to a variety of life areas (Cruice et al., 2003; Kagan, 1998). Autonomy is the ability to engage in

‘choosing, initiating, regulating and terminating’ participation in activities that align with the person’s priorities. Autonomy can be upheld by ensuring that adults with aphasia are able to co-direct the rehabilitation process. Increased satisfaction within the rehabilitation context has been noted when individuals are given choices (Haley, Womack, Helm-Estabrooks, Lovette & Goff, 2013; Constad & MacDermid, 2013). This has an influence on their buy-in to therapy and may assist identification of meaningful goals that can be worked on in the home environment (Hersh et al., 2012; Rohde et al., 2012). However, reductions in autonomy are usually noted after a stroke and due to communication difficulties, people with aphasia experience more difficulty in understanding therapy goals and participating in the rehabilitation process (Haley et al., 2013). This may contribute to frustration and decreased motivation in therapy and a lack of insight into what is difficult at home (Rohde et al., 2012; Darrigrand et al., 2011).

The significant others of adults with aphasia are part of the environmental factors described by the ICF framework that may impact their social participation (Code, 2003) and rehabilitation (Glozman, 2004). This is because significant others spend a significant amount of time with the adult with aphasia and know them on a personal level, understand their needs and are aware of their capabilities and difficulties in the home and social environment; they also perceive these capabilities differently from the adults with aphasia (Hersh et al., 2012; Johansson et al., 2012; Lawrence & Kinn, 2011; Johansson et al., 2011;). Since adults with aphasia have communication restrictions to some degree or another, it is likely that they will always be accompanied by a significant other to assist with various social interactions (Ferguson & Harper, 2010; Worrall et al; 2011 Hersh, et al., 2012; Sherratt et al., 2011). They are the conversational helpers who can provide a different perspective on the capabilities of adults with aphasia for their rehabilitative planning process (Hersh et al., 2012; Johansson et al., 2012; Lawrence & Kinn, 2011; Johansson et al., 2011).

Studies have been conducted to understand the impact of aphasia on significant others, the family’s perception of how aphasia influences a person who has suffered the stroke, the family and the home environment (Hersh et al., 2012; Worrall et al., 2011; Worrall et al, 2010). These studies highlighted that clinicians need to understand that aphasia affects the family and therefore the family needs to be involved in rehabilitation—hope and positivity needs to be captured in the rehabilitation process (Hersh et al., 2012; Worrall et al., 2010). Studies such as these highlight that communication difficulties become a concern of

the family, not only of the adult with aphasia. Despite these findings, little research exists on how to include significant others in identifying priorities for rehabilitation for adults with aphasia.

Table 2.1 summarises studies that have focussed on the use of the activities and participation domains of the ICF for identifying rehabilitation priorities for adults with acquired neurological communication difficulties, including aphasia between, 2004 and 2014. A search of four databases namely Academic Search Premier, CINAHL, MEDLINE and PsychARTICLES provided 266 such studies. The parameters used in the search for these studies included combinations of the following key words: ICF, aphasia, rehab, goals, teams and excluded children. On the abstract level, 271 studies were excluded, as these were based more on broad aphasia rehabilitation and the perspectives of people involved with aphasia or on the application of the ICF in various clinical settings, disorders and core sets. Three of the selected studies made specific links between the ICF, communication difficulties and implementation of the Talking Mats™ tool for identification of rehabilitation priorities or goal identification, while the other two selected studies considered the application of the ICF in aphasia specifically. Thus, five studies conformed to the researcher's criteria. They are therefore listed, in chronological order, in Table 2.1.

Table 2.1

Studies and Theoretical Frameworks on the Activities and Participation Domains of the ICF and Aphasia between 2004 and 2014

Author/s and year	Aim	Design	Participants	Procedures	Findings
Murphy & Boa, 2012	To explore the use of symbol sets depicting the activities and participation domains of the ICF as well as selected codes from these domains within the Talking Mats™ framework to assist adults with communication difficulties (as a result of head injury or stroke) in establishing rehabilitation goals	Descriptive: Clinical cases are described.	Twelve participants with communication difficulties were used in the pilot study. They were not described further. Three case examples were provided (ages varied from 32-57 years and they presented with a variety of diagnoses: expressive aphasia and apraxia resulting from a cerebral haemorrhage, severe receptive and expressive aphasia resulting from a subarachnoid haemorrhage, expressive aphasia from a CVA.	Symbols sets were piloted with 12 participants with communication difficulties. Three case examples were described of the use of the symbol sets with adults with aphasia.	Using Talking Mats™ with the ICF for goal setting for people with communication difficulties was found to be effective.
Harty et al., 2011	To determine how clients with acquired communication difficulties in an acute rehabilitation setting and their treating professionals rated the importance of the nine	Comparative design	Twelve clients (adults with acquired expressive difficulties resulting from head injury or stroke, age range: 2 participants below 25 years, 7 between 25 and 40	Participants were required to rate the importance of the ICF activities and participation domains for rehabilitation of the adults with expressive difficulties using the	The results indicated a high degree of consensus for the domains that participants rated as important in rehabilitation. Consensus was possible

Author/s and year	Aim	Design	Participants	Procedures	Findings
	ICF activities and participation domains in terms of including this in the rehabilitation programme of the specific client		years and 3 above 40 years of age) and 20 corresponding rehabilitation professionals (speech-language pathologists, occupational therapists, physiotherapists and social workers) participated in the study.	Talking Mats™ tool. Interviews were conducted separately.	for professionals and clients in an acute rehabilitation setting.
Worrall et al., 2011	To describe the goals of people with aphasia and code goals according to the ICF	Qualitative descriptive approach	Participants (50) between the ages of 53 and 73 with aphasia were interviewed in their homes.	Participants were interviewed (using semi-structured interviews) that were videotaped and transcribed for analysis.	Nine broad categories of goals were identified. Goals linked to the ICF activities and participation domains.
Simmons-Mackie & Kagan, 2007	To described aphasia using the ICF framework	Descriptive study	/	The key aspects of the ICF are described in relation to the main goal in aphasia rehabilitation (optimising quality of life). A case example highlighted the use of this framework.	By considering the ICF constructs on quality of life, more effective outcomes for people affected by aphasia were achieved.
Bornman & Murphy, 2006	To describe how Talking Mats™ could be used with the activities and participation of the ICF when setting goals	Descriptive: Clinical cases are described	Case examples based on two people, one who had a brain haemorrhage (at 32 years of age) resulting in severe speech dyspraxia and mild expressive aphasia The	Both cases described the implementation of Talking Mats™ to assist with problem areas in their rehabilitation and to identify goals within specific domains with	Using Talking Mats™ when reflecting on the ICF domains and contextual factors was beneficial. This framework was useful for teams to identify problem areas in

Author/s and year	Aim	Design	Participants	Procedures	Findings
			other had a brain injury (at 51 years of age) resulting in poor memory recall, disturbed sleep, reduced motivation and mobility.	their team members' assistance.	rehabilitation.

From Table 2.1 it is clear that the activities and participation domains of the ICF are relevant and correlate with what adults with aphasia want for themselves (Worrall et al., 2011). In the study conducted by Worrall et al., (2011), 50 participants with aphasia were interviewed about the goals they wanted to work on and these goals were then coded according to the ICF. Nine categories were identified and some of these included: returning to their pre-stroke life, communicating both basic needs and opinions, independence, respect and dignity, participating in social, leisure and work activities, regaining physical health, assisting others and obtaining more information about stroke, aphasia and related services. These goals connected to the ICF components, particularly to the activities and participation domains. This highlighted that adults with aphasia were able to express goals that linked to the activities and participation domains of the ICF. The ICF activities and participation domains (represented by picture symbols) can be used by adults with acquired communication difficulties within the Talking Mats™ framework to identify priorities or problem areas (Boa & Murphy, 2012; Harty et al., 2011; Bornman & Murphy, 2006) and it also allows comparisons of perspectives between team members (Harty et al., 2011). Harty et al., (2011) researched the utilisation of the nine ICF domains for team collaboration/consensus. Participants included 12 adults with communication difficulties, and 20 corresponding rehabilitation professionals to identify rehabilitation priorities from the ICF domains. The domains selected by the adults with communication difficulties and the rehabilitation professionals were compared and it was found that all participant groups rated *Coping, Communication, Mobility, Self-care* and *Relationships* as important domains to include in the rehabilitation programme in the acute setting. There was a degree of consensus between the prioritisation of domains among rehabilitation professionals and clients.

This study will consider the perspectives of team members by rating the nine activities and participation domains of the ICF, specifically for the rehabilitation of adults with aphasia. Although studies have identified that significant others are important members of the rehabilitation process, they have not been included in the identification of rehabilitation priorities. Therefore, this study will include the significant others as members of the team in the identification of problem areas for the rehabilitation of adults with aphasia. The Talking Mats™ tool will be used in this study for adults with aphasia to rate their rehabilitation priorities.

2.4 Talking Mats™ framework for adults with aphasia

To participate optimally in various life areas, even with the presence of aphasia, various communication modes or alternative and augmentative communication (AAC) have been implemented and noted to be effective tools in daily life activities and interactions to assist adults with aphasia (Simmons-Mackie & Kagan, 2007; Johnson et al., 2008; Lyon, 1992). The communication difficulties that adults with aphasia experience may include limitations in verbalising their needs or thoughts, reduced sentence construction and speech planning abilities (Haley et al., 2013) that has an impact on their participation in conversation.

Despite these difficulties, adults with aphasia have been able to use the Talking Mats™ framework to communicate their needs, topics of interest and goals for rehabilitation (Murphy, 2000; Murphy, 2007; Murphy & Boa, 2012; Bornman & Murphy, 2006). Murphy (2000) introduced Talking Mats™ to assist adults with aphasia in actively addressing their needs. Talking Mats™ was developed to help people with various communication difficulties as a result of dementia (Murphy, Gray & Cox, 2007), intellectual disabilities (Murphy & Cameron, 2008) or simply ageing (Murphy et al., 2005) and all these studies showed the benefits of using this form of AAC. Many studies have used Talking Mats™ to identify and understand the rehabilitative and functional goals of adults with expressive language difficulties (Bornman and Murphy, 2006; Murphy and Boa, 2012; Harty et al., 2011).

Talking Mats™ consists of line drawings and written words on topic cards that can be selected and placed under the appropriate column on a Velcro mat to participate in a variety of topics. In studies conducted by Bornman and Murphy (2006), Harty et al. (2011) and Murphy and Boa (2012), Talking Mats™ was used in conjunction with the ICF framework to assist adults with acquired communication difficulties to participate in goal setting. The domains of the ICF were represented as simple drawings supplemented by written words on topic cards. The adults could use the cards to participate in what they felt was important in rehabilitation. These studies demonstrated that, when using a framework that allows clients and professionals to identify rehabilitative priorities or goals, an understanding of relevant needs could be achieved.

Implementation of the ICF domains within the Talking Mats™ framework allows adults with aphasia to participate in problem identification for their rehabilitation. The identified domains can then be compared to those identified by their SLPs and significant others to enable collaborative teamwork.

This study will describe the ICF domains rated as important by adults with aphasia, their significant others and respective SLPs for the rehabilitation of adults with aphasia and compare the perspectives of these three groups.

2.5 Summary

This chapter has shown how the ICF has contributed to research into stroke and aphasia and how the adapted framework of the ICF activities and participation domains that were used in studies with adults with aphasia, could assist them to identify problem areas for rehabilitation. The extent to which aphasia can have an impact on communication and daily life interactions was discussed. The importance of team collaboration in assisting the adults with aphasia in the identification of their rehabilitation areas was described, highlighting the necessity of using a visual framework (Talking Mats™) that all team members can refer to, and particularly to aid adults with aphasia to express their needs.

This study will consider how the adapted ICF activities and participation domains can assist adults with aphasia to identify important domains to be worked on in their rehabilitation and whether their significant others and respective SLPs can assist by identifying relevant problem areas from the ICF format that the adults with aphasia can work on in rehabilitation. The important domains identified by the adults with aphasia, their significant others and SLPs will be compared.

CHAPTER 3

Methodology

3.1 Introduction

This chapter describes the research methodology used. The main aim, sub-aims and research design are also described. Results of the pilot study are provided and participants as well as the materials and equipment required for the data collection are described.

Furthermore, the procedure for data collection is explained. A description of the procedure used to analyse the data is provided and, finally, methods to determine procedural integrity and reliability of data are explained.

3.2 Aims

3.2.1. Main aim

The main aim of the study was to describe and compare the perspectives of adults with aphasia, their significant others and their SLPs regarding the importance of the nine ICF activities and participation domains for the rehabilitation of the adult with aphasia.

3.2.2. Sub aims

The following sub-aims were identified:

- i.) To determine ratings of the importance of the nine activities and participation domains of the ICF for their rehabilitation by the adults with aphasia;
- ii.) to determine significant others' ratings of the importance of the nine activities and participation domains of the ICF for the rehabilitation of the adult with aphasia;
- iii.) to determine the SLPs' ratings of the importance of the nine activities and participation domains of the ICF for the rehabilitation of the adult with aphasia.
- iv.) to compare the ratings of the domains given by adults with aphasia, the significant others and SLPs.

3.3. Research design

This study used a quantitative, descriptive, comparative survey design (McMillan & Schumacher, 2006). A descriptive design allows phenomena to be described without manipulating conditions. A comparative design additionally allows the investigation of similarities and differences across the groups on the phenomena being studied (McMillan & Schumacher, 2006). In this study, the perspectives of adults with aphasia, their significant others and their SLPs regarding the importance of the nine ICF domains for the rehabilitation of the adult with aphasia were described and compared. Data from adults with aphasia was collected by means of the Talking Mats™ framework, which is an adapted structured interview format. Data from the significant others and SLPs were collected by means of rating scales. Questionnaires or rating scales and interviews allow for beliefs, opinions and other types of information to be identified and described (McMillan & Schumacher, 2006). The participants were required to rate the nine domains of the ICF in terms of their importance for rehabilitation for the adult with aphasia. The results obtained were described for adults with aphasia, significant others and SLPs.

3.4 Stages of the study

The stages of the study included recruitment, screening for selection and data collection, as illustrated in Figure 3.1. Recruitment involved the process of contacting potential participants from various rehabilitation facilities. Screening and selection involved meeting with potential participants, obtaining background information through biographical questionnaires and conducting visual and language screening with the adults with aphasia to ensure they fit the selection criteria in order to participate in the study. Data collection involved conducting the interviews with the adults with aphasia and collecting completed questionnaires from the significant others and SLPs.

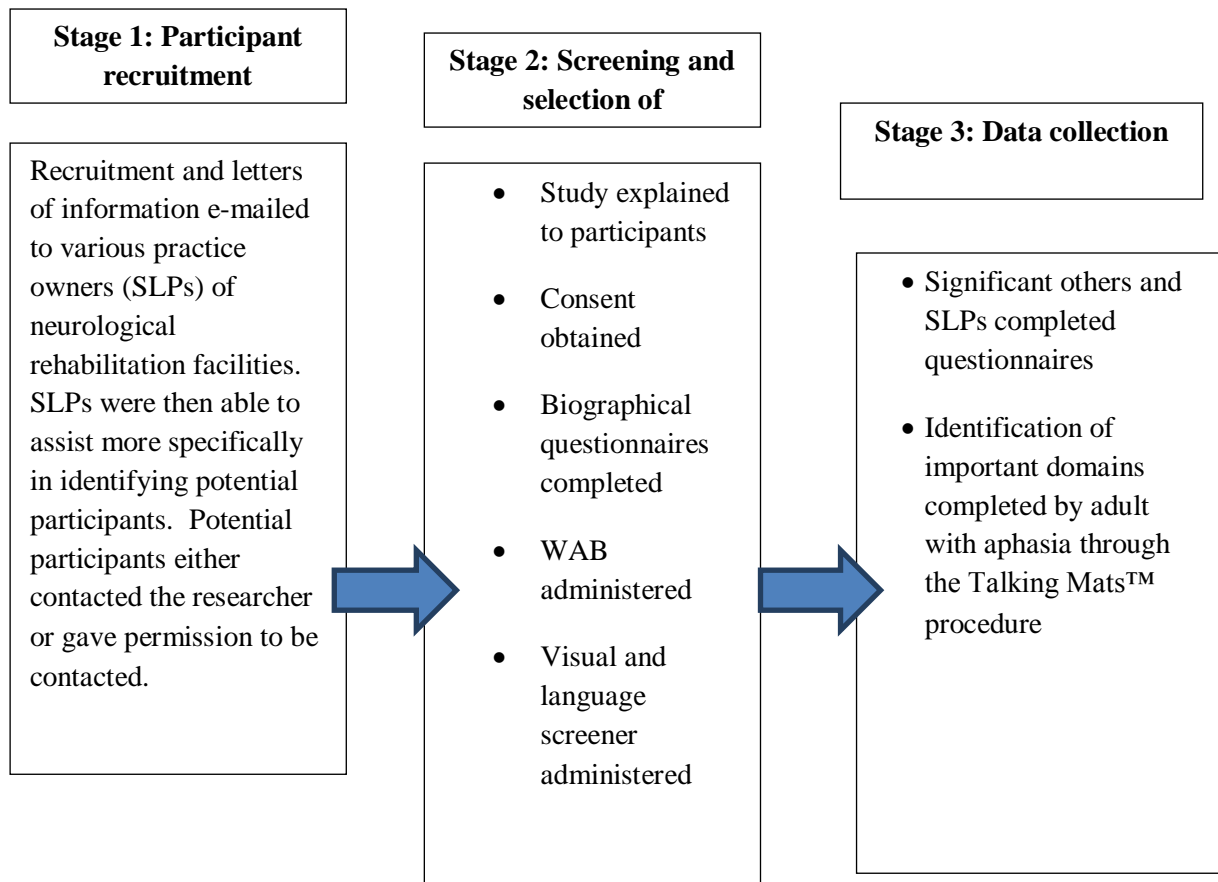


Figure 3.1. Stages of the study

3.5 Pilot study

A pilot study was conducted to assess the materials and to make the necessary changes to the procedure, should this be required for the main study. A pilot study was conducted with two teams, each consisting of an adult with aphasia, his/her significant other and a SLP. Selection criteria for participants in the pilot study were the same as those for the main study (Section 3.6.2). The adult with aphasia in the first team was 61 years old and retired. He presented with mild-moderate receptive language difficulties and severe expressive language difficulties. His significant other was his sister, whom he lived with. His SLP had been treating him for about one year. The adult with aphasia in the second team was 47 years old and presented with mild receptive language difficulties and moderate expressive language difficulties. His significant other was a friend who had known him since they were at school. The SLP had been working with this adult with aphasia for over a year.

The adults with aphasia were interviewed and their respective significant others and SLPs were required to complete rating scales for the study. Table 3.4 provides a description of the aims, procedures, results and recommendations of the pilot study.

Table 3.5

Aims and Procedures of Pilot Study

Aims	Procedure	Outcome	Changes made for main study
To establish whether the selected method of obtaining informed consent from the adults with aphasia was effective	The study was verbally explained to the adult with aphasia and his/her significant other according to a script (Appendix A). The second information letter and consent form (Appendix B) containing visual aids were then given to the adult with aphasia. He/she was given the choice whether he/she would like to read it by him/herself, or have the researcher read it to him/her. The adult with aphasia was then encouraged to complete the consent form by ticking the appropriate answers and signing the form. Significant others were given information letters and consent forms to complete (Appendix B) and SLPs were sent forms via e-mail (Appendix D). A significant other of the adult with aphasia was requested to complete an observer form (Appendix E) after observing the adult with aphasia complete the consent form to participate in the study. This was to verify that the adult understood the	<p>The researcher noted that the adult with aphasia in the first team required assistance to read the consent letter, whereas the adult with aphasia in the second team was able to read the letter without the researcher reading it aloud.</p> <p>Both adults with aphasia expressed comprehension of what the study involved. They were willing to participate in the study.</p> <p>Both significant others within each dyad reported that they felt the adult with aphasia understood the content of the study, and consented out of their own free will to take part. No further comments were noted.</p>	<p>No changes were made.</p> <p>The researcher read the consent letter aloud together with the adult with aphasia if he/she requested this assistance and particularly if he/she had some difficulty with reading comprehension.</p>

Aims	Procedure	Outcome	Changes made for main study
	<p>procedures and gave consent to participate without being coerced.</p>		
<p>To establish whether the biographical questionnaires provided adequate information about each participant</p>	<p>Each participant was required to complete biographical questionnaires about him/herself. The significant other and researcher could assist the adult with aphasia to complete the form.</p>	<p>It was noted that the responses to the closed-ended question about the relationship of the adult with aphasia with his/her significant other did not provide enough options to capture the necessary detail. In the second team, an open-ended question was used instead.</p>	<p>An open-ended question was added to capture specific detail about the relationship of the adult with aphasia with his/her significant other. Examples were provided.</p>
<p>To establish whether the sequence of tasks during each session could be executed effectively</p>	<p>The sequence of tasks for each interview session was planned before the session was conducted. The procedure or sequence was typed out for the researcher to follow. The tasks were administered according to this schedule.</p>	<p>Participants (adults with aphasia and significant others) reported that the sequence of tasks was easy to follow.</p>	<p>No changes were made.</p>
<p>To determine whether the procedure of rating domains using the Talking Mats™ approach could be executed by the adult with aphasia</p>	<p>Adults with aphasia were interviewed using the Talking Mats™ format.</p>	<p>Both the adults with aphasia were able to follow the procedure to rate the domains using the Talking Mats™ (despite having mild-moderate receptive language difficulties).</p>	<p>No changes were made.</p>

Aims	Procedure	Outcome	Changes made for main study
To determine whether the rating scales completed by SLPs and significant others were appropriate for gathering the information	Significant others were required to complete rating scales that rated the importance of domains for adults with aphasia. SLPs were e-mailed the rating scales for completion. They were asked not to discuss the responses with other team members, or to consult client files. It was necessary to determine if the format of the rating scale allowed accurate and appropriate information to be gathered.	The SLP in the second team commented that she was unsure how to rate domains for the adult with aphasia. She requested that the researcher clarify more specifically what was required of her.	If the SLP could not be present for the interview, a telephone discussion was held prior to emailing the questionnaire. A more detailed written instruction (SLP brief (Appendix F) was also included in the email to ensure understanding of the process.
To determine whether the logistical arrangements for the completion of the screening tasks, the Talking Mats™ interview and the written rating scales were appropriate for the participants	A meeting was arranged for the adults with aphasia and their significant others. At this meeting, the significant others were required to complete their rating scales in separate rooms following an explanation of the study once consent was obtained. Adults with aphasia could choose to continue with the rating of ICF domains interview after the screening tasks were conducted, or request another interview session to complete this. Both adults chose to continue. As none of the SLPs could attend the face-to-face meetings, the researcher e-mailed the information letter, consent form,	Participants with aphasia in both pilots felt that they could complete the screening tasks and the Talking Mats™ interview in one session. The researcher noted that the adult with aphasia in the first team tired easily; however, he wanted to continue once he had short breaks. As the SLPs for both teams were unable to attend the meeting time, the route of e-mailed instructions, consent letters and	The option of a second session for the adult with aphasia was still provided in the main study. During a session, breaks were provided where necessary. The significant others were asked to complete the consent and rating scale in one session. To ensure understanding of the study, the SLPs were contacted, and an ‘SLP brief’ containing instructions and procedures was included with the emailed forms. SLPs were still encouraged to attend the meeting.

Aims	Procedure	Outcome	Changes made for main study
	biographical questionnaires and rating scales for completion.	rating scales, rather than providing these in a face-to-face meeting, was followed. The SLP in the first team followed the instructions and completed the forms accurately. The SLP in the second pilot got in touch with the researcher to clarify questions they she had.	
To determine whether the instructions provided to all participants were clear and easily comprehended	Participants were asked to provide feedback on the instructions provided during the study.	The adults with aphasia and significant others felt that both the written and verbal instructions were clear. As previously mentioned, the SLP in the second team requested clarification of what was expected of her.	Instructions provided for the adults with aphasia and significant other remained the same. A written brief was provided via e-mail to ensure that SLPs (who could not attend the meeting) followed all instructions.
To determine whether the rating scales completed by the significant others and SLPs could be effectively coded and analysed	The results were analysed using frequency counts of the member's <i>Yes</i> , <i>Maybe</i> and <i>No</i> responses within each domain. In order to get an impression of consensus within a team, identical ratings by team members were counted.	The analysis of the data was easy and effective.	No changes were made.

3.6. Participants

3.6.1. Sampling and recruitment

This study involved adults with aphasia, their significant others (that is, a person who knows the adult well, who spends time with and was involved in the adult with aphasia's rehabilitation programme) and their SLPs. The study population was thus very specific, and participants were recruited with the selection criteria in mind (Section 3.6.2). The sampling technique used combined elements of convenience and snowball sampling (MacMillan & Schumacher, 2010). Initially, the researcher contacted eight private neurological rehabilitation practices in the Johannesburg metropolitan area. These facilities included both private hospital-based and rehabilitation centre-based out-patient therapy practices.

These rehabilitation practices were chosen because the researcher had previous contact with some of the therapists at these practices. Therapists were then able to provide an additional four contacts for therapists at other rehabilitation practices in adjacent areas (snowball sampling). A total of 12 neurological rehabilitation practices were contacted for the study.

After receiving ethical clearance for the study from the Research Ethics Committee of the Faculty of Humanities of the University of Pretoria (Appendix G), information letters (Appendix H) were sent to practice owners from these practices via e-mail to request consent to assist in the recruitment of participants who met the selection criteria. If no response was received from practice owners within a week of sending the email, they were contacted via a follow-up email or telephone call. Of the 12 practices, two practices refused to participate, ten consented to participate, while four of the practices did not have appropriate participants for the study. Participants were therefore recruited from only six facilities—five in the Johannesburg metropolitan area, and one in Pretoria. The practice owners were requested to provide the initial written information letters (Appendix I) to adults with aphasia, their respective significant others and SLPs who, in the practice owner's opinion, met the selection criteria (Tables 3.6-3.8). Potential participants either contacted the researcher or gave their permission for the researcher to contact them. Fifteen adults with aphasia showed an interest in the study. Three individuals contacted the researcher and the remaining 12 requested that the researcher contact them. The respective SLPs who worked with the adults with aphasia also showed an interest in participating in the study. The 15 significant others were all also

willing to participate. The researcher set up a meeting with the adult with aphasia and his or her significant other at a place of convenience, either at their home or at their rehabilitation facility. Of the SLPs, two were able to participate at this initial meeting, while 13 were unable to attend. These SLPs were contacted telephonically and via e-mail in order to explain the study to them.

A total of 15 adults with aphasia, 15 significant others and 15 SLPs gave written consent to participate in the study.

3.6.2. Selection criteria

The selection criteria for the respective participant groups are provided in Tables 3.6 to 3.8.

Table 3.6

Selection Criteria for Adults with Aphasia

Criterion	Justification for inclusion	Measure
Adult (18 years or older)	Aphasia is primarily an adult impairment. The adult with aphasia needs to participate in decision-making and prioritising the ICF domains for his/her rehabilitation.	Information was obtained from the biographical questionnaire (Appendix J).
Diagnosis of expressive aphasia	Adults with expressive aphasia would typically benefit from visual support to assist them in selecting and describing their needs for rehabilitation (Hux et al., 2001; Bornman & Murphy, 2006).	Participants had to obtain an aphasia quotient (AQ) of between 10 and 94 on the Western Aphasia Battery (WAB) for an expressive aphasia score (Kertesz, 1982). The SLP's diagnosis also needed to confirm the presence of expressive aphasia.

Criterion	Justification for inclusion	Measure
Receptive language skills: Unaffected to mildly/moderately affected, therefore exclusion of adults with severe receptive language difficulties	Adults with expressive aphasia may have mild to moderate receptive language difficulties. However, their receptive language needed to be on a level that enabled them to understand instructions for the study in order to participate meaningfully in this study.	Receptive language severity score obtained from subtests used from the Western Aphasia Battery (WAB) (Kertesz, 1982) needed to show no or only mild-moderate receptive impairment (receptive score between 4 and 10). The SLP's diagnosis needed to confirm this.
Minimum of 6 months post injury	At this stage, adults with aphasia are outside of the period for spontaneous recovery. Priorities in terms of the ICF domains and life goals may differ from those during the period where spontaneous recovery still takes place (Cherney & Robey, 2001).	Information was obtained from SLPs.
Premorbid first language English speaker	Adults with aphasia were required to comprehend all instructions to participate in the study.	Information was obtained from the SLP and from the biographical questionnaire.
No diffuse neurological injury	Absence of cognitive-communication difficulties is required for aphasia classification.	Information was obtained from SLP. The SLP referred to neurologist's report if necessary.
No reports of learning/psychiatric disorders	Any learning or psychiatric disorders may have a negative effect on	Information was obtained from SLPs. The SLP referred to the neurologist's

Criterion	Justification for inclusion	Measure
	participation and therefore participants with these disorders were excluded.	report if necessary.
Functional vision and hearing	Participants were required to see domain cards and follow oral instructions.	Information was obtained from SLPs and from conducting the language and visual screener based on Harty et al. (2011).
Functional use of one arm	Participants were required to select goal cards during the Talking Mats™ interview.	Information was obtained from the biographical questionnaire.
Receiving intervention from an SLP at least once every two weeks	The study aimed to compare perspectives of adults with aphasia, their significant others and their SLPs. The SLPs needed to conduct regular therapy with the adult with aphasia to plan for and understand the person and the chronic difficulties.	Information was obtained from the biographical questionnaire.
Availability of a significant other (family member/friend or carer) who knew and understood the adult well and had some involvement in the rehabilitation programme (e.g., occasionally attending therapy with the adult with aphasia, assisting with strategies or meeting with the SLP) and who consented to take part in the study	The study aimed to compare perspectives of adults with aphasia, their significant others and their SLPs.	The rehabilitation professionals assisted with identifying a significant other. Some adults with aphasia were able to identify their significant other themselves. Information was also obtained from the biographical questionnaire for the significant other (Appendix K).

Table 3.7

Selection Criteria for Significant Other (Family Member, Friend or Carer)

Criterion	Justification for inclusion	Measure
Adult (18 years or older)	The significant other needed to be someone with potential decision-making power in the rehabilitation programme of the adult with aphasia.	Information was obtained from biographical questionnaire.
Literate in English	The significant other needed to comprehend instructions given in English.	Information was obtained from biographical questionnaire.
Knew and understood the adult well and had some involvement in the rehabilitation programme (e.g., occasionally attending therapy with the adult with aphasia, assisting with strategies or meeting with the team of professionals)	The study aimed to compare perspectives of team members and the significant other needed to be someone who could or did take an active role in the rehabilitation programme or assisted the person outside of therapy.	The rehabilitation professionals assisted with identifying a significant other. Some adults with aphasia were able to identify their significant other themselves. Information was also obtained from the biographical questionnaire for the significant other (Appendix K).

Table 3.8

Selection Criteria for SLPs

Criterion	Justification for inclusion	Measure
SLP registered with the Health Professions Council of South Africa and with experience in adult neurological rehabilitation (at least 4 months).	The SLP needed to have experience in adult neurological rehabilitation in order to make a meaningful assessment of rehabilitation priorities.	Information was also obtained from the biographical questionnaire (Appendix L)
Treating the client regularly	The SLP needed to know the	Information was obtained

Criterion	Justification for inclusion	Measure
(at least every second week), and having treated the client for at least 3 months at the time of the study	client well and to treat the client regularly in order to have a good overview of the client's goals and progress.	from the biographical questionnaire.
Literate in English	To ensure comprehension of instructions and the questionnaire and scale.	Information was obtained from the biographical questionnaire.

3.6.2. Descriptive criteria

Participant descriptions are provided in Tables 3.9 to 3.11.

Table 3.9

Descriptive Information for Adults with Aphasia

Participant number	Age	Gender	Education	Occupation/previous occupation	Currently working	Handedness (right or left)	Functional use of hands	Marital status	Aphasia type and WAB score (AQ)	Receptive language and score	Time post onset (years; months)	SLP Therapy attendance
1	62	M	Diploma	Farmer	No	Right	Both	Single	Severe Broca's (28)	Mild-mod (7.4)	1;4	1x weekly
2	44	M	Post-grad (CA)SA	CA	No	Right	Left	Married	Moderate Anomia (66)	Mild (9.2)	2;6	3x weekly
3	43	M	Post grad (advocate)	Advocate	No	Right	Both	Other	Mild anomia (90)	Mild (9.3)	1;0	3x weekly
4	52	F	Matric	Senior legal secretary	No	Right	Both	Divorced	Moderate anomia (74)	None (9.9)	3;0	2x weekly
5	49	F	Matric	Partner in air charter company	No	Right	Left	Widow	Mild anomia (88)	None (9.8)	1; 4	3x weekly
6	51	M	Diploma	Internal audit manager	No	Right	Both	Married	Mild anomia (90)	None (9.8)	1;3	2x weekly
7	71	F	Diploma	Chef, now retired	No	Left	Left	Married	Severe Broca's (28)	Mild-mod (4.9)	0;7	2x weekly
8	61	F	Standard 8 or lower	Real estate agent	No	Right	Left	Married	Severe Broca's (25)	Mild-mod (7.0)	2;0	1x weekly
9	38	M	Matric	Tool room miller	No	Right	Left	Other	Severe Broca's (29)	Mild-mod (7.9)	0;9	1x weekly
10	67	M	Matric	Director	Yes	Right	Both	Married	Moderate anomia (70)	None (9.8)	2;0	1x weekly
11	69	M	Diploma	Owner of carpet shop	Yes	Right	Both	Married	Moderate anomia (70)	None (9.7)	2;6	1x weekly
12	43	F	Diploma	Educator	No	Right	Left	Single	Moderate Anomia (64)	Mild (8.6)	1; 3	1x weekly
13	60	M	Degree	Chartered accountant, chairperson	No	Left	Both	Married	Moderate anomia (76)	Mild (9.4)	1; 1	1x weekly
14	58	M	Post-grad CA(tax)	Chartered accountant, tax	No	Right	Both	Married	Mild anomia (84)	Mild (9.3)	1;8	every 2 nd week
15	61	M	Matric	Director	No	Right	Left	Married	Severe Broca's (25)	Mild-mod (6.6)	1;6	2x weekly

Table 3.10

Descriptive Information for Significant Others

Participant	Age	Gender	Languages spoken	Education	Occupation	Relationship to adult with aphasia	Resides with adult with aphasia	Time period of relationship (years; months)	Communication frequency with adult with aphasia
1	56	F	English	Post graduate	Custom care manager	Sister	Yes	56;0	Daily
2	47	M	English, Afrikaans	Matric	Self-employed	Friend	No	3;0	Often as possible
3	43	M	English, Afrikaans	Post-graduate	Attorney	Friend	No	6;0	At least once weekly
4	23	M	English	Diploma	Personal trainer, fitness instructor	Son-in-law	No	3;11	3-4x weekly
5	42	M	English	Matric	Self-employed	Friend	No	4;0	Daily
6	44	F	English, Afrikaans	Matric	Home executive	Wife	Yes	20;6	Daily
7	44	F	English, Afrikaans	Post-grad	Marketing director	Daughter	No	44;0	Several times a week
8	60	M	English, Afrikaans	Matric	Business owner	Husband	Yes	38;0	Daily
9	34	F	English, Afrikaans	Standard 8 or lower	Home executive	Fiancé	Yes	24;0	Daily
10	66	F	English, Afrikaans	College	Home executive	Wife	Yes	44;0	Daily
11	67	F	English, Hebrew	Matric	Sales manager	Wife	Yes	42;0	Daily
12	51	F	English, Zulu, Tsonga	Degree	Financial consultant	Sister	Temporarily	43;0	Daily
13	58	F	English, Spanish	Post-graduate	Home executive	Wife	Yes	40;0	Daily
14	57	F	English	Matric	Home executive	Wife	Yes	40;0	Daily
15	58	F	English	Matric	Book keeper	Wife	Yes	40;0	Often

Table 3.11

Descriptive Information for SLPs

Participant	Age	Gender	Qualification	Time spent in neuro-rehabilitation (years;months)	Period of time working with adult with aphasia (years;months)	Frequency of therapy with adult with aphasia	How goals are determined				Standardized test
							Informal assessment	Observations	Family input	Client input	
1	26	F	BSc SLP	1;8	1;0	1x weekly	X	X	X	X	
2	29	F	BSc SLP	5;0	2;0	3x weekly	X	X		X	
3	26	F	BSc SLP	1;8	1;0	3x weekly	X	X		X	
4	29	F	BSc SLP	5;0	1;0	2x weekly	X	X		X	
5	29	F	BSc SLP	6;0	1;0	3x weekly	X	X		X	
6	38	F	MA SLP	1;5	1;5	Daily	X	X		X	
7	31	F	BA S & H Th, MAAC	9;0	0;4	once, every two weeks	X	X			
8	27	F	B Comm Path	2;0	2;0	5x weekly	X	X		X	
9	27	F	B Comm Path (SP)	2;0	0;9	5x weekly	X	X	X	X	
10	42	F	BA S & H Th	20;0	2;0	2x weekly	X	X	X	X	X
11	42	F	BA S & H Th	20;0	2;0	2x weekly	X	X	X	X	X
12	29	F	BSc SLP	5;5	1;0	1x weekly	X	X		X	
13	29	F	BSc SLP	6;0	1;0	2x weekly	X	X		X	
14	27	F	B Comm Path (SLT)	3;0	1;6	Once every two weeks	X	X	X	X	X
15	42	F	BA S & H Th	1;8	1;0	2x weekly	X	X	X	X	X

3.7. Materials and equipment

3.7.1 Equipment

A video camera (Sanyo, model: Xacti) and Ipad 2) was used to capture the Talking Mats™ interview conducted with the adult with aphasia. A digital camera (Sanyo, model: Xacti) was used to record the completed Talking Mats™ interview mat.

3.7.2 Materials

3.7.2.1 Biographical questionnaires

Biographical questionnaires were given to the adults with aphasia, the significant others and the SLPs to gather relevant background information on the participants, the rehabilitation programme and the relationship between the adults with aphasia and their significant others. These questionnaires are provided in Appendices J-L.

3.7.2.2 Screening task

Nine Picture Communication Symbols™¹ (PCS) line drawings printed on 4.5 cm.x.4.5.cm cards were used for the screening task (Appendix M). This screener is based on Harty et al. (2011). A textured mat (39 x 34 cm) with three category cards representing a three-point rating scale (*Yes, Maybe and No*) was used to provide adults with aphasia with an opportunity to give their responses (see Appendix N).

3.7.2.3 Western Aphasia Battery (WAB)

Subtests from the WAB (Kertesz, 1982) were used to determine the severity of language difficulties. The WAB is designed to evaluate the main clinical areas of language function. The AQ is the Aphasia Quotient and indicates the severity level of aphasia. It is calculated by adding the total scores of the oral language subtests (spontaneous speech-information content and fluency-comprehension, repetition and naming) and multiplying the

¹ Picture Communication Symbols are a registered trade mark of Dynavox Mayer-Johnson, Pittsburgh, PA.

total by two, to arrive at a maximum of 50. The receptive language scores were also included to understand the receptive language severity levels. The comprehension subtests were used to obtain the severity level of the receptive language. The receptive language score is obtained by adding the scores of the comprehension subtests (yes/no questions, auditory word recognition and sequential commands) and dividing the sum by 20 to arrive at a maximum of 10 points.

3.7.2.4 Material used for the Talking Mats™ interview

Nine 4.5 cm x 4.5 cm topic cards that depicted the nine individual activities and participation domains of the ICF were used during the study (Harty et al., 2011) (see Appendix O). The nine activities and participation domains of the ICF included: *Domestic Life, Relationships, Work and Education, Leisure, Self Care, Learning and Thinking, Coping, Communication and Mobility*. These items from the ICF were depicted using PCS (Harty et al., 2011; Bornman & Murphy, 2006). The pictorial representation of complex concepts has allowed adults with communication difficulties to participate in the identification of rehabilitation priorities (Harty et al., 2011).

The same textured mat (comprising of three category cards representing a three-point rating scale (*Yes, Maybe and No*) as those used for the screener) (Section 3.6.2.2) was used for the Talking Mats™ interviews to enable adults with aphasia to classify the nine domains.

3.7.2.5 Rating scale

A written rating scale was provided for significant others and SLPs and (Appendix P). The rating scale consisted of an introductory question, asking participants to rate each of the nine ICF domains in terms of whether or not they saw this domain as important for the adult with aphasia to work on in rehabilitation. Each domain was then given a three-point rating scale. Comments could be written adjacent to the rating of each domain. A page of the domain descriptions was also provided together with the questionnaires to give examples of items under each domain (Appendix Q).

3.8. Procedures

3.8.1 Ethical issues

Approval for the study was obtained from the Research Ethics Committee of the Faculty of Humanities, University of Pretoria (Appendix G).

A study involving human participants needs to follow the principles of autonomy, beneficence and confidentiality (McMillan & Schumacher, 2010). The process of obtaining informed consent is very important to ensure that all participants are fully aware of and understand their role in the study as well as their autonomy and right to choose to participate (Penn, Frankel, Watermeyer, & Muller, 2008). Informed consent was obtained from all participants. Additional measures were taken to ensure that adults with aphasia had the opportunity to grant informed consent without being coerced, and with full knowledge of the study (Murphy, Gray, & Cox, 2007). This involved having the researcher read through the second information letter and the consent forms for those adults with aphasia who required the assistance. Others read their consent forms independently. Visual aids (pictures) were included in the consent form for the adults with aphasia to enhance understanding (Appendix B). Information letters and consent forms were provided for the significant others (Appendix C) and SLPs (Appendix D). The significant other was present to observe the adult with aphasia give his/her consent and was requested to ensure that the adult with aphasia understood the study and gave consent without being forced or coerced (Appendix E). Ongoing consent was followed, whereby the researcher ensured that the participant with aphasia was aware of what was expected of him/her and gave opportunities for the participant to indicate whether he/she understood and was willing to continue. The researcher asked the adult with aphasia if he/she was willing to continue after each question in the Talking Mats™ interview (Murphy et al., 2007; McMillan & Schumacher, 2006). Some participants who had no or mild receptive language fallout often demonstrated their wish to continue with the next question (via body language, eye contact) without being asked directly. Some participants with mild-moderate receptive difficulties were occasionally more reliant on the researcher to ask if they wished to continue. The researcher ensured they understood each question by implementing repetition and clarification. The participants could withdraw from the study at any time. Should a participant have wished to withdraw, the procedure was stopped and his/her data was excluded from the study.

The principles of non-maleficence and beneficence require that participation in the study should not harm or actively benefit the participants. The researcher avoided any possible negative consequences of participation by conducting the study outside of the times in which participants had scheduled therapy and in an environment that was familiar to the participants (at their respective homes or therapy rooms of the private practice). The Talking Mats™ framework that was used to conduct the interviews with the adults with aphasia provided a format for participants to rate the importance of the domains to work on in terms of their rehabilitation and to voice their needs in these areas.

Confidentiality was upheld by ensuring that all responses to the interview and the questionnaires were kept confidential. The researcher offered to provide the teams with a Talking Mat™ and the nine ICF topic cards, should teams wish to discuss the importance of domains for future goal setting within a clinical setting. All teams requested results and fourteen teams showed an interest in obtaining the topic cards. After the study, participants received overall results across the teams. Team members were also provided with their own responses in written format and could decide whether they wanted to share responses with the other members of their team.

3.8.2 Screening of participants

At the first meeting, participants were provided with biographical questionnaires to complete (Appendices J - L). The significant other or researcher could assist the adult with aphasia to complete the questionnaire.

The subtests from the WAB (Kertesz, 1982), including spontaneous speech, comprehension, repetition and naming, were conducted with the adult with aphasia to determine the aphasia severity level. All adults with aphasia met the inclusion criteria (Tables 3.6 and 3.8).

The researcher conducted a screening task with the adult with aphasia, based on previously published studies (Harty et al. ,2011; Beringer et al. ,2012) with adults with acquired communication difficulties, including aphasia. This task aimed to ensure that participants had the visual abilities to take part in the Talking Mats™ interview and were

able to comprehend the task. The screening task included nine PCS symbols (Appendix M). The adult with aphasia was asked to determine the importance of each item (depicted on the card) for survival, and was required to respond by using the Talking Mats™ format. They were required to place the item cards under one of the following headings: *Yes*, *Maybe* or *No*. Each heading was supported by a pictorial image (Appendix N). In order to qualify for inclusion, participants were required to place the three item cards depicting *food*, *water* and *air* under the heading *Yes*. *Clothing* and *housing* could be placed under the headings *Yes* or *Maybe*. *Having a tennis racket*, *having a dog*, *having a television* and *having a cell phone* could be placed under any heading. All adults with aphasia passed this screening.

3.8.3 Data collection

Significant others and SLPs were required to complete questionnaires to rate the importance of each ICF domain for the adult with aphasia, as well as to provide appropriate comments or examples under each domain. A page of the domain descriptions was attached to the questionnaires to provide examples of items under each domain (Appendix Q). These descriptions were verbally explained to significant others and those SLPs who attended the meeting. The significant others and two SLPs completed their questionnaires in separate rooms, to ensure that they did not influence each other's responses. They were asked to return the questionnaire to the researcher once completed. The 13 SLPs who could not be present at the time of this meeting, were contacted a few days before the scheduled meeting, either telephonically or via e-mail. The consent forms, biographical questionnaires and domain questionnaires were emailed to them for completion. An instruction brief (Appendix F) was also e-mailed to reiterate the procedures and requirements. It was also emphasised that SLPs were not to share their responses with their clients. The SLPs returned their information on the same day. The data collection was coordinated in such a way that the adults with aphasia would not have seen the SLPs on the same day that the interviews were conducted and therefore would not have an opportunity to discuss responses.

Adults with aphasia completed their rating of the nine ICF domains through a Talking Mats™ interview with the researcher. All interviews were held directly after completion of the language assessment and screening task, in the same session. Time taken to complete the interviews ranged from one hour to two hours.

During the interview, adults with aphasia were presented with nine cards with PCS symbols relating to the activities and participation domains of the ICF (Appendix O). A description of each domain was provided in written form and read aloud in order to provide examples for the participants (Appendix Q). Each domain was described to the adult with aphasia and then they were required to rate the importance of improving this aspect of their life. The researcher followed a set script (Appendix R). Participants were required to respond to the same question posed for each domain, namely “Is it important for you to work on improving [name of domain] in your life?” They were required to respond by placing the domain card under the appropriate heading on the Talking Mats™ format, as well as verbally, if possible. For example, the researcher would show them the *Self Care* card and ask, ‘Is it important for you to work on improving self care in your life?’ and they could answer by placing the card on the mat under *Yes*, *Maybe* or *No*. After placement of the card, or on completion of all nine questions, participants were asked to comment on each domain as they felt appropriate. For example, adults with aphasia could explain why they rated a domain in a particular way and if there were specific items within that domain that they wanted to mention:

Adult with aphasia (AA) 12: “I can't engage in a conversation. I hardly engage. Yes...Reading. I hardly er, ...reading...is hard”.

AA 5: “...let me, er...file my nails...”.

After the nine domain cards were placed on the mat, the adults with aphasia were asked to check that they were satisfied with their choices. If adults with aphasia hesitated or looked unsure or verbalised that they wanted to make a change, they were given the opportunity to change placement of the domain cards if they so wished. All of the adults with aphasia were satisfied with their responses. Once they were satisfied, a photograph of the completed mat was taken. The Talking Mats™ interviews were video-recorded for analysis for both procedural and data reliability.

3.8.9 Data analysis

Information obtained from the biographical questionnaires was documented in tables. This information was used to describe teams and groups. The responses provided by all

individuals and teams were transcribed from the digital photographs of the completed Talking Mats™ interviews and from the completed questionnaires onto MS Excel spreadsheets. The frequency of *Yes*, *Maybe* and *No* responses for each domain and within each group (adults with aphasia, significant others and SLPs), were calculated and converted into percentages using descriptive statistics. From these frequencies and percentages, the domains selected as most important by each group could be identified in order to address the first three aims. The Fisher's exact test was used to determine if there was a statistically significant difference between the groups in terms of the domains that were rated as important (McMillan & Schumacher, 2006). Descriptive statistics were used to show the number of teams (each team consisting of an adult with aphasia, his/her respective significant other and SLP) who selected the same responses for domains and therefore demonstrated team consensus in terms of domain importance. To describe how much agreement existed within a team, the number of times team members gave the same ratings to a domain was noted and added, (i.e. all three team members rated *Yes*, or all three rated *Maybe*, or all three rated *No* for a specific domain). The number of times team members demonstrated no consensus (all three responses, namely *Yes*, *Maybe* and *No*. varied, i.e. different responses were given for a specific domain) was also noted and added.

Table 3.12

Study Aims and Type of Analysis Conducted.

Aim	Analysis
Aim 1: Rating of domains by adults with aphasias	Descriptive statistics
Aim 2: Rating of domains by significant others	
Aim 3: Rating of domains by SLPs	Descriptive statistics
	Descriptive statistics
Aim 4: Comparisons of ratings given by the three groups	Fisher's exact test

3.8.10 Validity

Two specific threats to internal validity of a descriptive survey design are a reduced response rate and participant effects (Schumacher & McMillan, 2010). To ensure a good

response rate, the researcher set up the initial interview to meet the relevant persons as soon as possible, once they had indicated an interest in the study. In this way, a time delay and consequent loss of interest in the research study was prevented. Participant responses were kept confidential. Participants were made aware of this to further encourage truthful responses. Participants were also supplied with information related to items within the domains, so that they had a good understanding of the domains and could make an informed decision regarding the relevance of this domain in their rehabilitation, thereby further ensuring valid data. This decreased the possibility of participant effects.

Due to their language difficulties, it was important to establish that adults with aphasia understood the task and did not randomly assign domain cards to the Talking Mat™. It was clear that all adults with aphasia considered their responses carefully. Sometimes adults hesitated in their responses, vocalizing *um* or moving a card between the *Yes* and *No* options. Others commented verbally when they were not sure which option to choose, such as *Ja but I can't, you see...either here* (indicated maybe) *or there* (indicated yes). Sometimes the adults explained their hesitation, and this often related to some aspects of the domain being seen as important while another aspect of the same domain was not seen as important. For example, referring to the *Work and Education* domain, a couple of participants referred to the *earning money and finances* aspect within the domain, and commented on this item, saying that aspect was important to them, rather than the *study and education* aspect that falls under the same domain. Adults with aphasia also often provided verbal, nonverbal, and sometimes both verbal and nonverbal explanations for the reasons behind their selection and placement of important domains on the mat. Nonverbal explanations consisted of gestures, vocalisations, eye contact, facial expression and body language. These findings indicate that the adults with aphasia carefully considered the placement of the domain cards. All adults with aphasia passed the screening.

3.8.12 Procedural integrity

The researcher read from a script when introducing and explaining the ICF domains for rehabilitation to the participants (Appendix A). A script was also used when conducting the Talking Mats™ supported interview with the adults with aphasia (Appendix R), in order to minimize possible experimenter effects (McMillan & Schumacher, 2010). The screening tasks and the Talking Mats™ interviews were video-recorded. A post-graduate research

student in Psychology watched 30% of the video-recordings and completed checklists to determine to what extent the researcher followed the proposed procedures (Appendix S). Procedural integrity was expressed as a percentage and was calculated by using the following formula:

$$\frac{\text{Number of correctly computed steps}}{\text{Total number of steps}} \times 100$$

= Procedural reliability (%) (McMillan & Schumacher, 2010)

$$\frac{430}{495} \times 100$$

= 86.9%

Procedural integrity was high, at 86,9%, indicating good procedural consistency (McMillan & Schumacher, 2010).

3.8.13 Reliability of data collected

Data from the questionnaires and the digital photographs of the Talking Mats™ interviews were captured onto an MS Excel spreadsheet. A research student in Psychology was asked to independently transfer the data from 30% of the questionnaires and digital photographs of the Talking Mats™ interviews, also onto an MS Excel spreadsheet. Percentage agreement (McMillan & Schumacher, 2006) was calculated to determine whether the researcher recorded this data correctly. The formula is as follows:

$$\frac{\text{total number of agreements}}{\text{total number of agreements} + \text{disagreements}} \times 100$$

= Percentage agreement (%) (McMillan & Schumacher, 2010).

$$\frac{135}{135 + 0} \times 100 = 100$$

Agreement was 100%, indicating good reliability (McMillan & Schumacher, 2010).

3.9. Summary

The research methodology was described in this chapter. The aim, sub-aims, and research design were explained. The recruitment and selection of participants was described. The pilot study procedures and results were provided, as well as the recommendations from the pilot study. The material and equipment used in the study was described. The procedures for the screening of participants and also for collecting the data were given. Finally, the procedures to analyse the data as well as methods to determine procedural integrity and reliability of data collection were described.

CHAPTER 4

Results and discussion

4.1 Introduction

The results of this study are presented and discussed in this chapter. The results are presented and discussed according to the four sub-aims of the study as described in Chapter 3. Firstly, the ratings given by the adults with aphasia regarding the importance of the nine activities and participation domains of the International Classification of Functioning, Disability and health (ICF) for their rehabilitation are described. Secondly, the ratings given by the significant others regarding the importance of the nine activities and participation domains of the ICF for the adults with aphasia are described. Thirdly, the ratings given by the speech-language pathologists (SLPs) regarding the important domains of the nine activities and participation domains of the ICF for adults with aphasia are described. Fourthly, the ratings of the adults with aphasia, the significant others and SLPs are compared and discussed. Verbatim comments are provided to exemplify findings.

4.2 Ratings by adults with aphasia

The percentages of *Yes*, *Maybe* and *No* ratings of the nine ICF domains provided by adults with aphasia are presented in Figure 4.1.

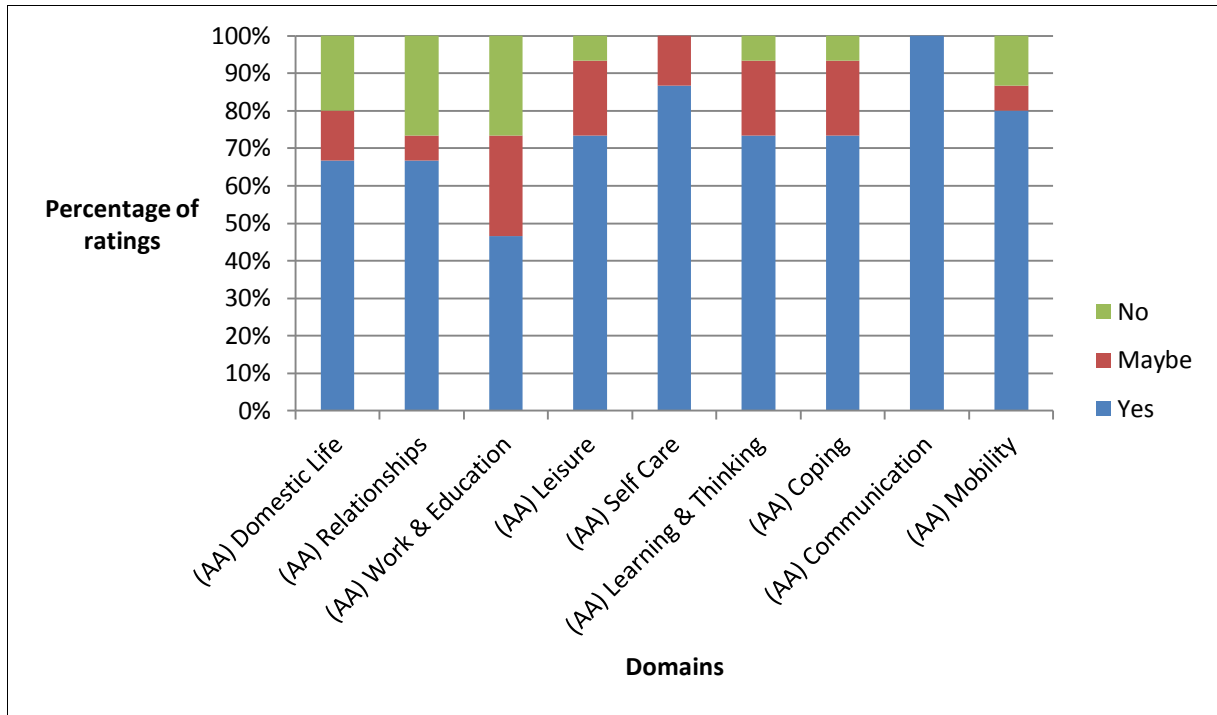


Figure 4.1. The percentages of *Yes*, *Maybe* and *No* ratings for the nine ICF domains provided by adults with aphasia.

All domains received more *Yes* ratings than *Maybe* or *No* ratings. The highest percentages of *Yes*-ratings within this study were given for the following domains: *Communication* (100%), *Self Care* (86.7%), *Mobility* (80%) and *Leisure, Learning and Thinking* and *Coping* (73.3%) respectively. These domains were all identified as important domains for rehabilitation by the adults with aphasia. The highest percentages of *Maybe* ratings included: *Work and Education* (26.6%) and *Leisure, Learning and Thinking* and *Coping* (20%) respectively. The highest percentages of *No* ratings were given for *Relationships* and *Work and Education* (26.6% each), and *Domestic Life* (20%). Overall, 74% of the domains received a *Yes* rating, 14% received a *Maybe* rating and 11.9% received a *No* rating.

The *Communication* domain was rated as important by 100% of the adults with aphasia in this study. Some adults with aphasia in this study commented on their communicative difficulties:

AA3: “Well of course that's important, it's very important. ...it's only when you lose the ability to talk, that you then only know how important communication is.”

AA 12: “I can't engage in a conversation. I hardly engage. Yes...Reading. I hardly er, ...reading...is hard”.

Due to the communication difficulties experienced by adults with aphasia, it is not surprising that the *Communication* domain was rated important by all the adults with aphasia. Adults with aphasia experience expressive language difficulties that have an impact on the extent to which they are able to participate in conversational interactions effectively and efficiently; therefore participation in higher level language tasks, such as goal setting, can be difficult (Worrall et al., 2011; Rohde, Townley-O'Neill, Trendall, Worrall & Cornwell, 2012).

Self-Care was a domain rated important by adults with aphasia within this study. Adults with aphasia commented on different items within this domain that were important to them to work on in rehabilitation:

AA 5: “...I wanted to file my nails and I had a breakdown because I um, couldn't. And I can dress myself and...I brush my teeth, put make up on and everything, but a a...little things is coming through the front now and my mom see to trim my nails...you know ...little things and I can't um um...blow dry my hair”.

This shows that *Self Care* is a domain that requires focus. This domain is focussed more on activities of daily living (AsDL) such as the ability to dress and wash and groom oneself, and is therefore less focussed on communication, yet adults with aphasia identified difficulties within this domain. They are therefore able to view all areas of life participation, and are not only focussed on communication difficulties. A study conducted in Sweden by Holfgren, Bjorkdahl, Esbjornsson, & Stibrant-Sunnerhagen, (2007) showed that both cognitive function and AsDL improve in the first year after stroke, however, 20% of people

still required assistance in care activities at this time. Hence, adults with aphasia in this study, rated *Self Care* as important to work on in rehabilitation.

The *Relationships* domain was one of the highest *No* rated domains (26.6%) for adults with aphasia. Although 66.7% rated this domain as a *Yes*, it was not one of the highest rated *Yes* domains. About a quarter of the adults with aphasia felt they did not need to improve in this domain. Those adults with aphasia who rated the domain *No* felt that they had the relevant people in their lives and did not see this as a domain to work on improving. One adult commented as follows in this regard:

AA 5: “No. My relationships; I have the best, best, best friends in the whole wide world. And I can only say thank you, thank you, thank you, and my relationships with even the people from rehab... I feel so comfortable coming here and um, my husband died at the age of forty in a car crash...And um, you know I have never met somebody that could fill his place...”.

Others highlighted the importance of relationships with many people in their lives and the contribution these people have in their lives and therefore rated this domain as *Yes*:

AA 14: “Yes it is. It is important. Um...right um, my wife, friends, everyone...I think it's important to always be understanding, always thinking about other people, keep in touch with them, and...um you know, whether it's from our kids or friends...we always like to keep in touch with everyone...”

Aphasia is known to have an impact on social communication and friendships (Howe et al., 2008) and it can cause social withdrawal, isolation and frustration (Darrigrand et al., 2011). In this study it can be seen that some people are continuously aware of making connections with people. Others already had relationships that may have continued after the stroke, and did not see the need to specifically create or build on other relationships. A number of factors could influence this and one of these could be the fact that communicating is not as simple as it was prior to the stroke. Some studies showed how adults with aphasia long to participate in social conversations, but required the assistance of communication partners and communication strategies (Johansson et al., 2011). In a Finnish study conducted by Rautakoski (2014), it was found that adults with aphasia engage less with people other

than their significant others and Cruice, Worrall & Hickson, (2006) found that social relationships with people with aphasia mostly include the immediate or extended family only. It seems that in this study, some of the adults with aphasia were comfortable in communicating with well-known family members and friends, who could perhaps assist with communication strategies:

AA11: “For relationships with my wife and me we must get on together, but uh, other - other relationships, I dunno”.

Clearly, the *Work and Education* domain within this study was less important to adults with aphasia; with *Maybe* and *No* ratings making up more than half of the ratings (53.2%) for this domain.

With regards to a *No* rating, AA14: “...in my case, I've been working for a long time and er, if it was, if I'd got sick perhaps ten...years earlier or something like that, this might have been at the top. But now it's not really a major issue.”

It must also be acknowledged that many factors influence work return, including communication difficulties and barriers such as speaking on the telephone and interacting with unfamiliar clients (Garcia, Barrette & Laroche, 2000). Good concentration, speed of visuo-motor skills and communicative ability are factors noted to aid the possibility of return to work after stroke. Communication, therefore, plays an important role in this domain (Holfgren et al., 2007). Adults with aphasia do not have adequate communication abilities to be functioning at work in the same capacity as previously. Many of the adults with aphasia in this study did not see work return or further education as an important domain, potentially due to their age and change in priorities since the stroke. In the study by Holfgren et al. (2007), few people had returned to work one year after discharge and only 20% of people returned to work three years later. In this study two adults with aphasia were currently working, whereas the remaining 13 were not.

Four adults with aphasia commented on how they saw domains inter-linking, which further emphasises the importance of the activities and participation domains in their daily lives.

AA 10: "...it (coping) links to communication and learning and thinking. ...learning and thinking links to communication...I have to ...think before speaking..."

AA 3: "...To cope on a day to day basis. ...although there is a bit of overlapping...Because a lot of these other areas (domains) also actually incorporate what it means to cope."

These adults with aphasia felt that the domains including *Communication*, *Learning and Thinking* and *Coping* were closely inter-related and that one domain had an impact on the other. Other studies have not commented on the domains that may interlink. It is yet to be determined whether difficulties in one domain are likely to lead to difficulties in another domain.

Two other studies investigated the priorities of adults with aphasia and/or acquired neurological conditions for their rehabilitation. The first involved prioritising rehabilitation domains using the activities and participation domains of the ICF framework in an acute rehabilitation facility with 12 adults with communication difficulties and 20 of their respective rehabilitation professionals (Harty et al., 2011). Direct comparisons cannot be made between this study and the study conducted by Harty et al., (2011), since different rating scales were used in each study; however, similar trends can be noted. The ratings by adults with communication difficulties for the nine ICF domains in the Harty et al., (2011) study indicated that most adults rated the domains as important. This links with current findings, where eight of the nine domains received over 50% *Yes* ratings. The *Self Care* domain was rated as important in both studies—it received the highest average score for importance (an average score equal to that given to one other domain and higher than that of the remaining seven domains) in the study by Harty et al. (2011) and it received the second-highest number of *Yes* ratings in the current study. Similarly, the domain *Relationships* received the third lowest average score for importance in the study by Harty et al. (2011) and also received less *Yes* ratings than six other domains in the current study. *Communication*, receiving the most *Yes* ratings in the current study, received the second-highest average score in the study by Harty et al. (2011). On the other hand, *Work and Education* received the least *Yes* ratings in the current study, whereas it received the highest average score for importance in the study by Harty et al., equal to the average score allocated to *Self Care*.

The adults in the study by Harty et al. (2011) were therefore slightly less focussed on the *Communication* domain, but more focussed on the *Work and Education* domain. Most of the adults in the study by Harty et al. (2011) had mild expressive communication problems, whereas the majority of adults with aphasia in this study had moderate to severe expressive problems, which may account for the fact that the *Communication* domain was rated differently. The adults in the study by Harty et al (2011) were also younger on average, which may have meant that *Work and Education* was more relevant to that group. However, participants in the two studies differed on a number of aspects, including time post onset (acute versus chronic stage) and diagnosis. Differences in the results could stem from any of these factors.

In the second study Worrall et al. (2011) asked adults with aphasia to identify priorities and goals for rehabilitation during semi-structured in-depth interviews. A percentage of the participant's responses were then also coded using the ICF. Nine categories of goals that were selected by adults with aphasia were described, and some of these categories included: improved communication, physical function and health, as well as participation in social life, work and leisure activities. The authors found that goals linked most closely with the *Activities* and *Participation* domains of the ICF. The high percentage of *Yes* ratings given by adults with aphasia in the current study supports the findings of Worrall et al., (2011), and taken together, both studies support that the *Activities and Participation* domains of the ICF are relevant to the priorities and goals that adults with aphasia identify for their own rehabilitation. Both studies confirm that people with aphasia feel the effect of aphasia in a variety of life areas, such as relationships, leisure and work aspects.

4.3 Ratings by significant others

The percentages of *Yes*, *Maybe* and *No* ratings of the nine ICF domains provided by significant others are presented in Figure 4.2.

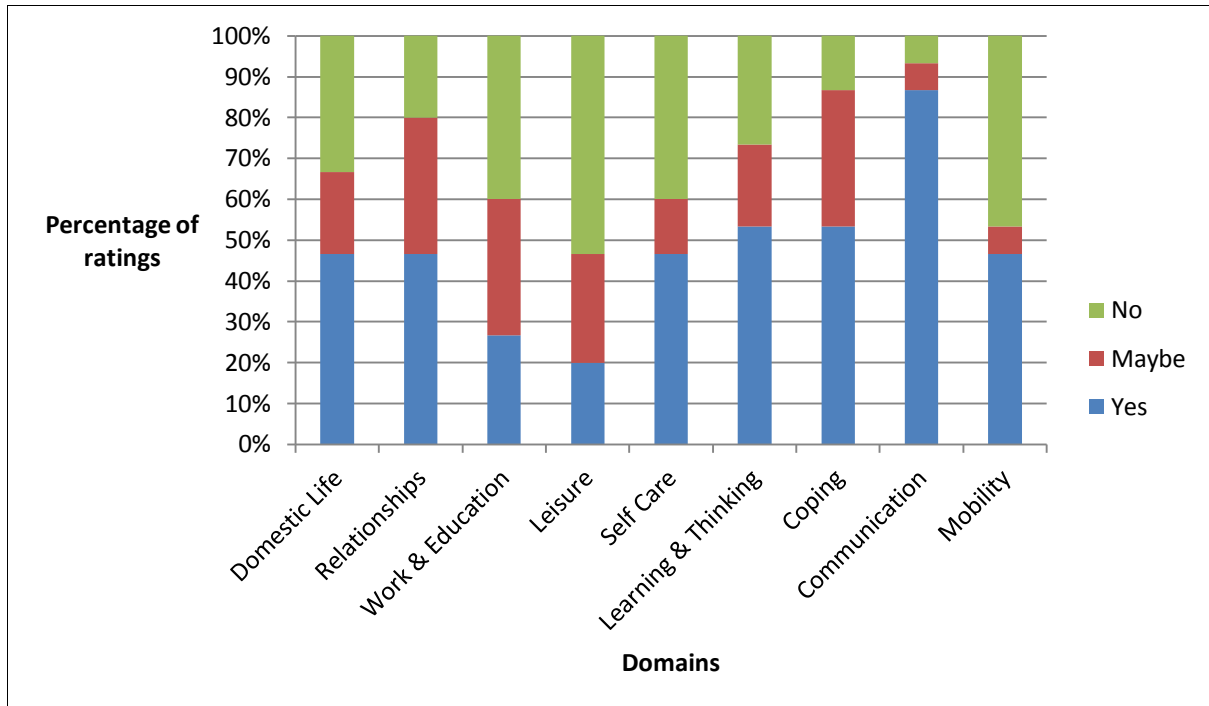


Figure 4.2. The percentages of *Yes*, *Maybe* and *No* ratings for the nine ICF domains provided by significant others for adults with aphasia.

While six of the nine domains received more *Yes* than *No* ratings, significant others clearly gave more *Maybe* and *No* ratings than adults with aphasia did. The domains with the highest percentages of *Yes* ratings were: *Communication* (86.67%) and *Learning and Thinking* as well as *Coping* (53.3% each). The highest *No* ratings included: *Leisure* (53.3%), *Mobility* (46.7%), *Work and Education* and *Self Care* (40% each). The highest *Maybe* ratings were given for *Relationships*, *Work and Education* and *Coping* (33.3% each). Overall, 47,4% of the domains received a *Yes* rating, 21,48% received a *Maybe* rating, and 31,1% received a *No* rating.

Two of the domains rated mostly as important were *Communication* and *Coping*. Many of the significant others in this study were family members (spouse or child), or close friends, and therefore spent a great deal of time with adults with aphasia and experienced the daily communicative difficulties and stresses of the adults with aphasia (Johansson et al.,

2012). Identifying the difficulties with communication and coping, and assisting with communicative coping strategies in daily life situations are probably very familiar to these significant others. It is therefore not surprising that they identified *Coping* and *Communication* as important domains for the adults with aphasia. This links to studies conducted by Johansson et al., (2011); Worrall et al., (2010) and Visser-Meiley et al., (2006) who identified that significant others were very much involved and shared the daily stresses of communication interactions and restrictions.

Eight of the significant others commented on difficulties within the *Learning and Thinking* domain and the lack of focus in this area:

SO 12: “This is a little challenging, especially problem-solving. She does make decisions but this will be a challenge in a working environment”.

SO 13: “...but he tends to get confused when making appointments and often double books. Learning is difficult because of concentration issues”.

The above quotes emphasise that the significant others see some of the difficulties that the adults with aphasia experience on a daily basis.

The ratings from the significant others demonstrated that they did not feel all domains were important for the adults with aphasia to work on. Reasons may include insufficient time spent with the adult with aphasia to understand his/her management of various life domains. The highest *No* ratings included *Leisure, Mobility, Work and Education* and *Self Care*. These domains were rated *No* if significant others felt that the adults with aphasia were managing in these areas:

SO 4 regarding *Leisure*: “She regularly does gardening and takes her dogs for walks”.

SO 6 regarding *Self care*: “Able to look after himself. Can wash, dress, feed self”.

Others commented that domains, such as *Work and Education* were no longer relevant:

SO 7: “I don’t think this is important at mom’s stage of life”.

This particular adult with aphasia had retired from her work prior to her stroke. Other significant others explained the *No* rating by acknowledging that the respective adult with aphasia was currently working and was managing:

SO 11: “Good at work”.

The low *Yes* and *Maybe* ratings of these domains may have to do with how the significant others view the abilities of the adults with aphasia in the home and work environment. They did not view these domains as important to work on further in therapy.

Studies by Cruice, Worrall, Hickson and Murison (2005), and Hesketh, Long and Bowen (2001) showed that significant others perceived the disability to be worse than adults with aphasia perceived it; however, these differences were small. In this study the significant others seemed to think that less focus needed to be placed on the nine domains in the rehabilitation of the adult with aphasia in comparison to what adults with aphasia thought. There may be various reasons for this—they may have had a more positive view of the functioning of the adults with aphasia than the adults themselves had. They may also have perceived that certain domains (e.g. *Work and Education*) were not relevant to the lives of the adults with aphasia.

4.4 Ratings by SLPs

The percentages of *Yes*, *Maybe* and *No* ratings of the nine ICF domains provided by SLPs are presented in Figure 4.3.

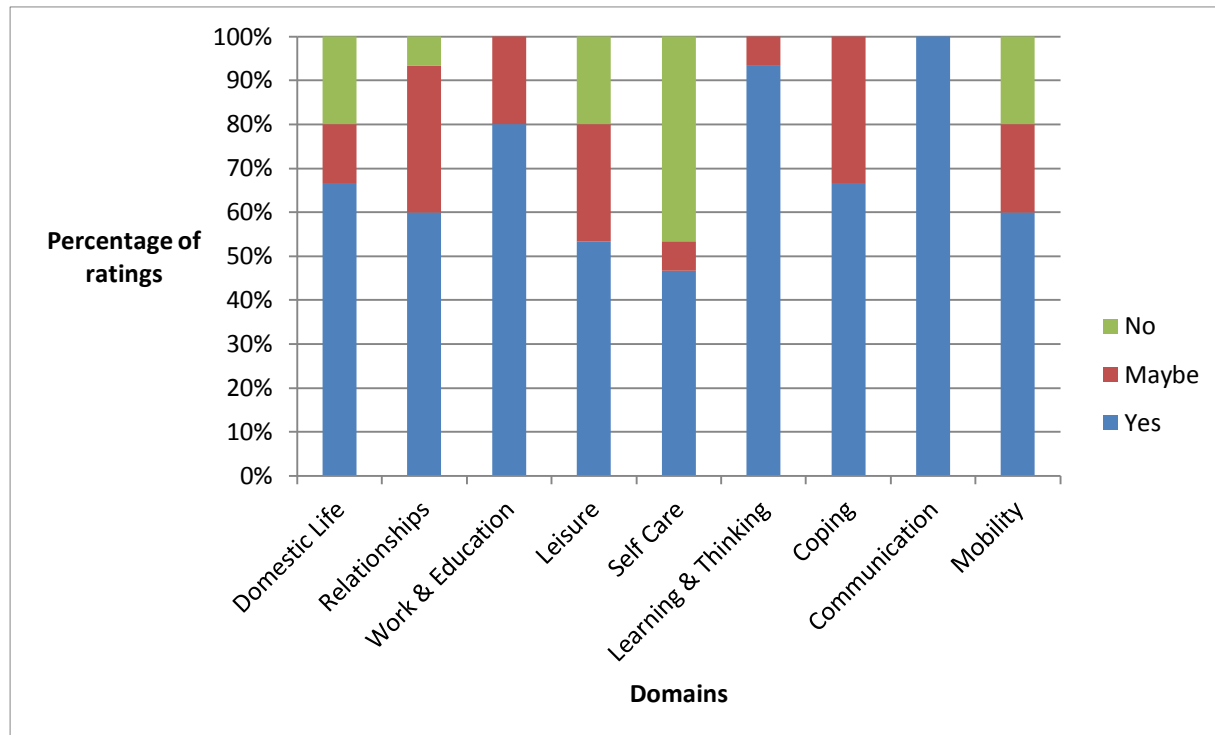


Figure 4.3. The *Yes*, *Maybe* and *No* ratings for the nine ICF domains provided by SLPs for adults with aphasia.

SLPs rated eight of the nine domains with more *Yes* than *No* ratings. They gave slightly more *Maybe* and *No* ratings than the adults with aphasia did. The highest percentage of *Yes* ratings were given for *Communication* (100%), *Learning and Thinking* (93.3%) and *Work and Education* (80%). The highest percentage of *Maybe* ratings were given for *Relationships* and *Coping* (33.3%), and *Leisure* (26.7%). The domain that received the highest *No* rating was *Self Care* (46.7%). Overall, 69.6% of the domains received a *Yes* rating, 17.8% received a *Maybe* rating and 12.6% received a *No* rating.

The fact that SLPs gave the most *Yes* ratings to the domains *Communication*, *Learning and Thinking* and *Working and Education*, may suggest that they selected domains that pertained to their scope of practise. The fact that more physically focussed domains (that is, the domains that pertain more to physical strength or movement, such as *Mobility* or *Self Care*, rather than communication,) were not rated as important, may suggest that some of the

SLPs felt the adults with aphasia had progressed well in these domains. These domains are also traditionally seen as the responsibility of the occupational therapist (Occupational Therapy Association of South Africa [OTASA], 2014) and physiotherapist (South African Society of Physiotherapy [SASP], 2008), and SLPs may not have been including these domains in their rehabilitation plan, since these domains do not fall within the communication-related focus that the SLP would be trained in (ASHA, 2007).

In terms of addressing the Communication domain, many SLPs commented on the importance of this area and its impact on other areas of life for the adult with aphasia:

SLP 12: “Her communication difficulties impact many aspects of her life - especially prevent her work return”.

The SLPs could also identify some specific goals in this domain:

SLP12: “Improve initiation and participation in social greetings, ...improve sentence construction. Improve her verbal output and participation in conversation (better use of strategies)”.

Many other comments mentioned that communication is a ‘priority’.

Regarding *Learning and Thinking*, SLPs commented as follows:

SLP 2: “Included in many goals in therapy and spoken about”.

SLP 3: “(He) is able to learn new material but at a much slower rate than before his CVA”.

SLP 12: “(Her) planning, thinking skills and memory are not great but her basic communication has been more of a focus”.

With reference to the *Work and Education* domain, some of the comments made were:

SLP 10: “Very important to get patient back into work environment, even if performing a different role”.

SLP 5: “Her communication difficulties affect her work return and she is very keen to return to work”.

SLPs occasionally commented on the connection between communication and work return (as seen in one of the above quotes). Studies show how SLPs are able to assist with the return to work process in terms of the communicative difficulties and barriers that may exist in a work environment and provide recommendations to compensate for difficulties, or may lessen barriers (Garcia, Laroche, & Barrette, 2002). SLPs need to assist with communicative work return goals, if this is indicated by the adult with aphasia and is a possibility (Garcia et al., 2002; Cassar, & Neilson, 1997).

The domain that received the highest *No* rating was *Self Care* (46.7%). SLPs did not consider *Self Care* an important domain to work on. It may have been perceived that many of the adults with aphasia were managing elements related to *Self Care* and this domain is therefore not addressed by SLPs, may not have been addressed or discussed in speech-language therapy sessions.

In the study by Harty et al. (2011), SLPs indicated that seven of the nine domains were rated as having high priority. The remaining two domains were regarded as neither important nor unimportant. Results from the current study show some similarities, in that most domains (eight of the nine) received *Yes* ratings more than 50% of the time. In both studies, SLPs therefore regarded most domains as important for rehabilitation. Three domains—*Communication*, *Mobility*, and *Relationships*—received only *Yes* ratings from the SLPs in Harty et al.’s study. In the current study, SLPs also rated *Communication* as a priority 100% of the time. *Relationships* and *Mobility*, however, were not rated as highly, receiving the third-lowest percentage of *Yes* ratings given by SLPs in the current study. It must be noted that many factors could account for the differences in results between the study conducted by Harty et al., (2011) and the current study. The participants in each study differed in terms of age, diagnosis, skills profile and stage post onset.

Brown et al. (2011) determined the perceptions of SLPs regarding the priorities of adults with aphasia for rehabilitation. The themes identified in the SLPs' responses included participation and community engagement, communication and meaningful relationships and independence. These themes link closely with the priorities that adults with aphasia identified for themselves in previous studies (Brown, Worrall, Davidson & Howe, 2010a, b, 2011). The SLPs taking part in the study by Brown et al.'s (2011) were therefore well aware that adults with aphasia tend to prioritise goals related to participation and life activities rather than focussing on discrete, discipline-specific goals. The results of the current study corroborate these findings, in that SLPs rated many of the activity and participation domains as important for the rehabilitation of their clients and were not only focussed on skills directly linked to communication. SLPs' scope of practice includes assessment and management of expressive and receptive language, cognitive-communication and speech, to name but a few areas (ASHA, 2007). It is easy to see how these aspects would influence performance and participation in domains such as *Communication, Learning and Thinking, Work and Education, and Relationships* (in terms of communication interactions and strategies). Links to domains such as *Mobility and Self Care* may be less obvious, although communication skills may influence participation in these domains (e.g., expressing needs, making choices and asking for assistance or directing others to perform care or transporting tasks). Although problems in these areas may be more likely addressed by an occupational or physiotherapist, SLPs nevertheless need to understand the adult with aphasia holistically; as well as be aware of problem areas and assist adults with aphasia to express concerns they have. In this way, they can ensure client-centred rehabilitation, which is seen as best practice (Constad & MacDermid, 2012; Brown et al., 2011; Lawrence & Kinn, 2011; Leach et al., 2010).

4.5 Comparison of the rating of domains

Table 4.1 presents the overall ratings of the domains given by the adults with aphasia, their significant others and SLPs.

Table 4.1

The Percentages of Yes, Maybe and No Ratings for each Domain across the Groups and Corresponding Fisher Exact test p-Values

Domain	Percentage of responses									p-value	Effect size
	AA			SLP			SO				
	Yes	Maybe	No	Yes	Maybe	No	Yes	Maybe	No		
Domestic life	67.67	13.33	20	66.67	13.33	20	46.67	20	33.33	0.8314	0.19
Relationships	66.67	6.67	26.67	60	33.33	6.67	46.67	33.33	37.50	0.2581	0.39
Work & Education	46.67	26.67	26.67	80	20	0	26.67	33.33	40	0.0233*	0.48
Leisure	73.33	20	6.67	53.33	26.67	20	20	26.67	53.33	0.0258*	0.49
Self care	86.67	13.33	0	46.67	6.67	46.67	46.67	13.33	40	0.0143*	0.46
Learning & Thinking	73.33	20	6.67	93.33	6.67	0	53.33	20	26.67	0.0963	0.42
Coping	73.33	20	6.67	66.67	33.33	0	53.33	33.33	13.33	0.6067	0.26
Communication	100	0	0	100	0	0	86.67	6.67	6.67	0.3182	0.30
Mobility	80	6.67	13.33	60	20	20	46.67	6.67	46.67	0.1892	0.38

Note: AA: adults with aphasia SO: significant others

Effect size: 0.1= small, 0.3= medium, 0.5= large (* $p < 0.05$)

Fisher's exact test was used to obtain the p-values and effect sizes. According to these values, the ratings did not differ significantly across the three groups (adults with aphasia, significant others and SLPs) for the following domains: *Domestic Life*, *Relationships*, *Learning and Thinking*, *Coping*, *Communication* and *Mobility*. Statistically significant differences were found in the response patterns for adults with aphasia, significant others and SLPs for the domains: *Work and Education* ($p = 0.0233$, medium effect size), *Leisure* ($p = 0.0258$, medium effect size), and *Self Care* ($p = 0.0143$, medium effect size).

Six domains (*Domestic Life*, *Relationships*, *Learning and Thinking*, *Coping*, *Communication* and *Mobility*) received similar ratings from the three groups. These domains were generally rated as important to work on in rehabilitation. These domains cover a broad scope of life areas, including physical, cognitive and social elements. All of these domains contribute to participation in life. This may mean that team members are aware of the pervasive nature of aphasia and the need for functional approaches.

Life participation needs to be addressed in aphasia rehabilitation (Boles & Lewis, 2003). Boles and Lewis (2003) discussed various studies that highlight the benefits of implementing life participation therapy rather than focus on the impairment-level, particularly for people who are at the chronic stage of recovery. Many studies included partner training, such as training of spouses or volunteers to improve their communication with adults with aphasia within various real communicative interactional settings (Boles & Lewis, 2003).

Three domains (*Work and Education*, *Leisure* and *Self Care*) were rated statistically significantly different across the three groups ($p = 0.0233$, 0.0258 and 0.0143 respectively).

For the *Self Care* domain, some of the comments made by the SLPs and significant others demonstrated that they felt that the respective adults with aphasia were managing with regards to the aspects of *Self Care*. However, the adults with aphasia still felt that this domain needed to be addressed in rehabilitation, also in terms of managing aspects of health:

AA 5: "I wanted to file my nails and I had a breakdown because I um, ...couldn't".

In this case, the adult with aphasia indicated that there were still areas she could work on within the *Self Care* domain. Her significant other, on the other hand, rated this domain

Maybe and the SLP rated it *No*. Her significant other is therefore aware of some areas within the *Self Care* domain that she could improve on, whereas the SLP may feel that she has mastered this area, and that it therefore does not require further attention or work.

In the current study, *Self care* was rated more important to work on by adults with aphasia than the significant others or SLPs. Significant others may not spend sufficient time with the adults with aphasia to understand how they may be managing in this particular domain or they may have perceived the management of the domain better than the adults with aphasia did. The SLPs, on the other hand, may not traditionally address this domain in therapy, as it is not communication-related.

Similar results were also obtained for the *Leisure* domain. Here too, the adults with aphasia rated it as important to include in their rehabilitation programme, more frequently than the other groups.

AA 14 "... having got ill but the positive side of having more time..."

This adult with aphasia rated that *Leisure* was important to work on, whereas both his significant other and SLP rated this domain *No*.

In this case, the significant other may not have felt that this domain was important. The SLP commented that this adult with aphasia was "independent" in this area. It seems that leisure time is a very important aspect of people's lives (Cruice, Worrall & Hickson, 2006). Some studies indicate that dependence in daily activities may mean that individuals will consequently have difficulty carrying out leisure tasks, which they used to prior to the stroke (Sjogren & Fugl-Meyer, 1982). Leisure activities are shown to give meaning to life, as opposed to other daily activities. Motor and processing skills are required for leisure activities and these aspects may be affected after stroke (Sveen, Thommessen, Bautz-Holter, Wyller&Laake, 2004).

For the *Work and Education* domain, 80% of the SLPs highlighted this as an important domain to work on, whereas only 47% of the adults with aphasia and the 27% of the significant others rated this domain as important to work on in rehabilitation. It is interesting that many of the SLPs saw this domain as a priority, whereas significant others

mostly did not. While SLPs can assist with the communicative areas of work return, it seems that some of the SLPs in this study were not in synchrony with their clients about their priorities for this domain. Some SLPs assumed that this domain needed to be worked on, while adults with aphasia and significant others did not rate it as important. The SLP in team 10 commented:

“Very important to get patient back to work environment, even if performing a different role”

However, in this particular case, the adult with aphasia was already working and he and his significant other rated the domain as not important to work on in rehabilitation.

Another SLP commented on how the communication difficulties impact work tasks:

SLP:14: “Due to (his) agraphia and alexia, he still has difficulty compensating and working at a pre-morbid level—it is one of the goals to improve his ability to complete basic work and education tasks independently”.

However, the adult with aphasia rated this domain as *Maybe*, saying that if his stroke occurred about ten years previously, it would perhaps be more important to work actively on this domain. His significant other did not rate this domain as important at all. This is perhaps an example of the clinician applying knowledge within her scope of practice; however, the end goal does not align with the perspectives of both the adult with aphasia and significant other.

Discrepancies across some of the domain ratings indicate that adults with aphasia, significant others and SLPs may be viewing domain importance from individual perspectives. This may impact identification of functional and meaningful goals that may be required in the home environment. Social integration can be affected if SLPs are not discussing social communication goals with the significant others and adults with aphasia. The relationship between the adult with aphasia and significant other may have an impact on how the significant other views the abilities of the adult with aphasia in this domain. Significant others who spend time with the adult with aphasia may have a better understanding of their capabilities (Johansson et al., 2012; Lawrence & Kinn, 2011; Johansson, Carlsson &

Sonnander, 2011; Hersh et al., 2012); however, these significant others may not spend time with adults with aphasia in a work context to understand their capabilities.

As discussed by Worrall (2010), goals change over time and people with aphasia see this, particularly in the chronic stages of stroke rehabilitation. They follow a short term goal setting process, often guided by the SLP, but as they realise their communication difficulties are more chronic, goals that incorporate their world need to be included and focussed upon. The best way to ensure this is to implement a client-family-centred approach to rehabilitation (Brown et al., 2011; Worrall et al., 2010; Visser-Meiley et al., 2006), meaning that SLPs and other rehabilitation professionals need to include adults with aphasia, as well as their significant others in the problem identification and goal setting process. Significant others understand some of the areas of difficulty that adults with aphasia experience at home and these needs to be shared and discussed in rehabilitation. Together with the adult with aphasia, problem areas can be identified and focussed upon in rehabilitation.

Results from this study show that the rating selected by adults with aphasia, significant others and SLPs are mostly the same, although differences still occurred. There is room for teams to further collaborate and communicate in these areas.

4.7. Summary

This chapter presented the results of the study, which were organised, analysed and described according to the sub-aims of the study. The results of the ratings of the nine ICF domains by adults with aphasia followed by the ratings of the significant others and SLPs, were described and discussed. The similarities and differences of the ratings given to the domains by adults with aphasia, significant others and SLPs were subsequently discussed.

CHAPTER 5

Summary and conclusion

5.1 Introduction

This chapter summarises and integrates the findings of the study. The study is evaluated in terms of its strengths and weaknesses. The implications for clinical practice in implementing the ICF in aphasia rehabilitation are discussed, as are recommendations for future research.

5.2 Summary

The activities and participation domains of the ICF provides a basis for teams to work from in rehabilitative planning. These domains provide a ‘common language’ for team members to identify problem areas related to functioning of people with disabilities in daily life. Adults with aphasia often have difficulty participating in the selection of rehabilitation priorities due to their communication difficulties. The Talking Mats™ tool can assist adults with aphasia to express their views regarding rehabilitation priorities using the domains of the ICF. Their views can then be compared to those of other team members.

The main aim of the study was to compare the ratings of the nine activities and participation domains of the ICF for the rehabilitation of adults with aphasia given by the adults with aphasia, their respective significant others and the SLPs treating them.

A family member or close friend (significant other) who knew the adult with aphasia well and who had some involvement in their rehabilitation was chosen to participate in the study. The adults with aphasia rated the importance of the domains using the Talking Mats™ tool. The significant other was requested to participate in the study by rating the important domains of the ICF for the rehabilitation of the respective adult with aphasia. The SLP was required to do the same.

For six domains, no statistically significant differences were found between the ratings given by the adults with aphasia, significant others and SLPs, indicating that all

groups had an understanding of the pervasive nature of aphasia as well as an understanding of the importance of addressing functional goals.

The *Communication* domain was given the highest rating of importance by adults with aphasia, significant others and SLPs, indicating that this domain is important to continue to work on in rehabilitation.

However, differences in overall ratings were still evident—adults with aphasia rated domains as important more frequently than the other two groups did, while significant others gave the least *Yes* ratings of all the groups. There was a statistically significant difference for three of the domains rated important for adults with aphasia, by the adults with aphasia, their significant others and SLPs, namely *Work and Education*, *Self Care* and *Leisure*. *Self Care* and *Leisure* were rated as important by most adults with aphasia, whereas most significant others did not see this domain as important. Approximately half of the SLPs rated these domains as important. SLPs mostly rated *Work and Education* as important to work on in rehabilitation, whereas adults with aphasia did so less frequently and significant others did so least of all groups. This may indicate that SLPs rated domains (such as *Work and Education*) that fell within their scope of practice and expertise to be important. Significant others may not have rated these domains as important to work on for the adults with aphasia due to various reasons. Reasons may include insufficient time spent with the adult with aphasia to understand his/her management of various life domains.

5.3 Critical evaluation of the study

This study has various strengths. It is the first that compares the perspectives of adults with aphasia, significant others and SLPs regarding the importance of the nine ICF activities and participation domains for rehabilitation.

A further strength is that the Talking Mats™ tool was effective for adults with aphasia to understand the process and express their rehabilitation priorities. This tool allows adults with aphasia to refer to visual options that supplements or replaces their expressive output.

The design used in this study allowed comparisons to be drawn between domains rated by adults with aphasia to the domains rated by significant others and SLPs.

The procedures (obtaining consent and screening of participants) used in the current study were previously also found to be effective (Beringer et al., 2013; Harty et al., 2011).

Despite three perspectives being determined, adults with aphasia, significant others and SLPs were able to express their responses independently of one another, which enhanced truthfulness and ensured confidentiality.

The limitations of the study included a small sample size, since only 15 adults with expressive aphasia, their respective significant others and SLPs participated in the study. The study targeted a very specific population of adults with aphasia with strict selection criteria making participant recruitment difficult. The findings of this study therefore have limited generalizability.

The relationships between the significant others and the adults with aphasia varied: seven dyads were married spouses, while others were sibling or parent-child relationships. Three were friendships rather than family relations. The type of relationship between the adult with aphasia and significant other could potentially have influenced how knowledgeable the significant other would be about the challenges that the adult with aphasia may experience in daily life. A friend, for example, would typically not be able to observe various self-care activities executed by the person with aphasia. The variation found in the types of relationships may have influenced the results and therefore these cannot be generalised to the larger population.

5.4 Clinical implications

One of the main clinical implications of this study is that adults with aphasia are able to identify ICF domains using the Talking Mat™ tool to express their problem areas for rehabilitation. In this way they have a choice in the selection of areas, which gives them control and a sense of independence. Some of the adults with aphasia were able to comment on the items within the domains to identify the specific areas that were important to them. Within a clinical setting, domains could be ranked and items within domains could be discussed in more detail for rehabilitative planning.

The use of the activities and participation domains within the Talking Mats™ framework provided adults with aphasia and their team members (significant others and SLPs) with a format to identify problem areas in rehabilitation. It also gave all participants the opportunity to analyse some domains in terms of how important it is for them to work on those domains in rehabilitation. Participants were eager to discuss their thoughts and perspectives with their team members and it was suggested that they use this format within a clinical setting which may be of value in future identification of problem areas and to use the ratings as a starting point to set goals for rehabilitation.

5.5 Recommendations for future research

Some trends were identified from the results of this study and future research could further investigate these trends:

- The study could be replicated with a larger sample of adults with aphasia, their significant others and rehabilitation professionals in order to generalise the findings to the broader population of adults with aphasia.
- Problem areas identified in this study could be used for future goal setting. In this study, the domains rated as important to work on only identify broad areas of focus and therefore it may be necessary for future studies to prioritise domains and to conduct case studies to identify the relevant items within the prioritised domain. This could be used as a basis for goal setting within the team.
- Qualitative case or phenomenological studies could be conducted to explore how the ICF domains may facilitate team dialogue and consensus building in the rehabilitation of adults with aphasia. Teams may be given guidance as to how to start this process, and reflect on their experience. In this way, the advantages and challenges of using the ICF for team consensus building may be highlighted.
- A study could be conducted that obtains the perspectives of other professionals who are typically involved in providing rehabilitation services to adults with aphasia, for example, physiotherapists, occupational therapists and psychologists. These health professionals are all part of the rehabilitation team and may provide some valuable insights from a discipline-specific perspective. Including all team members may

assist with appropriate and holistic problem identification and collaborative goal setting.

- Further qualitative studies should investigate the reasons for disagreement in ratings of domains, particularly between the adults with aphasia and their significant others. This may help to understand areas of breakdown in team work and selection of rehabilitation priorities that include the home environment.

5.6 Summary

In this chapter, a summary of the study was provided. The study was critically evaluated and implications for clinical practice were discussed. Recommendations for future research were provided.

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APPENDICES

Appendix A

Script: First meeting

- Good Morning/ Afternoon. How are you today? Thank you all for agreeing to meet with me today to discuss participating in this research study.
- This study involves rating the importance of nine cards in terms of your therapy for rehabilitation. These nine cards are domains or areas of life which the World Health Organisation decided was important to consider in people's rehabilitation. (Therapist's/ names) and (family member/friend or carer's name) will be required to rate these domains on a questionnaire. (Name of adult with aphasia) will be required to participate in an interview.
- If you give consent to participate, I will ask you to complete biographical questionnaires please. (Name of adult with aphasia) may complete these forms with the help of the therapist/s and/or significant other.
- (Therapist's/ name/s) and (significant other's name) will be asked to complete their questionnaires in separate rooms.
- Some short assessments will then be conducted with (name of adult with aphasia) to understand his/her skills? In this way I will be able to ensure that the interview I propose to do with (name) will be meaningful.
- If I can see that the interview will be meaningful, we will continue with this. If (name of adult with aphasia) is not tired, we will continue right away. If he/she is tired, we will continue at another time convenient for him/her.
- I would like to film the interview and photograph the responses on the interview mat when the interview is complete please.
- During the interview, (name of therapist/s) and (name of significant other) will leave the room to fill out their own questionnaires.
- The interview will involve rating the importance of the following nine domain cards on a velcro mat. We call this a Talking Mat™- where you are able to look at options and place responses under appropriate headings. The nine domain cards include; 'communication', 'self care', 'work and education', 'relationships', 'mobility', 'leisure', 'domestic life', 'learning and thinking' and 'coping'. Using this mat and a scale of importance, I will read out each card, explain it and the adult with aphasia can

either place it under the appropriate heading or indicate to me where I can place it on the adult's behalf.

- The adult with aphasia will be able to check his/her responses before I take a photograph of the completed Talking Mats™ interview.
- So we will be busy for about... minutes today, and then may schedule another session where I meet (name of adult with aphasia).
- I have summarised the procedures as well as other important information about your rights as a participant in these letters. If you are willing to consider participating, I would like you to read the letter. Should you then decide to participate, I would be grateful if you would sign the form at the back. Is this OK? *(Researcher to obtain feedback from team. If the whole team is fine to go on, she will hand out the letters to the participants.)*
- I would like to ensure that (name of adult with aphasia) understands the information letter and that he/she will complete the form without being coerced. I would therefore like to ask (name of significant other) to observe as I read and explain the information letter and consent form to (name of adult with aphasia), and ask for consent. I would like you, (name of significant other) to complete an observer form.
Please understand that it is your right to withdraw from the study at any point.

Appendix B

Second information letter and consent form for adult with aphasia



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

(Date)

Dear Sir/Madam

Thank you for agreeing to meet me today in order to obtain more information on the study and discuss your participation. In order to make sure you have all the information, I would like to repeat and add to the information given in my previous letter.

My name is Lauren Pettit. I am a speech therapist. I am busy studying for a Master's degree in Augmentative and Alternative Communication (AAC) through the University of Pretoria. I am conducting a study to find out what is important to you and the rest of your team for your rehabilitation.



I would like you to help me, please.

I would like to understand what is important to you for your rehabilitation. I will ask you to use picture cards to help me understand what is important for you.



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If you agree to take part, I will ask you to give me some information about yourself. Your family/friend can help you with this.

I will also do a language assessment with you. If you are tired after that, we can stop and carry on at another time. If not, we will then start using the picture cards to help me understand what is important for you in your rehabilitation programme. We will carry out a practice round first, to check you can see the picture cards well and that you understand what is expected of you.



I will video-record what you tell me using the picture cards.



If you change your mind about working with me at any time, you can tell me to stop. Then we will not carry on, and I will delete the video and destroy any of the information you gave me.



My supervisor and a research assistant may look at the video I made of you. However, I will not share your name with them. Nobody else will look at the video. I will be publishing a thesis and an article on the results. I may also present the results at a conference. However, your name will not appear anywhere in these publications, so nobody will be able to know what you shared with me.

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I will store the video and the other results for 15 years. If I am planning to use these for anything, I will ask you first, and you can tell me whether or not I can use them.

If you don't want to be a part of this study anymore, at any time, I will delete all your information from the records immediately.

If you are unsure of anything, you can ask me at any time. You can contact me at..... or on You may also contact my supervisor (see details below).

Yours sincerely



Lauren Pettit
Candidate MA (AAC)



Kerstin Tönsing
Supervisor

Consent form for adult with aphasia



Have you read the information sheet, or had it explained to you?

YES

NO



Have you had time to ask questions and talk about the study?

YES

NO



Are you happy with the answers you have been given?

YES

NO



Do you understand that it is your choice to take part in the study?

YES

NO



Do you understand that I will video-record during the study?

YES

NO



Do you understand that you can stop at any time during the study?
(You do not have to say why you wish to stop).

YES

NO

Do you want to take part in the study?

YES

NO

Name.....

Signature..... Date.....

Place.....

Researcher: Lauren Pettit

Signature.....Date.....

Place.....

Appendix C

Second information letter and consent form for significant others



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

(Date)

Dear Sir/Madam

Re: Request to participate in a study on rehabilitation team goal setting

Thank you for agreeing to meet me today in order to obtain more information on the proposed study and discuss your participation. In order to make sure you have all the information in written form, I would like to repeat and add to the information given in my previous letter.

My name is Lauren Pettit. I am a speech therapist and I am currently enrolled for a Masters degree in Augmentative and Alternative Communication (AAC), at the University of Pretoria. I am conducting a research project that is entitled: "Prioritising the ICF domains for rehabilitation for adults with aphasia: Comparing three perspectives". The study aims to determine the priorities which rehabilitation professionals set for clients with aphasia, as compared to those that clients set for themselves and those that their significant others (family member, friend or carer) set for them. As a person who is a friend/family member of a person with aphasia, I would like to request your participation in this study.

Should you provide consent, I will ask you to observe how I explain the study to your friend/family member with aphasia and to ensure that he/she understands it. I would also like you to ensure that I am in no way coercing your friend/family member to participate.

Should all of you (yourself, your friend/family member with aphasia and the rehabilitation professionals) provide consent to participate, you will be asked to complete two questionnaires. This should take about 20-25 minutes. The one questionnaire will concern background information while the other will require you to prioritize aspects that you consider important for the rehabilitation programme of the adult with aphasia. You will be asked to complete these questionnaires in a separate room, while the rehabilitation professionals each complete similar questionnaires all in separate rooms. In the meantime, I will be conducting a short language assessment with your friend/family member. Should your friend/family member tire, I will then arrange to meet him/her on another occasion to continue with an interview. If he/she is willing to continue, I will conduct an interview with him/her using pictures. In this interview I will ask him/her about his/her priorities for rehabilitation. This interview with the adult with aphasia will be video-taped. These videos will be viewed by the researcher, a research assistant and the researcher's supervisor only in order to code the data. Nobody else will have access to these video recordings.

The results of the study are intended to be published in the format of a Master's thesis, a research article and a conference publication. The adult with aphasia's name and your name as well as the names of the rehabilitation professionals will not be disclosed in any of these publications or in any other communication about the study, and confidentiality will be maintained at all times throughout the research process.

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Data pertaining to this study will be stored for 15 years for the purpose of archiving. The data will only ever be used for other purposes if your explicit consent has first been obtained.

Should you decide to withdraw from the study, any data pertaining to you will be immediately destroyed and removed from any communication about the study.

Please do not hesitate to contact me with any questions you may have. You may contact me at..... or on You may also contact my supervisor (see details below).

Your sincerely



Lauren Pettit
Candidate MA (AAC)



Kerstin Tönsing
Supervisor

Consent form for Significant Others

Consent form for study entitled: “Rating the ICF domains for rehabilitation for adults with aphasia: Comparing three perspectives”

I,
(fill in complete name)

as the significant other of

I have read and understood the information letter pertaining to the study and consent to taking part in the study.

Signature.....Date.....

Place.....

Researcher: Lauren Pettit

Signature.....Date.....

Place.....

Appendix D

Second information letter and consent form for SLPs



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

(Date)

Dear Sir/Madam

Re: Request to participate in a study on rehabilitation team goal setting

Thank you for agreeing to meet me today in order to obtain more information on the proposed study and discuss your participation. In order to make sure you have all the information in written form, I would like to repeat and add to the information given in my previous letter.

My name is Lauren Pettit. I am a speech therapist and I am currently enrolled for a Masters degree in Augmentative and Alternative Communication (AAC), at the University of Pretoria. I am conducting a research project entitled: "Prioritising the ICF domains for rehabilitation for adults with aphasia: Comparing three perspectives". This study aims to determine the priorities which rehabilitation professionals set for clients with aphasia, as compared to those that clients set for themselves and those that their significant others (family member, friend or carer) set for them. As a rehabilitation professional I would like to request you to participate in this study.

Should all of you (yourself, your client with aphasia and his/her significant other) provide consent to participate, you will be asked to complete two questionnaires. This should take about 20-25 minutes. The one questionnaire will concern background information while the other will require you to prioritize aspects that you consider important for the rehabilitation programme of the adult with aphasia. You will be asked to complete these questionnaires in a separate room, while the other rehabilitation professional(s) and significant others will complete similar questionnaires all in separate rooms. In the meantime, I will be conducting a short language assessment with your client. Should your client tire, I will then arrange to meet him/her on another occasion to continue with an interview. If he/she is willing to continue, I will conduct an interview with him/her using pictures. In this interview I will ask him/her about his/her priorities for rehabilitation. This interview with the adult with aphasia will be video-taped. These videos will be viewed by the researcher, a research assistant and the researcher's supervisor only in order to code the data. Nobody else will have access to these video recordings.

The results of the study are intended to be published in the format of a Master's thesis and a research article. The adult with aphasia's name and your name as well as the names of the other rehabilitation professionals and the significant other will not be disclosed in any of these publications or in any other communication about the study, and confidentiality will be maintained at all times throughout the research process.

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Data pertaining to this study will be stored for 15 years for the purpose of archiving. The data will only ever be used for other purposes if your explicit consent has first been obtained.

Should you decide to withdraw from the study, any data pertaining to you will be immediately destroyed and removed from any communication about the study.

Please do not hesitate to contact me with any questions you may have. You may contact me at..... or on You may also contact my supervisor (see details below).

Your sincerely



Lauren Pettit
Candidate MA (AAC)



Kerstin Tönsing
Supervisor

Consent form for SLPs

Consent form for study entitled: “Rating the ICF domains for rehabilitation for adults with aphasia: Comparing three perspectives”

Name.....

:

I have read and understood the information letter pertaining to the study and consent to taking part in the study.

Signature.....Date.....

Place.....

Researcher: Lauren Pettit

Signature.....Date.....

Place.....

Appendix E

Observer form

Name.....

Relationship to client with aphasia.....

Comments on the communication interaction observed?

.....
.....
.....
.....

I observed the project being explained to.....

Please circle the options that apply:

I feel that he/she understood what was required of him/her for participation: Yes No

I feel that he/she is happy to participate in the study without being coerced: Yes No

Signature.....Date.....

Place.....

Researcher: Lauren Pettit

Signature.....Date.....

Place.....

Appendix F

Speech-language pathologist (SLP) brief

Dear SLP

This is to reiterate the procedures of the study.

I will meet with your client and his/her significant other. I will explain the study, and if the adult with aphasia agrees to participate, he/she will sign the consent form. After he/she and his/her significant other have completed their biographical questionnaires, I will conduct a language assessment with your client to determine the aphasia severity level. If he/she manages this, I will conduct a short screener. After this is complete, I will conduct the Talking Mats interview with the adult with aphasia. I will read out the description of the domains to ensure he/she understands the content of the domains. He/she may then prioritize the domains important to work on to improve his/her life.

I would like you to read the description of the domains and then prioritize which domains you feel is important for your client and his/her team to work on in rehabilitation. It does not matter if some of the domains are not targeted in speech therapy. Please just rate what is important in your client's life currently. Please make comments/ provide explanations or examples. Please do not discuss your responses with your client or his/her significant other.

Many thanks

Lauren

Appendix G

Ethics approval letter



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Office of the Deputy Dean

29 April 2013

Dear Prof Bornman,

Project: Prioritizing the ICF domains for rehabilitation for adults with aphasia: comparing three perspectives
Researcher: LK Petit
Supervisor: Dr K Tönsing
Department: Center for Augmentative and Alternative Communication
Reference: 26315506

Thank you for the well written application that was submitted for review.

I am pleased to tell you that the above application was **approved (with comment)** by the **Postgraduate Committee** on 16 April 2013 and by the **Research Ethics Committee** on 25 April 2013. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof Elsabé alJard
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: elsabe.taljard@up.ac.za

Appendix H

Request to practice owners, hospital and/or rehabilitation facility managers to recruit participants for the study



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

2013

To: Hospital managers/ practice owners

Dear Sir/Madam

RE: Request for assistance in recruitment of participants for Master's Research

My name is Lauren Pettit. I am a speech therapist, currently registered for a Master's degree in Augmentative and Alternative Communication (M.AAC) through the University of Pretoria. I am conducting a research study that aims to determine the priorities which rehabilitation professionals set for clients with aphasia, as compared to those that clients set for themselves and those that their significant others (family member, friend or carer) set for them. I would like to ask your permission to recruit suitable participants for this study from your institution or practice.

The study aims to recruit twenty-five adults with expressive aphasia, along with a significant other (someone who knows the adult well and communicates with him/her often), as well as the rehabilitation professionals (that is, the occupational therapist, speech therapist or physiotherapist) providing regular rehabilitation services to the adult. These individuals will be asked to prioritize certain domains for rehabilitative goal setting.

In order to participate in the study, potential participants should comply with the following criteria:

Adults with aphasia:

- Diagnosis of expressive aphasia
- No or mild-moderate language difficulties
- English speaker (prior to onset of injury)
- Onset of aphasia is at least 6 months ago
- Normal/corrected vision and hearing
- Aged 18 or above
- Functional use of one hand/arm
- No diffuse neurological injury
- No learning or psychiatric disorders
- Receiving rehabilitation services from at least one discipline
- The person has a family member/friend/carer who lives with/visits or communicates with him/her well and has some involvement in the rehabilitation programme (e.g., occasionally attending therapy with the adult with aphasia, assisting with strategies or meeting with the team of professionals).

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Significant others:

- Aged 18 or above
- English speaker
- Corrected vision/hearing
- Lives with/visits or communicates with the adult with aphasia well and has some involvement in the rehabilitation programme (e.g., occasionally attending therapy with the adult with aphasia, assisting with strategies or meeting with the team of professionals).

Rehabilitation professionals:

- Occupational therapist/speech therapist or physiotherapist
- Must be treating the client in the chronic stage of rehabilitation (6 months post injury), although the professional may have worked with the client in the acute stage of therapy as well.
- Conducts therapy with the client at least once every two weeks.

Should you give permission for me to recruit participants from your practice or institution, I would be grateful if you could provide potential participants with the information letters included. They will then be able to contact me should they have an interest in participating in the study.

The involvement of these individuals in the study will entail the following:

- Interested teams may be contacted to arrange a meeting at a place convenient to them. I will then provide them with more information as well as a formal consent letter. I will ask significant others to observe how I explain the study to the adult with aphasia and to ensure that he/she understands it, and that the person with aphasia will not be coerced to participate.
- Should all team members provide consent for participation, they will be asked to complete a questionnaire with background information.
- Significant others and rehabilitation professionals will then be asked to prioritize aspects they consider important for the rehabilitation of the adult with aphasia by completing written questionnaires. They will do so in separate rooms so that they will not view each other's responses.
- In the meantime, I will conduct a short language assessment with the adult with aphasia. Seeing that the person with aphasia may tire during the session, a second session may be arranged to complete procedures. If they are happy to continue in the same session, an interview will be conducted with him/her, using pictures to explain the questions. In this interview, the adult with aphasia will be asked to prioritize some aspects relating to his/her rehabilitation, by placing picture cards on a mat. The interview with the adult with aphasia will be video-recorded.

I would appreciate your help in recruiting participants for this study. If you have any queries regarding this study, please do not hesitate to contact me. My email is..... and my contact number is..... You may also contact my supervisor (see details below).

Yours sincerely



Lauren Pettit
Candidate MA(AAC)



Kerstin Tönsing
Supervisor

Consent form for study entitled: “Rating the ICF domains for rehabilitation for adults with aphasia: Comparing three perspectives”

I,
(fill in complete name)

as the manager/owner of
(state name of practice/institution)

have read and understood the information letter pertaining to the study. I hereby consent to assist with recruitment of participants by providing the relevant information letter to potential participants.

Signature.....Date.....

Place.....

Researcher: Lauren Pettit

Signature.....Date.....

Place.....

Appendix I

Initial information letter



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

September 2013

To: Adults with aphasia, their significant others and their speech-language pathologists

Dear Sir(s)/Madam(s)

Re: Study on rehabilitation team goal setting

My name is Lauren Pettit. I am a speech therapist and I am currently enrolled for a Masters degree in Augmentative and Alternative Communication (AAC), at the University of Pretoria. I am conducting a research project that aims to determine the priorities which team members set for clients with aphasia. I am particularly interested in comparing the priorities set by speech-language pathologists (SLPs) to those that clients set for themselves and those that their significant others (family member, friend or carer) set for them. I would like to approach you as members of a rehabilitation team (i.e. as a person with aphasia, a significant other of a person with aphasia and a SLP) to consider participating in this study.

If you, as a team, are interested in participating, I will arrange to meet all of you at a place convenient to you. I can then provide all of you with more information as well as a formal consent letter. I would ask you to observe how I explain the study to your friend/family member/client with aphasia and to ensure that he/she understands it. I would also like you to ensure that I am in no way coercing your friend / family member / client with aphasia to participate.

Should all of you on that occasion provide consent to participate, you will be asked to complete a questionnaire with background information. Each of you (person with aphasia, significant other and SLPs) will then be asked separately to rate aspects that you consider important for the rehabilitation programme of the adult with aphasia. Significant others and SLPs will do this by completing written questionnaires. The adult with aphasia will do this by means of an interview which I will conduct with him/her, using pictures to explain the questions. This interview with the adult with aphasia will be video-taped. I will also be conducting a short language assessment with the adult with aphasia. Seeing that the person with aphasia may tire during the session, a second session may be arranged to complete the procedures.

None of your names will be disclosed in the study or in any communication about the study, and confidentiality will be maintained at all times throughout the research process. Data pertaining to this study will be stored for 15 years for the purpose of archiving. Should participants decide to withdraw from the study, any data pertaining to these participants will be immediately destroyed. The results of the study are intended to be published in the form of a dissertation as well as a research article. As indicated, no identifying information will be included to ensure confidentiality of participants.

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Should you be interested in participating in this study, kindly contact me at or on I will then arrange a time to meet with you in order to provide you with more information and to give you an opportunity to decide whether or not you would like to participate in this study. You may also contact my supervisor (see details below).

Yours sincerely



Lauren Pettit
Candidate MA(AAC)



Kerstin Tönsing
Supervisor

Appendix J

Biographical information form for adult with aphasia

Participant number _____

Please complete this questionnaire by writing the information in the spaces provided or ticking the boxes where appropriate.

The adult with aphasia's significant other or the researcher, may assist the adult to fill out this form.

1.) What is your age?

.....

Please tick the appropriate boxes:

2.) What is your gender?

Male

Female

3.) Did you speak English before the stroke?

Yes

No

4.) Were you left or right-handed prior to the onset of aphasia?

Left

Right

ambidexterous

5.) Do you have functional use of your right, left or both hands and arms since the stroke?

Right

Left

Both

6.) Do you have corrected vision?

Yes

No

7.) Do you have corrected hearing?

- Yes
- No

8.) What is your marital status?

- Married
- Single
- Divorced
- Widow/widowed
- Other:
-

9.) What is your highest level of education?

- Standard eight or lower
- Matric
- Diploma
- Degree
- Postgraduate qualification
- Other:
-

10.) Please describe your occupation prior to the onset of aphasia:

.....

.....

11.) What caused the aphasia?

.....

12.) How long have you suffered from aphasia?

.....

.....

.....

13.) Please indicate any other therapies you attend and how often you attend them.

Type of therapy	Do you attend? Write 'yes' or 'no'	If yes, how often do you attend (e.g. once a week)?
Physiotherapy		
Occupational therapy		
Speech-language therapy		
Other (please specify)		

14.a.) Do you have a family member/friend/carer (significant other) who knows you well and who has some involvement in your rehabilitation?

Yes

No

Please specify how you know this person:

b.) Please explain this person's involvement in your recovery/ rehabilitation and, or life:

.....

c.) Is this person able to assist you to carry out therapy goals at home or in a social environment? If so, please provide examples:

.....

Appendix K

Biographical information form for significant other

Participant number: _____

Please complete this questionnaire by writing the information in the spaces provided or ticking the boxes where appropriate.

1.) What is your age?

.....

2.) What is your gender?

Male

Female

3.) Do you speak English?

Yes

No

Please list any other languages you feel you are proficient in:

.....

4.) What is your relationship to the person with aphasia?

.....

5.) How long have you known the person with aphasia? (Please state how many months/years)

.....

6.) How often do you speak with the person with aphasia? What kind of topics are usually discussed? (E.g.: family/work/holidays/therapy/sport etc)

.....

.....

7.) When you see the person with aphasia, what do you typically do together/ talk about? (e.g., go to the shops, talk about daily chores/ family). Please be specific.

.....
.....

8.) Who typically decides on the joint activity?

- I do
- The person with aphasia does
- We both decide
- Other (please describe below)

.....
.....

9.) Do you have corrected vision?

- Yes
- No

9.)Do you have corrected hearing?

- Yes
- No

10.) What is your highest level of education?

- Standard eight or lower
- Matric
- Diploma
- Degree
- Postgraduate qualification
- Other: (Please describe below)

.....

11.) What is your occupation?

.....

.....

12.) How are you involved in the person's rehabilitation programme (e.g. transporting the person to therapy, sitting in on sessions, carrying out home programmes or assisting with homework etc? Please be specific and provide examples where possible).

.....

.....

13.) Do you know what goals are being worked on in speech therapy? If so, what are the goals as you understand? Please elaborate.

.....

.....

14.) Is the adult with aphasia able to transfer or carry over goals worked on in therapy to the home environment? If so, does the person require assistance to do so?

.....

.....

15.) Are there strategies you use to assist the person with aphasia to communicate/ interact or function more easily? Please provide examples.

.....

.....

Appendix L

Biographical information form for Speech-Language Pathologist

Participant number: _____

Please complete this questionnaire by writing the information in the spaces provided or ticking the boxes where appropriate.

1.) What is your age?

.....

2.) What is your gender?

Male

Female

3.) What is your qualification?

.....

4.) How long have you been practising as a professional in this private institution/hospital?

.....

5.) How long have you been practising in adult neurological rehabilitation?

.....

6.) How long have you been working with the adult with aphasia?

.....

7.) How often do you work with the person with aphasia?

.....

8.) What are your main goals for the client?

.....
.....
.....

9.) How did you determine these goals? Tick all that apply:

- Standardised tests
- Informal assessments and observations
- Family input
- Client input
- Other (Please specify below)

.....
.....

10.a.) Does your client attend other therapies? If so, do you have an opportunity to discuss your client's progress and goals with the other team members? Please explain:

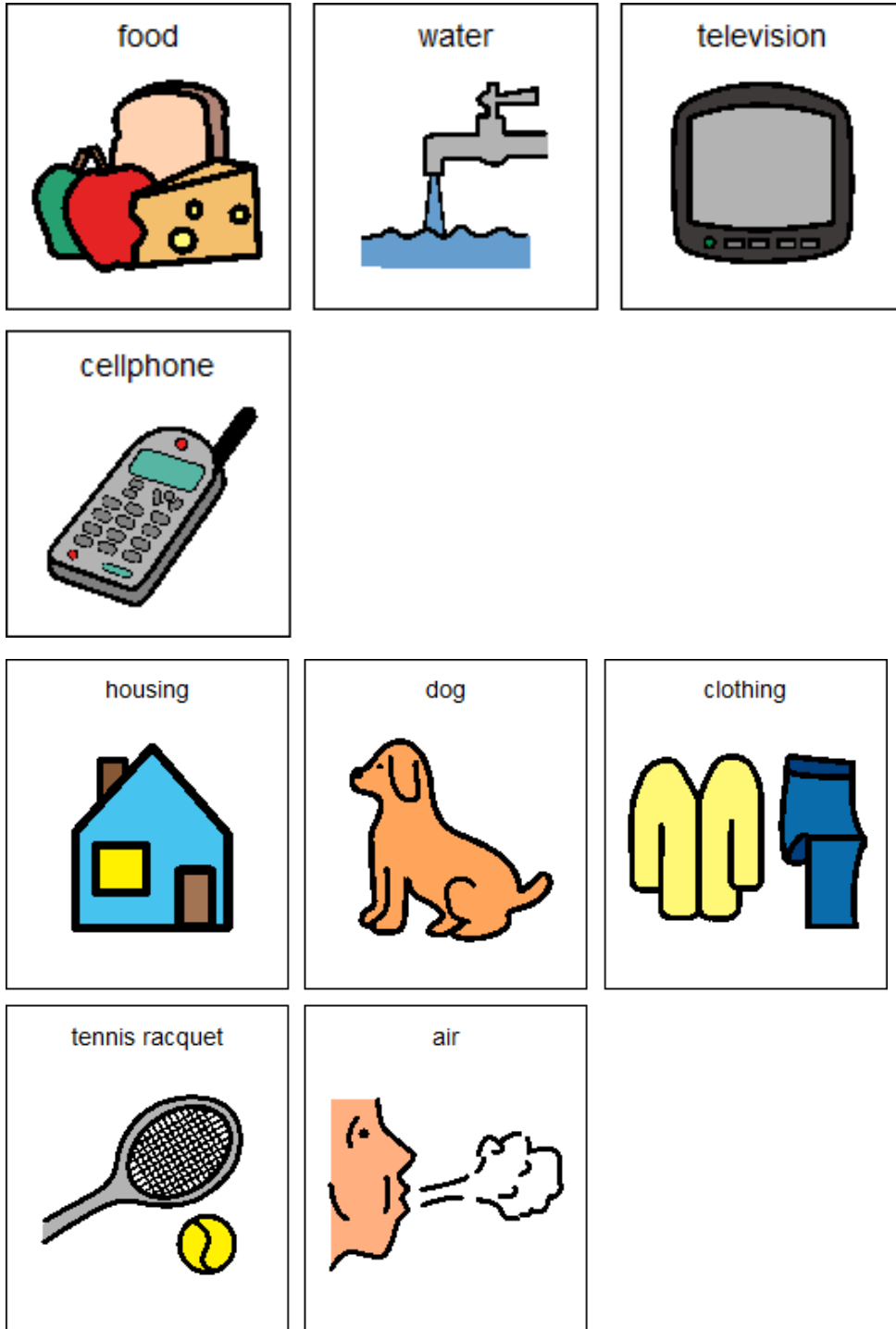
.....
.....

b.) If applicable, please can you briefly explain the team's goals for your client:

.....
.....

Appendix M Screening task

Images used in the screening task



Appendix N

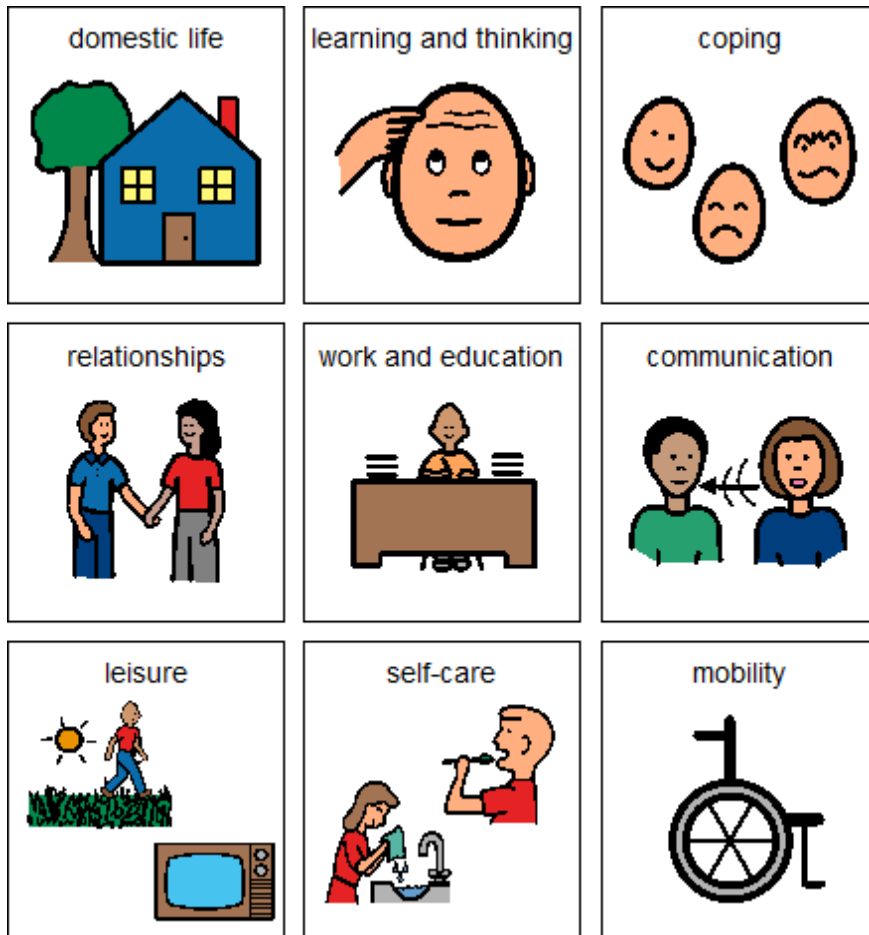
Photograph of Yes, Maybe No Talking Mats™ rating scale



Appendix O

ICF domains depicted in PCS symbols for use in the Talking Mats™ interview

Talking Mats™ ICF domains



Appendix P

Identifying important domains questionnaires for significant others and speech-language pathologists

Questionnaire for significant other

Below please find a list of domains that a person with aphasia may have difficulty with and that may therefore be addressed in a rehabilitation programme for such a person. Please think about your family member/friend with aphasia. In your opinion, is it important for your family member/friend to work on improving the following domains in their rehabilitation programme? Please tick the appropriate box and add comments/ examples where appropriate:

	Yes	Maybe	No	Comments
Domestic life				
Relationships				
Work and education				
Leisure/spare time				
Self care				
Learning and thinking				
Coping				

Communication				
Mobility				

Questionnaire for speech-language pathologist

Below please find a list of domains that a person with aphasia may have difficulty with and that may therefore be addressed in a rehabilitation programme for such a person. Please think about your client with aphasia. In your opinion, is it important for your client and his/her rehabilitation team to work on improving the following domains in their rehabilitation programme? Please tick the appropriate box and add comments/ examples where appropriate:

	Yes	Maybe	No	Comments
Domestic life				
Relationships				
Work and education				
Leisure/spare time				
Self care				
Learning and thinking				

Coping				
Communication				
Mobility				

Appendix Q

Domain descriptions:

Description of each domain:

Each domain or area of life includes various aspects. Please see below examples of the aspects included in each domain.

‘Relationships’- this includes relationships with a partner (like your wife/husband), family, friends, neighbours, strangers, carers.

‘Leisure/Free time or /spare time’- this is about how you spend your free time, like participating in hobbies or doing things for fun or relaxation, such as cooking, gardening, sports, reading, seeing friends, playing games.

‘Learning and thinking’- this includes making decisions, planning, problem-solving, memory, learning.

‘Self care’- this includes washing, dressing, grooming, eating, toileting and looking after your health, (like taking medicine or exercising).

‘Mobility’- this includes use of hands and arms, changing your position, moving from bed to chair etc, moving items around, your balance, driving, and using transport to get around.

‘Work and education’- this includes being employed or working, education or study, earning money and finances.

‘Domestic life’- this includes preparing meals, housework, helping others, shopping, handling your money, where you live.

‘Coping’- this includes coping with simple or complex tasks and daily routines, handling stress and energy levels, managing your feelings. When you are coping well you may feel confident and if you are not coping that well you may feel anxious.

‘Communication’- this includes understanding what others say, speaking, having conversations, (use of communication devices where applicable), reading and writing.

Appendix R

Script: Talking mats™ interview

- I am going to video-record the interview in order to check I followed the correct sequence.
- Before we begin the interview, do you recall the task with the 9 pictures (food, water, television, cellphone, dog, tennis, air, clothes and housing)? You were required to select the appropriate picture in response to questions and place the picture under the correct heading on the mat. The interview will involve the same process.
- Let us review/practise this task using 3 of the items (if necessary).
- I am going to show you 9 different cards that relate to different areas of your life. We will read through the examples of items under each domain or area of life. If necessary, I will read out each domain description as I present a card, then I will ask you a question. For each card, I would like you to indicate how important an area or domain is to you to work on and improve this area in your life? For example, if I showed you the ‘food’ card, I would say ‘Is it important for you to work on improving [‘food/eating’]? Your response may be ‘yes’, ‘maybe’, or ‘no’ depending on what is important for improvement in your life. You will place the card under the appropriate heading. You may check that you are satisfied with the placement of the card.
- If you are able to (and where appropriate), please comment on each domain after you have placed the card on the mat, or you may choose to comment after placement of all nine cards.
- I will ask you if you are happy to continue or you may indicate that you are ready and then I will ask the same question about another card.
- This process will continue until you have placed all 9 cards on the mat.
- I will ask you to check the mat and make any changes if you so wish.
- If you are happy with the placement of all 9 cards, I will take a photograph of the mat to record your responses.
- Remember, that you can stop at any time if you no longer wish to participate.
- Are you ready to begin?

Appendix S

Procedural integrity checklist: Talking Mats™ Interview

Guideline:	Observed during interview:		Comments:
	Yes	No	
Greeting (if necessary)			
Verbally explain what will be included in the interview			
Re-iterate to the participants the freedom to withdraw at any point.			
Practice mat used with adult with aphasia to ensure framework is understood (if necessary).			
Domain cards are presented one at a time with associated domain description.			
All verbal and non-verbal responses during the Talking Mats™ interview must be recorded. This includes comments on each domain.			
Once the mat is complete, the researcher must allow the participant to check and confirm his/her placement of the domain cards on the mat. The participant may move domain cards if necessary.			
A photograph will be taken of the completed mat.			
After completion, thank participant for participation in the study.			

Steps to be taken when presenting each of the domains

Domains	Card shown to participant	Card named and domain description read out	Researcher asks question: ('How important...')	Participant given the opportunity to place card	Researcher reads non-verbal cues and provides further explanation if participant is unsure	Researcher to clarify understanding of domain and card placement	Participant given about 10 seconds to place card (if required)	Participant asked to comment if appropriate after placement of each card or when mat is complete	Placement confirmed verbally or non-verbally	Researcher asks if participant is ready to continue or participant initiates continuation
Work & Education										
Communication										
Leisure										
Self Care										
Mobility										
Learning & Thinking										
Coping										
Relationships										
Domestic Life										

