AN INVESTIGATION INTO LIFE NEEDS ACROSS STAGES OF RECOVERY FROM APHASIA: IMPLICATIONS FOR SERVICE DELIVERY

By Julia Alberts

A report on a research project presented to:
The Division of Communication Sciences and Disorders
Faculty of Health Sciences
University of Cape Town

In partial fulfillment of the requirements for the degree
MSc (Speech-Language Pathology)

September 2002

ACKNOWLEDGEMENTS

"If I have been able to see farther, it was because I stood
on the shoulders of giants"
-Sir Isaac Newton

First and foremost I wish to express my sincere gratitude and appreciation to the participants of this study. I am indebted to each one of them for sharing their thoughts and feelings with me and providing me insight into what it means to live with aphasia.

A special thank-you to my supervisor and teacher Carol Legg, whose knowledge and passion for aphasiology has inspired my interest. I am grateful for her guidance and continuing support, which contributed to the successful completion of this research project.

With thanks to Shirley van Os, Deona Roets, Carol Metstern, Sue Rumble and Arina Coetzee for their assistance in recruitment of participants for this study.

To my mother and father for the hours spent on proof reading this paper.

To my boyfriend, Detleff, and his family for their continued interest in my research.

I am especially grateful to my family; my mother, father, and two brothers, for their consistent belief in me and unconditional love.

ABSTRACT

Recent shifts in the philosophy of aphasia rehabilitation have engendered research interests in the broad and long-term consequences of the condition. In response, this study aimed to describe and compare acute and long-term consequences of aphasia. In-depth interviews were conducted with fifteen adults at different stages of recovery post-stroke. Topics probed included communication, family relationships, friendships, daily activities, independence, emotional status and self-image. Data was analysed thematically and meaningful units were coded and classified according to the International Classification of Functioning, Disability and Health (ICIDH-2). Results revealed common themes across the broad psychosocial consequences for individuals with aphasia and a concerning lack of public awareness of the aphasic condition. Further, a pattern of declining participation across the continuum of recovery was apparent. Drawing on the data obtained, the importance of long-term service delivery that focuses on the psychosocial adjustment of the individual with aphasia and their environment is highlighted.

CONTENTS

PAGE

LIST OF TABLES

INTRODUCTION

METHODOLOGY: No tables

RESULTS AND DISCUSSION

DISCUSSION

LIST OF APPENDICES

INTRODUCTION

1.1 INTRODUCTORY PERSPECTIVE

"Knowledge is not achieved until shared"

-Diogenes Leantius

This study investigates the consequences of aphasia for individuals at different stages of post-stroke recovery through documenting the life needs and coding these needs according to the International Classification of Functioning, Disability and Health (ICIDH-2). The impetus for this study arose from recent rehabilitative shifts that emphasise the availability of services as needed at all stages of aphasia recovery. These shifts encompass the moving away from the medical model towards the social model of rehabilitation as proposed by the "Life Participation Approach to Aphasia" (Chapey, Dunchan, Elman, Garcia, Kagan, Lyon & Simmons-Mackie, 2000) and the International Classification of Functioning, Disability and Health (ICIDH-2) (WHO, 2001). Although several recent studies have investigated the consequences of aphasia and resulting life needs of adults living with aphasia (National Aphasia Association, 1988; Parr, 1994; Le Dorze & Brassard, 1995; Bethoux, Calmels, Gautheron & Minaire, 1996; Sarno, 1997), limited attention has been directed towards the changing consequences and life needs over the course of recovery from stroke. Life needs of adults with aphasia may be closely related to recovery stages and thus research into the dimensions of aphasia against the continuum of care is necessary. This will guide rehabilitation specialists in the provision of appropriate services as needed at all stages of recovery.

1.2 LITERATURE REVIEW

1.2.1 Historical Framework

Aphasia encompasses much more than just a disorder of communication. The person with aphasia experiences unexpected inability to function in the entire range of everyday life activities such as behavioural, social, vocational, family and leisure activities (Brumfitt, 1993; Parr, 1994; Le Dorze & Brassard, 1995; Sarno, 1997; La Pointte, 1999; Code, Hemsley & Herrmann, 1999). Negative emotional reactions, manifesting in the form of depression may be the response to these difficulties. This disturbance in emotional balance in turn affects motivation, physical performance and cognitive and language processing (Code, Hemsley & Herrman, 1999). These profound consequences are life-long and dynamic (Parr, 2001), and therefore it can be assumed that adults with aphasia experience different needs through the years of living with a communication disorder. A medical approach that doesn't accommodate long-term needs for support, however, is reflected in traditional approaches to aphasia (Simmons-Mackie, 1998).

Until recently, rehabilitative efforts have been directed mainly at the acute stages where rehabilitation is hospital based (bedside or outpatient) and targets speech training and Alternative and Augmentative Communication (Lyon, 1993; Sarno, 1993; Sarno, 1997). As a result of this focus, health care professionals and society have directed limited interest towards the long-term effects of aphasia. Small (2000) states that contemporary society views stroke as an acute disease similar to a heart attack rather as a chronic disease like diabetes mellitus. Whereas society is aware that treatment for diabetes are lifelong, stroke treatment is believed to be completed a few days or weeks after the stroke. According to Beeke, Maxim and Wilkinson (2000), these beliefs may stem from the observation of spontaneous neurophysiological recovery of function (due to neurological changes post-stroke), which are greatest in the first three months post-stroke. However, this recovery progressively slows down, reaching a plateau between six and twelve months. Beyond this twelve month period, even with intervention, many speakers will remain aphasic for the rest of their lives (Beeke, Maxim & Wilkinson, 2000). This realisation of the chronicity of aphasia has spurred recent attempts to expand the literature on the long-term consequences of stroke and aphasia.

Several authors have proposed underlying reasons for the current dearth of information on the chronic handicapping effects of aphasia. Pound (1998) suggests that, until recently, clinical researchers have not addressed long-term social consequences of aphasia because of an absence of appropriate theoretical frameworks to guide thinking about disability and handicap level therapies; an absence of acceptable and meaningful outcome measures, which relate to both the explicit aims of therapy and to the complexity and diversity of change in the individual with aphasia's emotional and psychological well-being, and a profound difficulty on the part of the clinician to step outside the predominant culturally determined attitudes and beliefs about disability was evident.

Lyon (1992) states that speech-language pathologists have not historically treated the psychosocial handicap because of conceptual bias. Lyon (1992) proposes four conceptual biases relating to aphasia as a handicapping condition. Firstly, Lyon (1992) proposes that handicap was not seen as the prime cause for the restricted use of communication. Although handicapping features were seen as part of aphasia, it was argued that no definite proof existed that dysfunctional states of psychosocial well-being in adults with aphasia interfered significantly with communication in natural settings. Secondly, Lyon (1992) proposes that even if psychosocial handicap was believed to effect use of communication, its influence on communication was seen as secondary to the prime cognitive and linguistic causes. A further bias according to Lyon (1992) arose from research directed to quantifying observable handicap and thus inferentially clinical practitioners and researchers were led to believe that not all adults with aphasia exhibit a psychosocial handicapping condition. Lastly, when the psychosocial handicap did warrant treatment, it was believed to be best managed by professional staff with special clinical expertise in this dysfunction (Lyon, 1992).

1.2.2 Philosophical Shifts

Lyon (1992) however proposes that disability and handicap cannot be separated from one another: Disordered communication (disability) leads to psychosocial handicap, and disordered psychosocial well-being leads to disordered communication. Research and experience has shown that it is not the impairment but rather the disability and handicap of aphasia that traumatises the individual most (Angeleri, Angeleri, Foschi, Gioquinto and Nolfe; 1993; Parr, 1994; Hoen, Thelander & Worsley, 1997; Pound, 1998). Angeleri *et al.* (1993) maintain that impairment often translates into disability and handicap when adults with aphasia have to cope with daily problems. According to Simmons-Mackie (1998), this is the direct responsibility of the aphasia clinician because speech- and language rehabilitation deals with communication, which has two goals: exchanging information and fulfilment of social needs. Thus, increasing attempts have been made to overcome historical conceptual biases.

These attempts specifically relate to the creation of theoretical frameworks for disability and handicap level rehabilitation, meaningful outcome measures for rehabilitation targeting disability and handicap and a growing awareness amongst clinicians about the nature of disability and handicap induced by aphasia (Pound, 1996; Byng, Pound & Parr, 2000; Chapey *et al.* 2000). This new movement in aphasiology is based on the social model of rehabilitation of which the goals are to increase successful participation in authentic communication events by focussing on communication at the level of conversation, providing communicative support systems within the community; identifying and reducing barriers to successful communication by increasing communicative confidence and empowering speakers with aphasia (Simmons-Mackie, 1998).

A philosophy of service delivery, the Life Participation Approach to Aphasia (LPAA), has been proposed to comply with this shift in rehabilitative focus (Chapey, Dunchan, Elman, Garcia, Kagan, Lyon & Simmons-Mackie, 2000). LPAA is a "consumer-driven service delivery philosophy that focuses on maximising re-engagement in life by meeting the needs of people affected by aphasia" (Chapey *et al.* 2000). LPAA has five core components.

Firstly, the explicit goal is enhancement of life participation. Secondly, all those affected by aphasia (immediate family and close associates) are entitled to service. Thirdly, both personal and environmental factors are targets of assessment and intervention. Fourthly, success is measured via documented life enhancement changes. The last value emphasis the availability of services as needed at all stages of "life with aphasia". Thus, LPAA services begin with the onset of aphasia and continue until consumers and providers agree that targeted life enhancement changes have occurred (Simmons-Mackie, 2001).

The principals of the LPAA concur with the theoretical framework of the World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICIDH-2) (Simmons-Mackie, 2000). The LPAA and the ICIDH-2 classification both recognise the social consequences of disease/injury. The LPAA however provides a theoretical framework for rehabilitation whereas the ICIDH-2 provides useful outcome measures. The ICIDH-2 has been defined as a multipurpose classification tool designed to serve various disciplines with the aim of providing a scientific basis for understanding and studying health and health-related stages, outcomes and determinants (WHO, 2001). It provides a description of situations with regard to human functioning and it's restrictions (WHO, 2001). According to the ICIDH-2, impairment refers to problems in body function or structure such as significant deviation or loss. Activity encompasses the execution of a task or action by an individual and activity limitations are difficulties an individual may have in executing activities. Participation comprises involvement in life situations and participation restrictions are problems an individual may experience in involvement in life situations. Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. Personal factors are the particular background of an individual's life and living, and are composed of features of the individual that are not part of a health condition or health states (WHO, 2001).

1.2.3 Recent Research Trends

In the context of these changing philosophies, recent research trends have been concerned with understanding the meaning of aphasia through documenting life-experiences of those who live with the condition. Studies into the consequences, psychosocial effects of aphasia, the needs of individuals with aphasia and personal narratives have resulted in a better understanding of the disability and handicap level of this complex condition.

One of the first studies targeting the understanding of the psychosocial impact of aphasia was a needs survey conducted by The National Aphasia Association (in The United States) in 1988. Over 2000 questionnaires were distributed to individuals with aphasia and their families (Sarno, 1997). The respondents represented a population of individuals who had acquired aphasia at least one year earlier. Ninety percent of the group reported that social isolation was their primary problem and over seventy-five percent felt that non-aphasic people often avoid contact with people with aphasia because of the difficulty in communicating. Fifty percent reported that they did not have adequate information about aphasia and that their doctors were uninformed about aphasia. Ninety percent felt that public awareness about aphasia is minimal and fifty-four percent expressed a need for support in the form of stroke clubs, therapy programmes or day-care services. Specific mention was made of loneliness, difficulty making friends, lowered self-esteem and depression. Although making a valuable contribution to the psychosocial literature on aphasia, the implicit nature of surveys suggest the use of researcher objectivity rather than the reality created by the subjects personal experience (Leedy, 1993). LaPointe (1999) suggests that that until one is actually in the patient role, it is difficult to place oneself in the role of that patient. This highlights the important contribution that personal narratives can make towards our understanding the aphasia experience.

Le Dorze and Brassard (1995) investigated the consequences of aphasia by analysing the personal accounts of 11 individuals with aphasia and their relatives or friends. The different dimensions of aphasia reported were classified into disability, handicap and coping behaviour according to the International Classification of Impairments, Disability and

Handicap (WHO, 1980). Results showed that consequences of aphasia reported were handicaps, including communicative handicaps, interpersonal relationship difficulties, reduced responsibilities, employment difficulties and reduced leisure activities. This study also illustrated that associated handicap is reduced by coping behaviours. Le Dorze and Brassard (1995) further showed that the ICIDH was a useful tool to classify the consequences of aphasia into different levels of functioning. Thus, the predominant report of the disability and handicapping consequences of aphasia suggests that therapy targeting impairment as main goal may be misguided.

Clark and Smith (1999) focused on one aspect of psychosocial functioning, namely family relationships. Their study chartered changes over time in the family functioning of a group of stroke rehabilitation patients and their families. Participants were 60 12-month stroke survivors who had undergone an inpatient rehabilitation program, 46 spouses, and 25 other family members. Participants were assessed with regards to problem solving, family communication, role definition, behaviour control and affective involvement. Family functioning was assessed using the McMaster Family Assessment Device, and functional outcome was monitored with the competence scale of the Australian ADL Index. These assessments were executed at the time of admission to and discharge from rehabilitation, and six and 12 months after discharge. The results illustrated that disability after stroke can increase family dysfunction as time progresses. Specific consequences included deterioration to resolve problems within and outside the family, a decline in family communication was reported, and problems related to role definitions increased with time. This suggests the importance of family counselling in that families should be warned of the possible difficulties they might face.

Parr (2001) also explored the meaning of aphasia by using interviews and narrative methods with 50 adults with long-term aphasia. Interview topics included understanding of aphasia, coping, perception of therapy and social services, issues of disability and needs. Results showed that the impact of aphasia is systemic and that the consequences of this disorder are dynamic and long term. Specific areas found to be affected by aphasia included self-esteem, relationships, identity and role change, impact on family and lifestyle and quality of life.

Furthermore, it was concluded that people with aphasia face numerous disabling barriers including environmental, structural, attitudinal and informational barriers. Thus, the impact of aphasia is extensive, affecting every level of social interaction and every aspect of life. Parr (2001) suggested that, in order to accommodate the psychosocial consequences of aphasia, therapy must target enhanced communication, address identity, include counseling, reduce barriers, increase autonomy and choice and promote health. These proposed rehabilitation goals are however generalized to all individuals with long-term aphasia, therefore failing to recognize that time since stroke might indicate different goals at different stages post-stroke.

A South African study that probes into the experience of "living with aphasia" was performed by Rabinowitz and Legg (2001). Ten interviews were conducted with adults with aphasia and their caregivers. Community affiliation was indicated as an important contributor to the well-being of individuals with aphasia. Furthermore, the results of the study indicated that coping behaviours and support facilitate acceptance of the condition. This study reinforces the importance of psychosocial affiliation and adaptive behaviours such as coping strategies for rehabilitation.

Band and Legg (2001) performed a descriptive multiple case study to explore the perceptions encompassing client satisfaction and effectiveness of treatment of South African individuals with aphasia. Ten adults with aphasia and five of their primary caregivers were interviewed. Several needs for service delivery emerged from the personal accounts. These included needs for self-empowerment, needs regarding the external environment, needs for increased participation in life and needs for increased emotional well-being. The implications of this research indicate a need for a client-driven service delivery model that ensures that the clients' needs are met (Band and Legg, 2001).

1.2.4 Implications for Service Delivery

The findings of the above-mentioned studies support the arguments for developing service delivery approaches that address the continuum of recovery within a psychosocial framework. Ultimately, a rehabilitation or management plan should consider the needs of people with aphasia, taking into account that the residual sequelae of stroke change over time. Penn (2000) proposes a selection of management suggestions, emphasising that treatment needs and activities will change depending on the time since stroke, the person involved and the team responsible for rehabilitation.

The rehabilitation suggestions made by Penn (2000) differentiate between three broad stages on the continuum of recovery for individuals with aphasia: immediately after the stroke, coming home and one year after the stroke and beyond. Penn (2000) stresses the importance of different treatment needs at these stages and suggests appropriate management at each of these stages. Penn (2000) makes the following management suggestions for the first stage: medical information, advice and reassurance about the condition, help with depression and distress, treatment of and advice about physical and communication problems, gradual commence of therapy and lastly telling the patient that it is in order to cry. Management guidelines for the second phase include: physical and nursing help, support for caregivers, continuing therapy, regular contact with the medical team for reassurance and information, contact with others in a similar situation and help with depression and distress (Penn, 2000). Lastly, Penn (2000) indicates the following rehabilitative needs at the third stage: ongoing psychological support for patients and caregivers, opportunities for joining advocacy and support group activities, careful evaluation and support in returning to work, if possible and regular medical support and advice.

For clinicians to manage the process of supporting the psychosocial needs of individuals with aphasia, their families and caregivers, it is essential that programmes of intervention and treatment be planned in a more comprehensive and holistic way (Muller, 1999). A rehabilitation model was proposed by Rabinowitz and Legg (2001). In line with the suggestions made by Muller (1999), this model addresses varied aspects of aphasia, including personal, environmental and cultural factors. The model is based on the finding that social barriers within the context of cultural beliefs, family- and community support need to be addressed in order to result in reduced disability, which in turn will lead to coping strategies.

The implications of these findings are that clinicians need to plan intervention, at the acute phase as well as beyond formal discharge from speech-language therapy (Muller, 1999). Intervention for individuals with aphasia can therefore rather be seen as a rehabilitation process in a context where both speech-language as well as psychosocial aspects of recovery are addressed (Muller, 1999). Whereas to some extent intervention at the acute stage is based in the medical model, adjustment to aphasia can be set more broadly within a social approach to rehabilitation (Muller, 1999). Pound (1998) states the therapist's role does not necessarily have to be either impairment or disability focused, but can actually encompass both traditional input on language remediation and enhancing communications skills as well as providing disability and handicap level therapy and support. Elman (1998) also suggests an expanded model of rehabilitation not reflecting a sudden shift from restorative to social treatment, but an integrated philosophy of communication management addressing interactive aspects of communication throughout the continuum of care.

Although recognising the importance of providing long-term management, Elman (1998) suggests a treatment array where individuals with aphasia are informed about the different services available to them. Elman (1998) suggests this approach rather than seeing treatment for aphasia as on a sequential, rigid continuum. However, aphasia is a chronic disorder, suggesting that an ongoing process of discovering the difficulties caused by aphasia is set in motion post-stroke. Although the consequences may not present in a linear sequence, certain patterns may arise along the continuum of chronicity. An example of these changes is inherent in the spontaneous recovery theory where it is believed that with time, a certain degree of spontaneous language recovery is observed, followed by a plateau of stagnation in the chronic stages of aphasia (Hersh, 1998).

1.2.5 Context of this study

The context for language rehabilitation in South Africa is a complex and under-researched area (Penn & Beecham, 1992). Penn and Vyncke (1998) state that there is little information available in South Africa on stroke and the impact of aphasia on the individual and his/ her environment. This information is integral to improving treatment services in South Africa (Penn and Vyncke, 1998).

A number of important changes have been made to the South African National Health System (NHS) since 1994, which also impacts on the rehabilitation services for individuals with aphasia. These changes include the implementation of a NHS based on Primary Health Care principles that are delivered through District Health Systems (Mbatasha & Mcintyre, 2001). A number of steps that have been taken to increase access to health services such as building mobile clinics, repairing dilapidated hospitals, extending free health care to primary care facilities and improving drug, equipment and personnel distribution (African National Congress – Western Cape, 2002).

Historically, the Western Cape Province has spent substantially more per capita on health care than most other provinces (African National Congress – Western Cape, 2001). Inequitable distribution of resources demonstrated racial differentials in access to health services. It is against this background that the local government in Cape Town is currently characterised by rapid shifts in a number of areas including structure and organisation, priorities for intervention, levels and lines of accountability and financial and other resources. Some of the key challenges for the Western Cape is therefore to render an equitable good quality, caring service through innovating expansion of resource bases, community involvement in health and implementation of the District Based Health System at Primary Health Care level (African National Congress - Western Cape, 2001).

Achieving these goals in South Africa will however remain a challenge, as the government is faced with a number of conflicting priorities (Barron, Lewin, London, Rumbelow, Seager & Truter, 1996). Limited funds have to be allocated to basic services such as adequate sanitation, solid waste removal and safe piped water (Barron *et al.,* 1996). Further difficulties arise with the allocation of funds within health services. Certain illnesses or individuals are considered to be priority such as HIV AIDS, pregnant woman and children under 6 (Barron *et al.,* 1996). Even more discrepancies exist between services provided for disabled individuals where wheelchair provision and cataract operations have been considered priority treatments.

It is therefore clear that the South African individual with aphasia faces a number of challenges when accessing the rehabilitative services provided within the NHS. The necessity for a model of rehabilitation that corresponds with the unique demands and diversity in the South African setting is therefore highlighted. The fact that the context for language rehabilitation, including treatment for aphasia, is a complex and under-researched area in South Africa complicates matters even further (Penn & Beecham, 1992).

Treatment of the South African individual with aphasia is confronted by various obstacles, primarily cultural diversity, language barriers and the lack of an adequate infrastructure for rehabilitation. Cultural and linguistic diversity, coupled with the high rate of illiteracy has highlighted the inappropriateness of traditional aphasia tests and therapy techniques for the South African situation (Penn, 1998). Incidence rates for most disorders that result in aphasia are among the highest in the world, but facilities for treatment and rehabilitation are inadequate (Fritz & Penn, 1992 as cited in Penn, 1993). Furthermore, only a small number of trained clinicians can deal with people that have aphasia (Fritz & Penn, 1992 as cited in Penn, 1993). Limited rehabilitation facilities are available for patients following discharge (Penn, 1993). Few patients except for those in urban areas have access to a range of rehabilitative therapies. This is magnified by unrealistic medical insurance, which limits patients in affording private treatment after discharge (Penn, 1993).

In summary, aphasia has tremendous consequences on the lives of both the affected individual and his/her relatives and friends. These consequences can be classified according to three dimensions: impairment, disability and handicap, and recent studies have delineated the needs of the adult with aphasia within these dimensions (Le Dorze and Brassard, 1995). It has also been recognised that life needs do not stay unchanged throughout the process of recovery from stroke and that the dimensions of disability and handicap may become apparent when the individual is "living with aphasia", that is, in the chronic stages of aphasia recovery. The changing impact of aphasia needs to be investigated in the South African context, as services are currently hospital based, therefore only addressing the acute stages of aphasia. As rehabilitation efforts should consider the life needs of an individual with aphasia at different stages of aphasia, the need to study the dimensions of the disorder along the continuum of care is highlighted. Further, the value of the measures of impairment, activity and participation, as portrayed in the ICIDH-2 (WHO, 2001), in aphasia needs to be investigated. This study is a preliminary investigation of these issues.

1.3 CONCLUDING COMMENTS

It is hoped that the study will yield empirical and clinical gains. Empirically, the study may add to the increasing body of literature that supports and describes the consequences and life needs of adults at different stages of aphasia. Additionally it is hoped that results will guide the rehabilitation specialist in adopting approaches to rehabilitation that are in line with unique, individual and changing needs in the context of recovery and coping. Furthermore, by using the ICIDH-2 as a tool of measurement, it is hoped that this study will provide insight into the value of this measurement for adults living with aphasia.

CHAPTER TWO: METHODOLOGY

> *"Marshall thy notions into a handsome method. –One will*
> *carry twice more weight packed up in bundles, than when it*
> *lies flapping and hanging about his shoulders."*
> -Thomas Fuller (1608 – 1661)

In the following section, the methodological issues in this study will be discussed in detail. This includes the aims and subjects of the study, the instruments used, the research method and design, ethical considerations and data collection and analysis procedures.

2.1 AIMS OF THE STUDY

The aim of this research project is to establish the consequences of aphasia and resulting needs of individuals with aphasia at three different stages of aphasia recovery namely the acute stage from nil to six months post-stroke; the early chronic stage from six months to two years post-stroke and the late-chronic stage from two years and beyond. Certain researchers have advocated the importance of differentiating timeframes of chronic aphasia (Penn and Smollan, 1996; Penn, 2000; Parr, Byng & Gilpin, 1997).

Further, this study aimed to analyse and structure these consequences and needs into the components of disablement stipulated by the International Classification of Functioning Disability and Health (ICIDH-2): impairment of body structure and/or functioning, activity/activity limitation, participation/participation restriction, environmental factors and personal factors (WHO, 2001).

Lastly, it was aimed to provide a report of the appropriateness of the ICIDH-2 document for use with individuals with aphasia, based on the experience of using the document in this study.

2.2 RESEARCH DESIGN

"General observations drawn from particulars are the jewels of knowledge"

-John Locke (1632 – 1704)

In order to address the research aims, a qualitative design has been adopted. Qualitative methods allow for the study of selected issues in an in-depth and open manner through the understanding of people's experiences with a particular phenomenon (Terre Blanche & Durrheim, 1999). Le Dorze and Brassard (1995) noted that the study into the personal experience of aphasia might provide valuable insights into its handicap, not uncovered through questionnaires and attitude scales and thus qualitative research is an appropriate methodology to uncover the complex real-life. As such, this study uses speech as elements of data, uses an inductive approach to analyses and attempts to build theory on the bases of the results (Leedy, 1993). In order to obtain this qualitative information, structured interviews were carried out with adults with aphasia.

2.3 PARTICIPANTS

"Every human being is the author of his own health or disease"

-Sivanada

2.3.1 Participant Selection Criteria

First of all, the study focused on individuals with expressive aphasia because of the difficulties that these individuals face when accessing South African rehabilitation services. Participants required for the research study needed to fall into three different post-stroke recovery stages: acute, six months to two years post-stroke and two years to six years post-aphasia onset. The use of the above time-frames followed consideration of post-stroke recovery stages. The first stage, nil to six months post-stroke, was chosen on the basis of several research indications that this is the first recognisable stage of post-stroke recovery (Penn & Smollan, 1997; Code, Hemsley & Herrman, 1999; Small, 2000). There is no definite evidence of timeframes that are attached to the meaning of long-term aphasia. For this reason, a combination of literature sources were used in discriminating between different long-term stages post-stroke. Penn and Smollan (1999), for example, considered up to two years post-stroke as "early" and three to five years post-stroke as a "middle stage when investigating depression in a South African stroke population. Groteau and Le Dorze (1999) specified three years post-stroke to be indicative of long-term aphasia. This study therefore further discriminates between different long-term aphasia stages: 6 months to two years post stroke and long-term aphasia.

The extensive analysis procedures inherent in the qualitative design of the study necessitated a small sample size. Five participants were selected for each of the timeframes mentioned above. The participants were recruited from stroke support groups, private practitioners and other sub-acute care facilities (for example rehabilitation centres). The following criteria had to be met in order to have qualified as participants for this study:

a) The presence of aphasia had to be confirmed by a speech-language pathologist.
b) The individual had to fall in one of the timeframes of post-aphasia onset stipulated earlier.
c) The individuals with aphasia had to be able to express themselves verbally to the extent that their utterances could be used for discourse analysis.
d) The individual with aphasia had to exhibit functional comprehension of everyday language.
e) The individual with aphasia had to be able to give informed consent for participation in the study. Prior to data collection, consent with regard to the participants' participation in the study was obtained. An information sheet and consent form was designed (Appendix A) supported by material from Pictographic Communication Resources manual (PCR) (Kagan, Winckel & Shumway, 1996) to ensure that subjects understood the study.

f) The individual had to speak English or Afrikaans as primary language, as the researcher, who executed the data analyses, is fluent in these two languages.

2.3.2 Description of the participants

The biographical information of the subjects is represented in Table 1. Fifteen adults with aphasia participated in this study. Relevant biographical and background data was obtained prior to the interview through using supportive conversational methods (Kagan, 1998) and pictographic resources (Kagan *et al.* 1996).

2.3.2.1 Group one

Group one consisted of five participants who had their stroke at the most six months prior to the interview. The time post-onset ranged between three weeks to four months, with a mean of 10 weeks post-stroke. The participants' ages ranged between 43 and 67 with a mean of 53 years. Two of the participants lived alone, one with his mother and two with their families. Two of the five participants were white and the other three coloured. Four spoke Afrikaans as first language and one was English first language speaking. Two were described by their speech pathologists as mild aphasics and the other three presented with moderate aphasia. Of the five participants from Group one, four are currently receiving rehabilitation services from a speech-language therapist, and one has never received such services before.

2.3.2.2 Group two

Five participants were selected for Group two. The time progressed since post-aphasia onset for Group two has a mean of 1 year, two months, ranging between eight months and one year, nine months. The ages of the participants from Group two ranged between 41 years and 64 years, with a mean of 52 years. Four of the participants lived with their families and one lived alone. Four of the five participants in Group one were coloured and one was white. All five participants in Group two were Afrikaans first language

Table 1: Biographical information for subject group one

	Subject one	Subject two	Subject three	Subject four	Subject five
Age	43	57	67	45	54
Gender	male	male	male	female	male
Marital status	Single	Married	Divorced	Married	Single
Time since onset	9 weeks	3 weeks	33 weeks	4 weeks	3 weeks
Living arrangement	With mother	With family	Alone	With family	Alone
First language	Afrikaans	Afrikaans	Afrikaans	English	Afrikaans
Cultural group	White	Coloured	Coloured	White	Coloured
Type of aphasia	Expressive	Expressive	Expressive	Expressive	Expressive
Severity	Mild	Mild	Moderate	Moderate	Moderate
Receiving speech therapy	Yes	Yes	Yes	Yes	No
Received speech therapy in the past	Yes	Yes	Yes	Yes	No

Table 1 (continued): Biographical information for subject group two

	Subject one	Subject two	Subject three	Subject four	Subject five
Age	64	41	52	60	43
Gender	Female	Male	Male	Male	Female
Marital status	Married	Divorced	Married	Married	Single
Time since onset	1 year, 2 months	1 year, 9 months	8 months	1 year	1 year 1 month
Living arrangement	With family	Alone	With family	With family	With family
First language	Afrikaans	Afrikaans	Afrikaans	Afrikaans	Afrikaans
Cultural group	Coloured	Coloured	Coloured	White	Coloured
Type of aphasia	Expressive	Expressive	Expressive	Expressive	Expressive
Severity	Mild	Moderate	Moderate	Mile	Mild
Receiving speech therapy	No	Yes	No	No	No
Received speech therapy in the past	Yes	Yes	No	Yes	No

Table1 (continued): Biographical information for subject group three

	Subject one	Subject two	Subject three	Subject four	Subject five
Age	27	38	62	72	49
Gender	Male	Female	Male	Female	Male
Marital status	Single	Married	Married	Widow	Single
Time since onset	6 years	3 years	2 years, 5 months	4 years, 5 months	3 years, 6 months
Living arrangement	Alone	With family	With family	With family	With friends
First language	English	Afrikaans	Afrikaans	English	Afrikaans
Cultural group	White	Coloured	White	White	White
Type of aphasia	Expressive	Expressive	Expressive	Expressive	Expressive
Severity	Moderate	Mild	Moderate	Mild	Moderate
Receiving speech therapy	Yes, in the form of a support group	No	Yes, in the form of a support group	No	Yes, in the form of a support group
Received speech therapy in the past	Yes	Yes	Yes	No	Yes

speaking. According to the referring speech-language pathologists, three of the participants presented with mild aphasia whereas the other two were diagnosed with moderate aphasia. One participant is currently receiving speech-language rehabilitation services. Three received such services in the past.

2.3.2.2 Group three

Group three consisted of five participants who had their strokes more than two years prior to the study. A mean of three years, nine months was calculated for the time post-stroke of Group three's participants, ranging between two years, five months to six years post-stroke. The ages of the participants ranged between 27 years and 72 years, with a mean of 50 years. One of the five participants lived alone whilst three lived with their families and one with friends. Four of the participants in Group three where white and one was coloured. Two of the five participants from Group three were English first language speakers and the other three spoke Afrikaans as first language. Of the five participants, three were described as having moderate aphasia and two as mild by the referring speech-language pathologist. Three of the five participants are currently receiving rehabilitative services in the form of support groups and four have received speech-language therapy in the past.

Seventeen interviews were undertaken, but two individuals had to be excluded on the bases of their aphasia being too severe for the execution of discourse analyses on the interview sample. Two other possible subjects were approached, but consent was not obtained from them to participate in this study.

2.4 INSTRUMENTS

Three instruments were used in this study namely a questionnaire, the International Classification of Impairments, Disability and Health (WHO, 2001) and a visual analogue scale. Following is a description of each of these.

2.4.1 Questionnaire and Interview

The face- to face interview was chosen because of the advantages that this method of data collection had for the study: it has higher response values, permits longer questionnaires and the interviewer can observe surroundings, interpret non-verbal communication and use visual aids (Neuman, 2000).

A set of questions was compiled in order to elicit sufficient discourse for the researcher to analyse (See Appendix B for the questionnaire used in the study). These questions were developed in accordance with consequences and needs identified by previous studies (Le Dorze & Brazzard 1995, Bethoux *et al.* 1996, Sarno 1997). The questionnaire was divided into two sections. Section one served to obtain biographical information from the subjects (discussed above). Section two encompassed the actual questionnaire, eliciting responses for consequences and needs respectively for the areas of communication, family relationships, friendships, community relationships, daily activities, independence, emotional status and self-image.

2.4.2 International Classification of Functioning Disability and Health (ICIDH-2)

The data obtained were classified into the ICIDH-2 components of: impairment, activity/activity limitation, participation/ participation restriction, environmental- and personal factors. The guidelines provided by the ICIDH-2 (see Appendix C) were further used to code reported consequences against the specific codes provided by the ICIDH-2 document.

2.4.3 Visual Analogue Scale

A visual analogue scale was developed in accordance with qualification specifications provided by the ICIDH-2 (WHO, 2001) (Appendix D). The qualifiers of the ICIDH-2, and as used in this study are as follows: "0" = no problem, "1" = mild problem, "2" = moderate problem, "3" = severe problem and "4" = complete problem.

2.3 PROCEDURE

> *"There are no mistakes. The events we bring upon*
> *ourselves are necessary to learn what we need to learn;*
> *whatever steps we take, they're necessary to reach the*
> *places we've chosen to go"*
>
> -Richard Bach, The Bridge Across Forever

Information was obtained from the participants through a semi-structured interview under favourable conditions either at a care facility or in the participants' homes. Before the interview started, informed consent was obtained from the participants by using a consent form that was designed to facilitate comprehension of the scope of the study (Appendix A). Open-ended questions served to allow the researcher a glance of the participants' perspectives (Neuman, 2000).

Interview questions were asked verbally and supported by material from the Pictographic Communication Resources Manual (PCR) (Kagan *et al.* 1996). The PCR (Kagan *et al.* 1996) is a collection of thematically organised pictographs, which acknowledges the value of visual stimuli in working with individuals with aphasia (Kagan, 1998). In order to prevent misunderstanding, wording was kept as simple as possible. If questions were misunderstood, the question was either reformulated (shortening, different wording or highlighting keywords) or supported by pictographic material. If the interviewer felt the response to be insufficient, elaboration was prompted through use of strategies such as silence, or further questions related to the topic under discussion. Participants were asked to rate reported consequences according to the visual analogue scale (Appendix D).

Responses were recorded on audiocassette and transcribed verbatim for analysis. The interviews were conducted either in English or Afrikaans, depending on the first language of the participant, and translated by the researcher into English for purposes of this report. Transcriptions and data analyses were done in the language the interviews were conducted in.

2.4 ETHICAL CONSIDERATIONS

Certain precautions were undertaken in order to adhere to professional research practice (Huysamen, 1994). Before the study was conducted a formal research proposal was submitted to the Ethics Committee of the University of Cape Town. Only after permission for execution of the study was obtained did the researcher proceed. The consent form served to inform the participants on the following: 1) the aims of the study, 2) the role of the subjects in the study, 3) that participation was entirely voluntary, 4) that interviews would be treated with confidentiality and 5) assurance that the results of the study would be beneficial to everybody with aphasia, including themselves. Furthermore, the use of Supportive Conversation Techniques (Kagan, 1998) served to verify conversational input from both sides: the researcher and the subject. Lastly, all information obtained from other researchers and writers received the necessary recognition in the written report of this study.

2.5 TREATMENT OF DATA

> *"In all human affairs there are efforts, and there are*
> *results, and the strength in effort is the measure of results"*
>
> -James Allan

2.5.1 Data analysis

This study was committed to a qualitative approach and this data were analysed descriptively. Trends within and between participant groups were highlighted. Data interpretation and analyses in qualitative research involves making sense of what people have said, looking for commonalities and themes. It is an inductive analysis, meaning that patterns, themes and categories emerged from the data (Neuman, 2000). Gee (1999) suggests that discourse analysis is an appropriate method of carrying out the above mentioned procedures.

Using the method of thematic analyses (See Appendix E for an example of the procedure followed), the researcher carried out the following steps to analyse data obtained during the interview. Firstly, the interviews were transcribed verbatim, using both written and aural recordings. Secondly, words, clauses or phrases that stated consequences and life needs were highlighted as meaningful units. These units of speech were summarised to capture the meaning. Next, similarities of consequences and life needs within and across the three participant groups were searched for. Analyses and categorisation of the consequences and life needs according to the International Classification of Functioning, Disability and Health (WHO, 2001) categories of impairment, activity/activity limitation and participation/participation restriction, environmental and personal factors were carried out. These categories were used to establish differences in consequences and life needs across subject groups. Lastly, the consequences that were identified were coded according to the codes provided by the ICIDH-2 (WHO, 2001) document (see Appendix E for an example of ICIDH-2 codes).

Once analyses have been completed, the data for each theme: communication, family relationships, friendships, community relationships, daily activities, independence, emotional status and self-image, were tabularised. At this point, Afrikaans data was translated into English. In order to verify the themes and ensure the inclusion of all necessary information, the transcripts were re-read alongside the corresponding tables. Finally, the themes were viewed in relation to the aims of the study and related back to the literature in the field.

2.5.2 Validity and Reliability

Neuman (2000) states that qualitative researchers are more interested in authentincy than validity, therefor giving a fair, honest and balanced account of social life from the viewpoint of he who lives it everyday. The researcher aimed to do exactly this in this study: to give a fair, honest and balanced overview of the consequences of aphasia and needs of individuals with aphasia from their perspective. This implies that the researcher will adhere to the core principal of validity: to be truthful (Neuman, 2000).

According to Neuman (2000) reliability is difficult to achieve in any field study because the observation made is bound to factors influencing behaviours at that specific moment. These factors may change over time. The researcher was however consistent in how the observations in this study were made. Furthermore, transcriptions were precise and conducted in a systematic manner.

This concludes the description of the methodology of the study. Followed are the results obtained after completion of data analyses, as well as the discussion of these results.

RESULTS

> *"It is a capital mistake to theorise before one has data.*
> *Insensibly one begins to twist facts to suit theories, instead*
> *of theories to facts"*
>
> -Sherlock Holmes

In this chapter, the results obtained from the interviews are presented and discussed thereafter. Results are presented in the same categorical order of the questionnaire, namely: communication, family relationships, relationships with friends, relationships with community, daily activities, independence, emotional status and self-image. Summaries of meaningful units are displayed in tables and discussed in terms of firstly consequences/needs for each section and secondly the coding of consequences against the ICIDH-2. Throughout the discussion of the results, the umbrella terms of body function/impairment, activity/activity limitation, participation/ participation restriction, environmental facilitator/environmental barrier and personal factor, as defined by the ICIDH-2, are used to discuss the emergent themes.

3.1 COMMUNICATION

> *"I believe Marx was only off by a suffix, it's not*
> *communism that can save us, but communication"*
>
> -Kirst Novoselic

3.1.1 Consequences of Aphasia on Communication

The consequences of aphasia on communication revealed broad reports at the levels of impairment, activity, participation, environmental- and personal factors according to the ICIDH-2 guidelines. Some commonalities were identified within and across subject groups and these will be presented and discussed in detail, based on the results displayed in Tables 3.1.1 to 3.1.4.

Table 3.1.1: Group one: Consequences and needs for communication

GROUP ONE: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I search for the right words (Q=3)	*People don't understand what I'm trying to say* (Q=4)	*I don't talk to other people* (Q=3)	*People don't get what I mean* (Q=3)	*I avoid talking to people* (Q=2)
I sound disoriented (Q=3)	*My words are not organized* (Q=3)	*My speech sounds unorganized* (Q=3)	*I talk very slowly* (Q=3)	*Everything I say is around about* *(Q=3)*
I struggle to put words together (Q=3)	*People don't talk to me* (Q=2)		*People think I'm dumb* (Q=3)	*I understand other people clearly* (Q=3)
	People don't know that I understand what they say (Q=4)			
	People think I'm stupid (Q=4)			
GROUP ONE: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I want my communication to be 100%	*I want my communication to be correct*	*I want to communicate more*	*I want to improve my speech on my own (want to be responsible for own success)*	*I want to be more confident when I speak*
	I want my speech to sound organized	*I want to be able to speak effortlessly*	*I want someone to talk to about my speak problem*	*I would like to continue with speech therapy*
	I want people to talk with me and not avoid me			

Key: Q = Qualifier ; 0 = no problem; 1 = mild problem; 2 = moderate problem; 3 = severe problem; 4 = complete problem

Table 3.1.2: Group two: Consequences and needs for communication

GROUP TWO: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
The words I want to say don't want to come out (Q=3)	*I struggle to say what I mean* (Q=3)	*I have to think before I talk* (Q=3)	*I can't find the right words. (I know them but can't find them)* (Q=3)	*I can't say the words that I* (Q=3)
I struggle to read (Q=3)	*I stay away from talking to people* (Q=3)	*I write like a small child* (Q=3)	*I can't read anymore (Q=3)*	*I can't read like I used to (Q=3)*
I can't write (Q=3)	*I can't use the phone* (Q=2)	*I stutter* (Q=3)	*I can't write anymore* (Q=3)	*I can't write like I used to* (Q=3)
I don't use the phone (Q=3)	*I can't talk to many people at once* (Q=3)	*I talk very slowly* (Q=2)	*I struggle to talk infront of a group of people* (Q=2)	*I struggle with the phone* (Q=3)
People go out of their way to not talk to me (Q=3)			*I try to avoid talking to people whenever I can* (Q=2)	*I avoid communicating with people I know* (Q=3)
People get impatient when I struggle (Q=2)			*I stutter (Q=2)*	*I have to think about what I'm going to say and how I'm going to say it (Q=3)*

GROUP TWO: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I want people to accept my way of communication	*I would like to read better*	*I don't want people to pity me when I talk*	*I want to communicate more often*	*I want to talk more*
I want to be comfortable with my speech	*I would like to write better*	*People must be more patient when I talk*	*I want to keep to the thing we are talking about*	*I would like to use the phone more comfortably*
	I want to cope better in group conversations	*I would like to stutter less*	*I don't want to stutter anymore*	*I want to be able to do every day reading and writing*

Key: Q = Qualifier ; 0 = no problem; 1 = mild problem; 2 = moderate problem; 3 = severe problem; 4 = complete problem

Table 3.1.3: Group three: Consequences and needs for communication

GROUP THREE: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I can't stick to the topic of conversation (Q=2)	*I don't talk ok when I'm in a group of people* (Q=3)	*I have difficulty to express what I'm meaning to say* (Q=2)	*Spelling is a big problem for me* (Q=3)	*What I want to say, doesn't come out right* (Q=2)
I really struggle when I have to talk to a group of people (Q=3)	*I struggle to use the telephone* (Q=2)	*I always wonder off of whatever it is that we are talking about* (Q=3)	*I have a big problem with remembering* (Q=2)	*I can only speak short phrases* (Q=2)
			I can't recall proper names (Q=3)	
			I cannot talk before groups (Q=3)	
			I struggle to read (Q=3)	
			I struggle to write (Q=3)	
			I have to think about what I'm going to say (Q=3)	
			I stutter (Q=2)	
GROUP THREE: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I want people to accept my communication	*I want conversations to be double-way*	*I don't want to give up hope*	*I want to talk easier when I'm in a group of people*	*When I'm talking, I want to feel comfortable*
	I want to communicate easier about personal issues		*I want to read easier*	*I want reading to be easier*
	I want people to be more patient when I talk			*I want writing as easy as it used to be*

Key: Q = Qualifier ; 0 = no problem; 1 = mild problem; 2 = moderate problem; 3 = severe problem; 4 = complete problem

Table 3.1.4: ICIDH-2 codes for the consequences of aphasia on communication

Consequence	Code and Qualifier	Component	Category	Page
GROUP ONE				
1. Word finding problems	b1442.3	Impairment	Retrieval of memory	42
2. Slow speech	b3302,3	Impairment	Speed of speech	55
3. Word combination Problems	a330,3	Activity	Speaking	102
4. Unorganised speech	a330,3; a330,3; a330,3	Activity	Speaking	102
5. Unclear meaning of speech	a330,3; a330,4	Activity	Speaking	102
6. Conversation with subject is avoided	e425,2	Environmental	Individual attitudes	143
7. Subject is perceived as being dumb	e425,4; e425,4	Environmental	Individual attitudes	143
8. People aren't aware of intact comprehension	e425,4	Environmental	Individual attitudes	143
9. Subject avoids communication with other people	Qualifier = 2	Personal	Personal factor: Not coded in ICIDH-2	n.a.
GROUP TWO				
1. Word finding problems	b330,2; b330,3; b330,3	Impairment	Retrieval of memory	102
2. Organize thoughts before speaking	b1603,3; b1603,3	Impairment	Control of thought	44
3. Reading problems	b16801,3; b1603,3; b1603,3	Impairment	Reception of written language	45
4. Written problems	b16811,3; b16811,3; b16811,4 b16811,4	Impairment	Expression of written language	46
5. Stutter	b3301,2; b3301,3	Impairment	Fluency of speech	54
6. Slow speech	b3302,2	Impairment	Speed of speech	55
7. Problems with expression	a330,3	Activity	Speaking	102
8. Problems in group conversations	p3504,3	Participation	Conversing with many people	104
9. Problems using the phone	p3600,2; p3306,3; p3306,3	Participation	Telecommunication devices	104
10. Impatience from other people when speaking	e425,22	Environmental	Individual attitudes	143
11. Avoids communication with other people	Qualifier = 2,2,3	Personal	Personal factor-not coded with ICIDH-2	n.a.
GROUP THREE				
1. Organize thoughts before speaking	b1603,3	Impairment	Control of thought	44
2. Reading problems	b16801,3	Impairment	Reception of written language	45
3. Writing problems	b16811,3	Impairment	Expression of written language	46
4. Word finding problems	b1442,2	Impairment	Retrieval of memory	42
5. Problems with expression	a330,2; a330,2	Activity	Speaking	102
6. Speak short phrases	a330,2	Activity	Speaking	102
7. Problems in group conversations	p3504,2; p3504,3	Participation	Conversing with other people	104
8. Problems with topic maintenance	p3501,2	Participation	Sustaining conversation	103
9. Problems using the phone	p3600,2	Participation	Telecommunication devices	104
10. Avoid conversation	Qualifier = 3	Personal	Personal factor= Not coded in ICIDH-2	n.a.

Key: b = impairment, a = activity, p = participation, e = environmental

Impairments were most prominently reported by participants in Group two, who further assigned higher qualifiers to these difficulties than the participants in Groups one and three. No impairments were reported by participants from Group one, and one of five participants in Group three conveyed impairments relating to writing, reading and fluency of speech.

A trend was apparent for activity limitation where reports of difficulties with speaking problems as well as the qualifiers assigned to these difficulties declined from Group one to Group three. Furthermore, Group one conveyed the largest variety of speaking limitations in the form of word combination difficulties, unorganised speech and unclear meaning of speech. Activity limitations predominantly comprised difficulties with expression for Groups two and three, reflected in statements such as: *"It's like you're meaning, but your meaning is not meant. All the time its just wanting to mean but saying is not that"* .

It was notable that communicative participation restriction increased from Group one to Group three. No participation restrictions were documented for participants in Group one. Participants in Groups two and three however reported restrictions related to conversational difficulties, for example problems with coping in group conversations and difficulties with topic maintenance, and they assigned qualifiers between two and three to these difficulties.

A pattern was apparent for environmental barriers across the three participant groups. Participants in Group one identified predominantly environmental barriers related to a lack of awareness about aphasia: *"People think I'm like a veggie or something, like uhm...like really stupid"*, *"Them out there don't know that I understand their words"*. This lack of awareness was reported by participants in Group one to be the most pressing of all the consequences identified, with qualifiers of four. One environmental barrier, pertaining to intolerance during the communication situation, was documented for Group two and no environmental barriers were stated by the participants from Group three.

Deliberate avoidance of communication was reported by participants from all three groups, with the majority in Group two. This report of restricted participation is related to personal factors according to the ICIDH-2 guidelines.

3.1.2 Needs for Communication

Both individual and concurring responses were documented for the needs reported. The ICIDH-2 components of impairment, activity, participation, environmental- and personal factors were reflected in the subjects' reports. Classification of needs was executed according to ICIDH-2 stipulations. The following themes and patterns were identifiable.

No overt patterns emerged for impairments, but it was notable that no such needs were stated by participants in Group one. However, four subjects from Group two and two from Group three conveyed needs reflecting impairments related to reading, writing and fluency of speech.

A pattern emerged across the three subject groups where participants in Group one reported needs for speaking activities (e.g. speech therapy and practising speech), but participants from Groups two and three reported needs for increased communicative participation (using the telephone and coping in group conversations).

Needs for reduced environmental barriers manifested in all three groups, but differed in nature. No identifiable patterns across subject groups were apparent, but it was notable that needs for patience and acceptance were prominent in Groups two and three.

No patterns were identified for personal factors, but some overlap was evident. Participants from Groups one and two reported the need of wanting to communicate more. Individual reports across the three participant groups include: a need for information regarding aphasia, the need to be comfortable with speaking, the need to communicate easier about personal issues and the need to never give up hope that speech will improve.

3.2 FAMILY RELATIONSHIPS

> *"A happy family is but an earlier heaven"*
>
> -John Bowling

3.2.1 Consequences of Aphasia on Family Relationships

Familial consequences, as reported by the 15 participants, revealed a wide-ranging impact of aphasia, with overlap and individual responses being evident. The ICIDH-2 guidelines were followed to place reports at the ICIDH-2 components of impairment, activity, participation, environmental- and personal factors. A description of results follow, based on the data displayed in Tables 3.2.1 to 3.2.4.

Data for consequences of aphasia on family relationships showed concurring and independent responses within and across subject groups. The ICIDH-2 classification revealed consequences to encompass participation- and environmental factors.

A pattern was notable for environmental factors, changing from facilitative factors for participants in Group one to barriers for participants in Groups two and three. Participants in group one reported facilitators of support and acceptance. Barriers encompassing a lack of awareness about aphasia, intolerance and high expectations were reported by participants in Groups two and three.

There was a trend notable for participation where participants in Group one reported no participation consequences, but participants from Groups two and three stated an array of participatory restrictions encompassing: spousal relationships, sibling relationships, child-parent relationships and general family relationships. Several authors have noted the progressing disruptions of family relationships as time passes (Lyon, 1992; Le Dorze & Brassarde, 1995; Sarno, 1997).

Table 3.2.1: Group one: Consequences and needs for family relationships

<table>
<tr><th colspan="5">GROUP ONE: CONSEQUENCES</th></tr>
<tr><th>Subject 1</th><th>Subject 2</th><th>Subject 3</th><th>Subject 4</th><th>Subject 5</th></tr>
<tr><td><i>They all support me</i> (Q=+4)</td><td><i>My family are the only people that try to understand me</i> (Q=+4</td><td><i>My family supports me a lot</i> (Q=+4)</td><td><i>They support me all the time</i> (Q=+4)</td><td><i>They support me beyond words</i> <i>(Q=+4)</i></td></tr>
<tr><td><i>My family helps me</i> (Q=+4)</td><td><i>All my family members help me</i> (Q=+4)</td><td></td><td><i>They accept me</i> (Q=+4)</td><td><i>We are much closer now</i> <i>(Q=O)</i></td></tr>
<tr><td><i>I have more contact with my family now</i> (Q=+4)</td><td></td><td></td><td></td><td></td></tr>
<tr><th colspan="5">GROUP 1: NEEDS</th></tr>
<tr><th>Subject 1</th><th>Subject 2</th><th>Subject 3</th><th>Subject 4</th><th>Subject 5</th></tr>
<tr><td><i>I want them to continue to support me</i></td><td><i>I want my family to be patient</i></td><td><i>I want more interaction with my family</i></td><td><i>I just want my family to be supportive</i></td><td><i>I want my family to continue to support me</i></td></tr>
<tr><td></td><td></td><td></td><td></td><td><i>I want my family to accept me</i></td></tr>
</table>

Key: Q= Qualifier; 0 = no problem; 1 = mild problem; 2 = moderate problem; 3 = severe problem; 4 = complete problem

Table 3.2.2: Group two: Consequences and needs for family relationships

GROUP TWO: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I have a lot of marital problems (Q=3)	*My daughter treats me like an outsider* Q=4)	*They are not patient* (Q=2)	*My children don't understand the problem* (Q=2)	*There is friction between me and my family* (Q=4)
My children doesn't know how to communicate with me (Q=3)	*There is a constant friction in the family* (Q=3))		*My children avoid me* (Q=2)	*My children treat me like an outsider* (Q=3)
My brothers and sisters have no real interest in my health (Q=2)	*My brother never contacts me* (Q=4)		*My wife expects too much of me* (Q=3)	

GROUP TWO: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I want my marriage to improve	*I want to improve my relationship with my daughter*	*I want my family to respect me*	*I want my family to be more patient*	*I want my family to accept the new me*
I would like my relationship with my children to improve	*I want to feel less guilty about my bad relationship with my daughter*	*I want to feel part of the family*	*I want more support from my family*	*I want my family to learn to deal with me*
	I want to be included in my family			

Key: Q= Qualifier; 0 = no problem, 1 = mild problem, 2 = moderate problem, 3 = severe problem, 4 = complete problem

Table 3.2.3: Group three: Consequences and needs for family relationships

GROUP THREE: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
My family rejects me (Q=2)	*My family is impatient* (Q=3)	*They treat me like an outsider* (Q=4)	*My children is very impatient toward me* (Q=3)	*There is a lack of communication* (Q=2)
I can't find a wife (Q=4)	*My family doesn't understand my problem* (Q=3)	*I divorced because of our communication problems* (Q=3)	*They don't understand the problem* (Q=3)	*Getting irritated is a big problem* (Q=3)
GROUP THREE: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I want my family to understand my problem	*I want my family to know what I'm going through*	*I want my family to understand*	*I want us to learn to work through disagreements*	*I want more communication to take place in this family*
I want to find a wife		*I want them to be more involved in my life*	*I want to be close to my family*	
		I want to be more involved in their lives	*I want a wife*	

Key: Q= Qualifier; 0 = no problem; 1 = mild problem, 2 = moderate problem, 3 = severe problem, 4 = complete problem

Table 3.2.4: ICIDH-2 coding of the consequences of aphasia on family relationships

Consequence	Code and Qualifier	Component	Category	Page
GROUP ONE				
1. Much closer now	p760,0	Participation	General family relationship	102
2. Support	e310+4; e310+4; 3310+4 e310+4	Environmental Environmental	Support from immediate family	141
3. Provision of help	e310+4; e310+4	Environmental	Support from immediate family	141
4. Empathy	e410+4	Environmental	Individual attitudes of immediate family	143
5. Acceptance	e401+4	Environmental	Individual attitudes of immediate family	143
GROUP TWO				
1. Friction between family as whole	p760,1	Participation	General family relationships	102
2. Marital problems	p7701,3	Participation	Spousal relationships	123
3. Daughter treats subject like outsider	p7601,3; p7601,4	Participation	Child-parent relationships	122
4. No interest in health status siblings	p7602,2; p7602,2	Participation	Sibling relationships	123
5. Children don't know how to communicate	e410,3	Environmental	Individual attitudes of immediate family	143
6. Children don't understand the problem	e410,2	Environmental	Individual attitudes of immediate family	143
7. Children avoid the subject	e410,2	Environmental	Individual attitudes of immediate family	143
8. Impatience	e410,2	Environmental	Individual attitudes of immediate family	143
9. Spouse's expectations too high	e410,3	Environmental	Individual attitudes of immediate family	143
GROUP THREE				
1. Treated like an outsider	p760,4	Participation	General family relationships	102
2. Lack of communication between members	p760,2	Participation	General family relationships	102
3. Can't find a wife	p7701,4	Participation	Spousal relationship	123
4. Divorced due to communication problems	p7701,3	Participation	Spousal relationships	123
5. Rejection from family	e410,2	Environmental	Individual attitudes of immediate family	143
6. Lack of understanding the communication problem	e410,2; e410,3	Environmental	Individual attitudes of immediate family	143
7. Impatience	e410,3	Environmental	Individual attitudes of immediate family	143
8. Frustration	e410,3	Environmental	Individual attitudes of immediate family	143
9. Irritation	e410,3	Environmental	Individual attitudes of immediate family	143

Key: b = impairment; a = activity; p = participation; e = environmental

3.2.2 Needs for Family Relationships

Data obtained from participants in Groups one, two and three for their needs regarding their relationships with friends, revealed overlap within and across subject groups. Responses were classified into the ICIDH-2 components of participation, environmental- and personal factors, according to the definitions provided by the ICIDH-2. Following is a discussion of the needs displayed in Tables 3.2.1 to 3.2.3.

A trend was documented where there was a notable increase in participatory needs from Group one to Groups two and three. One participatory need, namely that for increased interaction with family members, was documented for Group one. The needs for increased participation as reported by participants in Group two include needs for improved marital relationships, improved relationships with children and to be included into the family. Participatory needs stated by Group three were to "find a wife", to be included into the family, a need for increased communication between family members and the need for reciprocal interaction: *"I want them to be in my life and I want to be in theirs"*.

Needs for reduced environmental barriers were documented for all three groups. A trend was documented for familial lack of awareness, where there was an increase in participants from Group one to three reporting a need for this barrier to be reduced. The environmental needs documented for Group one was for the continuation of facilitative factors such as support, acceptance and patience. Needs reported by participants in Group two was for the reduction of the following barriers: lack of patience, lack of acceptance, lack of support and lack of awareness.

3.3 RELATIONSHIPS WITH FRIENDS

> *"In the end, we will not remember the insults of our*
> *enemies, but the silence of our friends"*
>
> -Martin Luther King Jr.

3.3.1 Consequences of Aphasia on Friendships

The consequences of aphasia on friendships as reported by the participants revealed the emergence of broad patterns. According to the specifications of the ICIDH-2, the components of participation- and environmental components were represented by participants' reports. Following is a discussion of the results obtained for the consequences of aphasia on friendships, based on the data portrayed in Tables 3.3.1 to 3.3.4

Diminution of participation within friendships from Group one to Group three is observed. Participants in Group one reported no participation restrictions, but four of five participants in Group two and five of five participants in Group three stated participation restrictions. Reports of fewer friends were documented for Group two and participants in Group three stated restrictions encompassing fewer friends and difficulties with initiating friendships, for example: *" I know that new friends are difficult"* and *" Whenever I have a friend over...uhm one that wasn't there before, It's like not deep stuff. You stay there up top and not go deep"*. Qualifiers between two and three (moderate and severe problem) were assigned to the above-mentioned restrictions. It was also notable that subjects in Group three assigned qualifiers between nil and one to describe the relationships they have with their remaining friends as no problem or a mild problem.

A pattern is notable for environmental factors, where only facilitators are reported by participants in Group one, with barriers being increasingly documented for Groups two and three. Environmental facilitators dealing with support, as conveyed by subjects in Group one, were reported to be complete facilitators ("+4") and those dealing with awareness were rated substantial facilitators ("+3"). Participants in Group two reported six environmental consequences of which three were facilitators such as attempts to help and understand, rated as substantial ("+3"), and three were barriers e.g. friends being uncomfortable and friends being insincere, rated as severe (three). No environmental facilitators and three environmental barriers, including friends being uninformed and friends pitying the participants, were documented for Group three.

Table 3.3.1: Group one: Consequences and needs for friendships

GROUP ONE: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
My friends give me a lot of support Q=+4	*They support me* (Q=+4)	*My friends try to help me* (Q=+4)	*They support me a lot* (Q=+4)	*They support me* (Q=+4)
	They know I understand (Q=+3)	*My aphasic friends support me more* (Q=+4)	*I've got more friends now* (Q=0)	*They try to understand what I say* (Q=+4)
	They try to lift my spirits (Q=+3)		*Some of my friends get uncomfortable when they're with me* (Q=2)	
	They try to understand why I struggle to talk (Q=+3)			
GROUP ONE: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I just want them to continue now	*They must be patient*	*I want to interact more with*	*I need them to support me*	*They must just support me*
	I want people to treat me the same as they did in the past			*I want to remain in contact with people with aphasia*
	They must know I'm not dumb			

Key: Q= Qualifier; 0= no problem;1= mild problem;2= moderate problem;3= severe problem; 4= complete problem

Table 3.3.2: Group two: Consequences and needs for friendships

GROUP TWO: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
The friends that stayed, tried (Q=+3)	*I have a lot less friends now* (Q=3)	*I have a few friends left* (Q=2)	*Most of my friends* (Q=2)	*I have less friends now* (Q=3)
They try to understand what I'm going through (Q=+3)	*They don't seem sincere in their interest in me* (Q=3)	*The remaining friends try to help me* (Q=3)	*I avoid my friends* (Q=2)	*The remaining friends treat me like an outsider* (Q=3)
Some of my friends get uncomfortable (Q=3)		*My friends try to understand my problem* (Q=3)		
GROUP TWO: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
Friends are not my priority, my family is	*I want my friends to be patient with me*	*I want my friends to be sincere*	*I just don't want them to pity me*	*I only want some more friends*
	I want my friends to include me	*I would like to have more friends*		
	I want my ex-colleagues to to show interest in my health			
	I want to be less lonely			

Key: Q= Qualifier; 0= no problem;1= mild problem; 2= moderate problem;3= severe problem; 4= complete problem

Table 3.3.3: Group three: Consequences and needs for friendships

GROUP THREE: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
My best friend also has aphasia (Q=0)	*My friends are a lot less now* (Q=2)	*I struggle to make new friends* (Q=3)	*My friends are uninformed* (Q=3)	*I have a lot less friends than I use to have* (Q=2)
I have very little friends left (Q=3)	*I get along fine with the friends that are left* (Q=0)	*I have less friends now* (Q=2)	*They try to help, but do the wrong things* (Q=3)	*I don't have problems with the friends I have* (Q=1)
		My relationship is ok with the friends that are left (Q=1)	*I lost my best friend* (Q=3)	
			My friends pity me (Q=3)	
			The new relationships I form, are shallow (Q=3)	

GROUP THREE: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I want normal friends too (not just friends with aphasia)	No needs	I want to make friends easier	I just want on close friend	Needs
			I want my friends to respect me	

Key: Q= Qualifier;0= no problem;1= mild problem; 2= moderate problem; 3= severe problem; 4=complete problem

Table 3.3.4: ICIDH-2 coding of the consequences of aphasia on friendships

Consequence	Code and Qualifier	Component	Category	Page
GROUP ONE				
1. Support	e320+3; e320+4; e320+4 e320+4	Environmental	Friends	141
2. Attempt to provide help	e320+4	Environmental	Friends (support)	141
3. Attempt to lift spirits	e320+3	Environmental	Friends (support)	141
4. More support from aphasic friends	e325+4; e324+4	Environmental	Acquaintances peers, colleagues	141
5. Know subject comprehends	e420+4	Environmental	Individual attitudes of friends	143
6. Attempt to understand the problem	e420+3; e420+4	Environmental	Individual attitudes of friends	143
7. Some friends appear to be uncomfortable	e420,2	Environmental	Individual attitudes of friends	143
GROUP TWO				
1. Less friends	p7500,2; p7500,2; p7500,3 p7500,3	Participation	Informal relationship with friends	122
2. Attempt to provide help	e320+3; e320+3	Environmental	Support from friends	141
3. Attempt to understand the problem	e420+3; e420+3	Environmental	Individual attitudes of friends	143
4. Some friends appear to be uncomfortable	e420,3	Environmental	Individual attitudes of friends	143
5. Friends aren't sincere (about interest in health)	e420,3	Environmental	Individual attitudes of friends	143
6. Subjects avoids friends	Qualifier = 2	Personal	Personal factor, Not coded in ICIDH-2	n.a.
GROUP THREE				
1. Less friends	p7500,2, p7500,2; p7500,2 p7500,3	Participation	Informal relationship with friends	122
2. Remaining friendships	p7500,0; p7500,1	Participation	Informal relationship with friends	122
3. Best friend also has aphasia	p7504,0	Participation	Informal relationship with peers	120
4. Struggle to make new friends	p7200,3	Participation	Forming relationships	120
5. New friendships are shallow	p7200,3	Participation	Forming relationships	120
6. Friends pity subject	e420,3	Environmental	Individual attitudes of friends	143

Key: p = participation; e = environmental

3.3.2 Needs for Friendships

The needs that were documented for friendships showed agreement and individual responses in-and across subject groups. The ICIDH-2 specifications indicated the needs reported to be environmental- and participation factors. Based on the data displayed in Tables 3.3.1 to 3.3.3, the needs for friendships will be discussed.

A declining pattern for environmental needs from Group one to Group three is apparent. Furthermore, the needs change from the continuation of facilitative factors to the reduction of environmental barriers. Environmental needs reported by participants in Group one were for continuation of support, patience and awareness about the individuals' intact comprehension. Participants in Group two reported needs for the following environmental barriers to be reduced: insincerity, impatience, pity and lack of interest from work colleagues. Documented as and environmental need reported by one participant in Group three is the need for respect from friends.

No apparent patterns emerged for participatory needs; however some individual responses were notable. The need for increased interaction with friends was documented for Group one. Participatory needs reported by participants in Group two are needs to have more friends and to be included into friendships. Reported by Group three as needs for increased participation are needs to make friends easier: *"I would have more friends if making them was easier"*, to have non-aphasic friends: *"I want normal people too...not just the ones like me"* and to have one close friend.

3.4 DAILY ACTIVITIES

3.4.1 Consequences of Aphasia on Daily Activities

Using the ICIDH-2 guidelines, the reports for daily activities were classified as participation restrictions. Varied areas of daily activities were reported to be influenced by aphasia. Following is a discussion of the data displayed in Tables 3.4.1 to 3.4.4.

Table 3.4.1: Group one: Consequences and needs for daily activities

GROUP ONE: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I lost my job (Q=2)	*I don't have a job anymore* (Q=2)	*I just sit and do nothing* (Q=2)	*My routine hasn't changed at all* (Q=0)_	*I sleep the whole day long* (Q=3)
My hobbies changed (Q=2)	*I do nothing all day long* (Q=2)		*I keep doing physical jobs where I don't have to talk* (Q=1)	*I can't do my old hobbies anymore*
I relax more now to avoid another stroke (Q=0)	*I can't do the social thing anymore* (Q=2)		*I try to be very calm and relaxed* (Q=0)	
GROUP ONE: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I just want to do my old hobbies	*I just want to keep busy*	*I want to practice my speech every day*	*I want to keep my job*	*I want to have speech therapy as often as possible*
I want to relax enough			*I want to keep busy*	
			I need to relax enough	

Key: Q=Qualifier; 0= no problem; 1= mild problem; 2 = moderate problem; 3= severe problem; 4= complete problem

Table 3.4.2: Group two: Consequences and needs for daily activities

GROUP TWO: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I can't work anymore (Q=2)	*I'm not allowed to work anywhere* (Q=2)	*I can never work again* (Q=3)	*I can't work because of my speech problem* (Q=3)	*I cannot go to the shops anymore* (Q=3)
I only do things in the house (Q=1)	*I never leave the house* (Q=2)	*I can't socialize with my friend or family anymore* (Q=3)	*My life revolve around watching TV* (Q=3)	*I can't go to anything social* (Q=3)
	I sleep a lot more than other people (Q=2)	*My life is much slower now to avoid another stroke* (Q=2)	*My life is very calm now to avoid another stroke* (Q=1)	*I can't go to the post office* (Q=3)
	I really miss my old job (Q=2)		*I'm not involved in my children's daily activities* (Q=3)	
GROUP TWO: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I want to have job	*I want some variation from the house tasks*	*I just want a job*	*I want a job again*	*I want to stay busy*
I want to keep busy	*As long as there is something for me to do*		*I want to help people like me in the community*	*I would like to be able to socialize again*
			I want to continue with my speech therapy	

Key: Q = Qualifier; 0 = no problem; 1 = mild problem; 2 = moderate problem; 3 = severe problem; 4 = complete problem

Table 3.4.3: Group three: Consequences and needs for daily activities

GROUP THREE: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I can never work again (Q=4)	*I can't do any job* (Q=4)	*I never leave the house* (Q=3)	*I can't find another job* (Q=3)	*I try to do things that will help my health* (Q=0)
I keep to non-communicative activities (Q=1)	*I can't go to social barbeques* (Q=3)	*I only do things where you don't have to talk* (Q=0)	*I only do things where I don't have to talk* (Q=2)	*I'll do anything, as long as I don't have to talk* (Q=3)
			I do a lot of therapy stuff for my health (Q=0)	*I used to love socializing, now it's a nightmare for me*
GROUP THREE: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I want a job like normal people do	*I want to take part in the community activities*	*I don't want to be bored and do nothing*	*My only need is for a job*	*I want to do more stuff that involves talking to people*
I want to do social things again	*I want to relax enough*	*I would like to do more communicative activities*		

Key: Q = Qualifier; 0 = no problem; 1 = mild problem; 2 = moderate problem; 3 = severe problem; 4 = complete problem

Table 3.4.4: ICIDH-2 coding of the consequences of aphasia on daily activities

Consequence	Code and Qualifier	Component	Category	Page
GROUP ONE				
1. Do nothing	p2301,2; p2301,2	Participation	Managing daily routine	100
2. Sleep the whole time	p2301,3	Participation	Managing daily routine	100
3. Keep to physical jobs	p2301,1	Participation	Managing daily routine	100
4. Routine hasn't changed	p2301,0	Partaicipation	Managing daily routine	100
5. Relax more (to avoid another stroke)	p2401,0; p2401,0	Participation	Handling stress	100
6. Can't word anymore	p8502,2; p8502,2	Participation	Full-time employment	125
7. Hobbies changed	p9204,2; p9204,3	Participation	Hobbies	127
8. Can't socialize anymore	p9205,2	Participation	Socializing	128
GROUP TWO				
1. Sleep the whole time	p2301,2	Participation	Managing daily routine	100
2. Watch TV the whole time	p2301,2	Participation	Managing daily routine	100
3. Don't leave the house	p2301,2	Participation	Managing daily routine	100
4. Relax more (to avoid another stroke)	p2401,1; p2401,2	Participation	Handling stress	100
5. Can't go shopping	p6200,3	Participation	Shopping	116
6. Can't go to the post-office	p6208,3	Participation	Acquisition of goods and service	116
7. Mostly house activities	p640,1	Participation	Doing housework	117
8. Not involved in children's daily activities	p7600,3	Participation	Parent-child relationship	122
9. Miss old job	p8452,2	Participation	Terminating job	125
10. Can't work anymore	p8502,2; p8502,2; p8502,3 p8502,3	Participation Participation	Full-time employment	125
11. Can't socialize anymore	p9205,3; p9205,3	Participation	Socializing	128
GROUP THREE				
1. Don't leave the house	p2301,0	Participation	Managing daily routine	100
2. Only undertake non-communicative activities	p2301,0; p2301,1; p2301,2 p2301,3	Participation Participation	Managing daily routine	100
3. More health-orientated activities	p5702,0	Participation	Maintaining one's health	115
4. Can't work anymore	p8502,3; p8502,3; p8502,4	Participation	Full-time employment	125
5. Can't socialize anymore	p9205,3; p9205,3	Participation	Socializing	128

Key: p = participation

Participation restrictions for full-time employment were documented for all three groups. The restriction posed by difficulties with employment was noted to enlarge from Group one to Group three, as increasingly severe qualifiers were assigned. Participants in Group one commented on their loss of employment, and partcipants in Groups two and three stated difficulties with acquiring and keeping a job.

Participants in all three groups conveyed difficulties with managing their daily routines. No apparent pattern emerged, but it was noted that qualifiers of two and three (moderate and severe problem) were assigned to this consequence of aphasia. Statements such as: *"I...do-do...I do nothing all...uhm...the whole day long"* and *"I just sit and do nothing"* are examples of difficulties with managing daily routine as reported by participants in Group one. Management difficulties reported by participants in Group two are reflected in *"My whole life is basically TV"* and *"I never go out and leave this house to just go"*. Difficulties with management as reported by participants in Group two related to confinement to the house.

There was a trend where a growing number of participants from Group one to Group three reported difficulties with socialising. Furthermore, the qualifiers that participants assigned to these difficulties increased from moderate for Group one to severe for Groups two and three. Statements such as *"I can't do the friends and together and social...uhm that thing...I can't do that no more"* and *"I can't go to social barbecues anymore"* were reflective of difficulties with socialising.

Reports of compensatory strategies increased from Group one to Group three. The strategy of keeping to physical jobs was reported by one of five subjects in Group one. Reports of only doing things in the house were documented for participants in Group two whereas Group three generalised coping strategies to "keeping to non-communicative activities. The coping strategy of relaxing more in order to avoid another stroke, was reported by participants in Groups one and two.

3.4.2 Summary of needs for daily activities

Report of needs for daily activities showed shared as well as distinctive responses. A range of daily activities was covered by the responses documented, comprising of the ICIDH-2 components of activity and participation. No clear pattern was identified with review of data in Tables 3.4.1 to 3.4.3, but the following is eminent.

Two needs for daily activities were classified under the ICIDH-2 component of activity, both related to speech activities, namely to practice speech everyday and to continue with regular speech therapy. These needs were respectively documented for one of five participants in Groups one and two.

Needs for participation enhancement were reflected in reports of participants in all three subject groups. A need to keep busy was documented for participants in Groups one, two and three, with no apparent pattern being notable. Participants in Groups two and three stated needs for socialising and employment and needs pertaining to relaxation were reported by participation in Groups one and three. Communicative needs, as reported by participants in Group three, were reflected in the following statements: *"I would like for my communication to happen more in activities that I do..."* and *"I-I want to do more stuff where talking is there"*. Individual responses include participatory needs dealing with hobbies, variation from house tasks and participating in community activities, as stated by one participant in Group one, two and three respectively.

3.5 INDEPENDENCE

> *" No one can build his security upon the nobleness of*
> *another"*
>
> -William Cobbett

3.5.1 Consequences of Aphasia on Independence

Broad patterns were identifiable from reports of the consequences of aphasia on independence. The ICIDH-2 guidelines indicated the participants' reports to be classified as participation- and environmental components. A discussion of the emergent trends for independence follows, based on the data displayed in Tables 3.5.1 to 3.5.4.

There was a trend where the number of participants reporting general dependence decreased from Group one to Group three. This pattern is supported by the reversed increase in number of participants from Group one to three stating to be independent. Dependence are however reported to be a more pressing problem by the participants in Groups two and three, as higher qualifiers are assigned to dependence by participants in these two groups. Reports of being dependent specifically with communicative activities, were documented for one of five participants in all three subject groups. The ICIDH-2 specifications guided the classification of all the above consequences to be participation restrictions.

It was notable that participants in Groups two and three reported on the environmental barrier posed by their families' overprotection on their independence. Participants in Group two rated this barrier as a moderate to severe (two to three) problem, and the participants from Group three qualified this barrier as severe to complete (three to four). Statements such as: *"It is difficult for my family to see that I can use my brain and my body for myself"* and *"I see them every day...struggling to let me do what I say I can for myself"* were indicative of familial overprotection.

3.5.2 Needs for Independence

The needs that were reported for independence showed changing patterns across the three subject groups. According to ICIDH-2 stipulations, participation, environmental- and personal factors were represented in the subject, reports. With reference to Tables 3.5.1 to 3.5.3, the needs reported for independence will be discussed.

Table 3.5.1: Group one: Consequences and needs for independence

GROUP ONE: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I am only dependent with talking things (Q=1)	*I am very dependent* (Q=2)	*I am dependent on other people with almost everything* (Q=1)	*I am only dependent when I ask people to help me* (Q=1)	*I still need people to do everything for me* (Q=1)
GROUP ONE: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I need all the help I can get at this stage	*For now, I actually need all the help*	*I want people to help me when they see I need it*	*I only want people to do things for me when I ask them to*	*I want to be independent in the future*
	Someday I would like to be independent again			

Key: Q = Qualifier; 0 = no problem; 1 = mild problem; 2 = moderate problem

Table 3.5.2: Group two: Consequences and needs for independence

GROUP TWO: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I is difficult for my family to realize that I can think and do for myself (Q=2)	*I can see my family struggle to let me try things for myself* (Q=3)	*I'm very dependent* (Q=3)	*I'm relatively independent* (Q=1)	*I'm very dependent on other people for help* (Q=2)
I started to do things on my own again (Q=0)	*I'm most dependent with things where I have to talk* (Q=3)			
GROUP TWO: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I want to be strong enough to break this routine	*I want to be alone with other people*	*I want to be my own person*	*No needs*	*I only want to be more independent when it comes to talking*
	I would like to be independent with things where I have to talk			
	My husband must learn to let me try			

Key: Q=Qualifier; 0 = no problem; 1 = mild problem; 2 = moderate problem; 3 = severe problem

Table 3.5.3: Group three: Consequences and needs for independence

GROUP THREE: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
My family refuses to let me do things for myself (Q=3)	*My family doesn't want to see that I can do things for myself* (Q=4)	*I'm very dependent, still after all these years* (Q=3)	*I have no problem when it comes to looking after myself* (Q=0)	*I'm relatively independent* (Q=0)
	I'm not a leader anymore (Q=3)			*I only need help when it comes to speaking/talking* (Q=1)
GROUP 3: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I want to be financially independent	*I want my family to realise that I can do things on my own*	*I want to go to the shops alone*	*No needs*	*I want my people to set me free*
		I want to go to social gatherings by myself		

Key: Q= Qualifier; 0 = no problem; 1 = mild problem; 2 = moderate problem; 4 = complete problem

Table 3.5.4: ICIDH-2 coding of the consequences of aphasia on the independence of the subjects

Consequence	Code and Qualifier	Component	Category	Page
GROUP ONE				
1. Only dependent with communicative activities	p2102,1	Participation	Undertaking a single task independently	99
2. Only dependent when help is requested	p2102,1	Participation	Undertaking a single task independently	99
3. Generally dependent	p2202,1; p2202,1; p2202,2	Participation	Undertaking multiple tasks independently	100
GROUP TWO				
1. Only dependent with communicative activities	p2102,3	Participation	Undertaking a single task independently	99
2. Generally dependent	p2202,2; p2202,3	Participation	Undertaking multiple tasks independently	100
3. Relatively independent	p2202,1	Participation	Undertaking multiple tasks independently	100
4. Difficult for family to let go	e425,2	Environmental	Individual attitudes of family members	143
GROUP THREE				
1. No more leadership characteristics	p179,3	Participation	Applying knowledge, other specified	98
2. Only dependent with communicative activities	p2102,3	Participation	Undertaking a single task independently	99
3. Generally dependent	p2202,3	Participation	Undertaking multiple tasks independently	100
4. Independent	p2202,1	Participation	Undertaking multiple tasks independently	100
5. Family won't leg go	e425,2	Environmental	Individual attitudes of family members	143

Key: p = participation; e = environmental

It is notable that independence deteriorates from Group one to Group three. According to the data gleaned from Group one, participants reporting dependence stated the need for assistance at this stage. The need for future independence was documented for two of five participants in Group one. Four of five participants from Groups two and three reported needs for greater independence in the form of either needs for increased participation: *"I want to be alone with other people"*, reduced environmental barriers: *"My husband must learn to let me fall and get up and learn"* or enabling personal factors: *"I want to be strong enough to make things different"*.

3.6 EMOTIONAL STATUS

> *"Wars aren't fought in the trenches. Rather in the mind,*
> *body and soul. For life is the battlefield, society and*
> *emotions are the adversaries and victory is determined by*
> *our reactions to those very forces*
>
> -Curtis Reeves

3.6.1 Consequences of Aphasia on Emotional Status

Reports of the consequences of aphasia on emotional status were wide-ranging, but patterns were identified. The ICIDH-2 definitions were used to classify consequences as impairments, environmental- and personal factors. Following is a discussion of the data summarised in Tables 3.6.1 to 3.6.4 for emotional status.

Reports of impairments dealing with depression and sadness were documented for participants in all three subject groups. There was a trend for depression to increase in both numbers of participants reporting depression and in the severity of the qualifiers from Group 1 to Group 3. Although depression was categorised as a body dysfunction in this study (according to the ICIDH-2 classification system), evidence suggests that depressive changes take place along the continuum of recovery (Robinson, Starr, Lipsey,

Table 3.6.1: Group one: Consequences and needs for emotional status

GROUP ONE: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I don't know yet, I still have to process the whole thing	*I feel very sad* (Q=3)	*I have this constant fear for another stroke* (Q=4)	*I feel very frustrated all the time* (Q=3)	*Most of the time, I feel sad* (Q=2)
	I can't control my emotions at all (Q=3)	*My emotions are all over the place* (Q=3)	*I feel depressed every now and again* (Q=2)	*I haven't dealt with the whole thing in an emotional way*
	I feel very powerless (Q=3)		*I mainly very despondent* (Q=3)	
GROUP TWO: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I don't want to be constantly scared of having another stroke	*I want to control my emotions*	*I want to be able to control what I feel and how I show it*	*I want to avoid stress*	*I want to have control over my emotions*
	I want to be more optimistic		*I don't want to have this fear of strokes*	

Key: Q = Qualifier; 2 = moderate problem; 3 = severe problem; 4 = complete problem

Table 3.6.2: Group two: Consequences and needs for emotional status

GROUP TWO: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
My emotions are like see-saw (Q=3)	*I accepted my speech problem* (Q=0)	*I get sad all the time* (Q=2)	*I accepted the problem* (Q=0)	*I get very sad* (Q=2)
	I feel very lonely (Q=3)	*Depression comes and goes* (Q=2)		*I feel depression every now and then* (Q=2)
	I constantly fear another stroke (Q=3)			*I'm scared of having another stroke* (Q=3)
GROUP TWO: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I want my emotions to stabilise	*I don't want to feel so lonely*	*I don't want to feel so sad*	*No needs*	*I want to feel less sad*
I want to control my emotions	*I would like to get rid of this fear for another stroke*			*I want to be more of a relaxed person*

Key: Q=Qualifier; O = no problem; 2 = moderate problem; 3 = severe problem

Table 3.6.3: Group three: Consequences and needs for emotional status

GROUP THREE: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I am mainly depressed (Q=3)	*I'm very depressed* (Q=3)	*I am constantly depressed* (Q=3)	*I am depressed* (Q=3)	*I'm entirely emotionless. I do not get happy, mad or sad* (Q=3)
		I have this intense sadness (Q=1)	*I am highly stressed* (Q=3)	
GROUP THREE: NEED				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I don't want to feel so depressed	*I don't want to be depressed*	*I want to get rid of this sad feeling*	*I don't want to be depressed anymore*	*I would like to feel emotions again*
I want to have a higher threshold for frustration		*I want to continue with my medication for depression*	*I want to feel less stressed*	

Key: Q= Qualifier; 1 = mild problem; 3 = severe problem

Table 3.6.4: ICIDH-2 coding of the consequences of aphasia on emotional status

Consequence	Code and Qualifier	Component	Category	Page
GROUP ONE				
1. No effects yet - still have to process	n.a.		n.a.	n.a.
2. Get very despondent	b1265,3	Impairment	Optimism	40
3. Sadness	b1522,2; b1522,3	Impairment	Range of emotion	43
4. Frustration	b1522,3	Impairment	Range of emotion	43
5. Lack of control over emotions	b1521,3; b1521,3	Impairment	Regulation of emotion	43
6. Depression	b1528,2	Impairment	Emotion os	43
7. Fear of another stroke	Qualifier = 3	Personal	Personal factor: not coded in ICIDH-2	n.a.
8. Feel powerless	Qualifier = 3	Personal	Personal factor: not coded in ICIDH-2	n.a.
GROUP TWO				
1. Sadness	b1522,2; b1522,2	Impairment	Range of emotion	43
2. Lack of control over emotions	b1521,3	Impairment	Regulation of emotion	43
3. Depression	b1528,2; b1528,2	Impairment	Emotion os	43
4. Accepted the problem	Qualifier = 0,1	Personal	Personal factor: not coded in ICIDH-2	n.a.
5. Fear of another stroke	Qualifier = 3,3	Personal	Personal factor: not coded in ICIDH-2	n.a.
GROUP THREE				
1. Experience very little	b1520,3	Impairment	Appropriateness	43
2. Sadness	b1522,1	Impairment	Range of emotion	43
3. Depression	b1528,1, b1528,3; b1528,3 b1528,3	Impairment	Emotion os	43
4. Highly stressed	p2401,3	Participation	Handling stress	100

Key: b = impairment, p = paraticipation

Race and Price, 1984; Angeleri *et al.* 1993; Herrmann. Johannsen-Horbach & Wallesch 1993). These authors maintain that depression changes from being related to impaired body functioning in the acute phase and, with time, changes to a psychological reaction resulting from living with aphasia. The impairment of a lack of emotional control, as reflected in the following statements: *"My emotions are...it's like all over the place"* and *"It's like sitting on a seesaw"* was documented for Groups one and two.

There was a trend observed for sadness, where both the number of participants reporting this consequence and the qualifiers assigned decreased from Group one to Group three. Reports of impairments encompassing regulation of emotions were documented for participants in Groups one and two.

Involvement/support from the church, was reported by participants in all three groups. Participants rated this environmental facilitator (according to ICIDH-2 guidelines) as substantial or complete facilitators ("+3" or "+4")

Statements of the fear of having another stroke: *"I have this constant thing in there...for it happening again"* and *"It's become part of how I feel everyday, this scaredness for another stroke"*, were documented for participants in Groups one and two.

A variety of personal factors were individually reported for emotional status. These include: despondence, powerlessness, frustration and the participation restriction of being stressed.

3.6.2 Needs for Emotional Status

Needs reported by the participants for emotional status revealed overlap within and across subject groups. According to ICIDH-2 guidelines, the needs were classified as body functions, participation functions and personal factors. Following is a discussion of the participants' needs for emotional status, referring to the data displayed in Tables 3.6.1 to 3.6.4.

Needs comprising impairments were documented for all three groups. Participants in Group one stated needs for optimism and greater control over emotions. Needs to feel less sad and for greater control over emotions was reported by Group two and needs to feel less depressed was conveyed by participants from Group three.

Needs in line with personal factors were documented for participants in all three groups. The need not to fear another stroke was stated by two of five participants in Group one and one participant in Group two. The need for continuation of medication for depression was documented for one of five participants in Group three.

3.7 SELF-IMAGE

"Man is made by his belief. As he believes, so he is"

-Bhagavad Gita

3.7.1 Consequences of Aphasia on Self-image

The consequences reported for aphasia on self-image, were far-ranging, but commonalities were evident. With reference to the data displayed in Tables 3.7.1 to 3.7.4, the discussion of the participants' reports follows.

A low self-image was reported by three of five participants in Group one and one of five in Group three. Participants tended to rate this consequence as a severe problem (three). Participants in Groups one and two reported a lack of self-confidence which also tended to be rated as a severe problem. Participants from all three groups conveyed self-acceptance, with the majority (four of five) belonging to Group two. Four of five participants in Group two stated consequences related to introversion: *" I'm more into myself"*, *"I'm quiet...I always was, but much more now"* and *"I'm not all loud and extroverty like I use to be"*.

Table 3.7.1: Group one: Consequences and needs for self-image

GROUP ONE: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I don't have any self-confidence (Q=3)	*My self-image is low* (Q=3)	*My self-image is very low now* (Q=2)	*I made the problem part of who I am* (Q=1)	*I have very little self-confidence* (Q=2)
My self-image is low (Q=3)				*The way I am now is not me* (Q=3)
My professional self-image is very low (Q=3)				
GROUP ONE: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I just want more self-confidence	*I want to be like I used to be*	*My self-image is not a priority for me*	*No needs*	*I just want to accept the way I am now*

Key: Q=Qualifier; 2 = moderate; 3 = severe

Table 3.7.2: Group two: Consequences and needs for self-image

<table>
<tr><th colspan="5">GROUP TWO: CONSEQUENCES</th></tr>
<tr><th>Subject 1</th><th>Subject 2</th><th>Subject 3</th><th>Subject 4</th><th>Subject 5</th></tr>
<tr><td>I'm much more of an introvert now (Q=3)</td><td>I'm ok with who I am (Q=1)</td><td>I see myself as half a person (Q=3)</td><td>I've accepted the new me (Q=1)</td><td>I'm not an extrovert like I used to be (Q=3)</td></tr>
<tr><td>I lack confidence in myself (Q=3)</td><td>I see myself as different from other people (Q=2)</td><td>I feel like a burden (Q=4)</td><td>I'm much more quiet now (Q=3)</td><td>I don't have confidence in myself (Q=3)</td></tr>
<tr><td>I accepted the way I am now (Q=1)</td><td></td><td>I am an introvert now (Q=3)</td><td></td><td>I made peace with who I am (Q=1)</td></tr>
<tr><th colspan="5">GROUP TWO: NEEDS</th></tr>
<tr><th>Subject 1</th><th>Subject 2</th><th>Subject 3</th><th>Subject 4</th><th>Subject 5</th></tr>
<tr><td>No needs</td><td>No needs</td><td>I just want to be a stronger person</td><td>No needs</td><td>No needs</td></tr>
</table>

Key: Q= Qualifier; 1 = mild problem; 2 = moderate problem; three = severe problem; 4 = severe problem

Table 3.7.3: Group three: Consequences and needs for self-image

GROUP THREE: CONSEQUENCES				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I feel dumb (Q=3)	*I'm not the same person I used to be* (Q=2)	*My self-image is a big problem for me* (Q=3)	*I feel like I have failed myself and my family* (Q=2)	*I accepted myself to a certain degree* (Q=1)
I see myself as a failure (Q=2)	*I feel very incompetent* (Q=2)			
GROUP THREE: NEEDS				
Subject 1	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
I just need some self-confidence	*I want to feel that I'm capable of doing what I want*	*I want to accept my problems as part of me*	*I want to feel good about myself*	*No needs*
			I want to feel that I'm worthy	

Key: Q = qualifier; 1 = mild problem; 2 = moderate problem; 3 = severe problem

Table 3.7.4: ICIDH-2 coding of the consequences of aphasia on the self-image

Consequence	Code and Qualifier	Component	Category	Page
GROUP ONE				
1. Lack self-confidence	b1266,3; b1266,3	Impairment	Confidence	40
2. Accepted the new me	b1268,2	Impairment	Temperament and personality function,os	40
3. General self image is low	b1268,2; b1268,2; b1268,2	Impairment	Temperament and personality function,os	40
4. Profession self-image is low	b1268,3	Impairment	Temperament and personality function,os	40
5. This is not me	Qualifier = 3	Personal	Personal factor: not coded in ICIDH-2	40
GROUP TWO				
1. More introverted now	b1260,3; b1260,3; b1260,3 b1260,3	Impairment	Extraversion	39
2. Lack self-confidence	b1266,3; b1266,3	Impairment	Confidence	40
3. Accepted the new me	b1268,1; b1268,1; b1268,1 b1268,1	Impairment	Temperament and personality function,os	40
4. See myself as a burden	Qualifier = 4	Personal	Personal factor: Not coded in ICIDH-2	n.a.
5. See myself as different	Qualifier = 2	Personal	Personal factor: Not coded in ICIDH-2	n.a.
6. Feel like half a person	Qualifier = 3	Personal	Personal factor: Not coded in ICIDH-2	n.a.
GROUP THREE				
1. General self-image is low	b1268,3	Impairment	Temperament and personality function,os	40
2. Accepted the new me	b1268,1	Impairment	Temperament and personality functions,os	40
3. See myself as a failure	Qualifier = 2, 3	Personal	Personal factor: Not coded in ICIDH2	n.a.
4. I'm a different person	Qualifier = 2	Personal	Personal factor: Not coded in ICIDH-2	n.a.
5. I feel dumb	Qualifier = 2	Personal	Personal factor: Not coded in ICIDH-2	n.a.

Key: b = impairment

Individual responses for self-image where no apparent pattern emerged, were also documented. A low professional self-image was stated by a participant in Group one. One participant in Groups one and three respectively conveyed a lack of self-acceptance. Self-failure was documented for two of five participants in Group three. Personal factors related to feeling like a burden, seeing self as different from other people and feeling like half a person were documented for two participants in Group two.

3.7.2 Needs for self-image

With reference to Tables 3.7.1 to 3.7.3, the needs reported by the three participant groups were mostly individual responses. Although no patterns were apparent, the following observations were documented for needs related to self-image.

Participants in all three groups stated to have no needs for self-image, with the majority (four of five) being in Group two. The need for self-confidence was documented for participants in Groups one and three. Individual responses include the following personal factors: to be a stronger person, to feel capable, to accept self and to feel worthy.

3.8 SUMMARY

The aphasic individuals interviewed in this study reported wide-ranging consequences and needs. Commonalities and individual responses were observed in and across subject groups for the areas of communication, family relationships, friendships, daily activities, independence, emotional status and self-image. The ICIDH-2 stipulations were used to place consequences at all components of the ICIDH-2: body functioning, activity, participation, environmental- and personal factors.

This concludes the discussion of the data for this study. Following is a discussion of the emergent themes and trends within and across subject groups one, two and three and the implications of these trends for long-term service provision.

GENERAL DISCUSSION

"Everything has been thought of before – the problem is to
think of it again"

-Goethe

In this section, attention is given to the emergent themes and patterns obtained in the study and the implications thereof for service provision. The data are drawn together and summarised in Table 4. Common threads and trends that highlight the changing consequences and needs of aphasia along the continuum of recovery are discussed. In addition to this focus, investigation of the International Classification of Functioning, Disability and Health (ICIDH-2) (WHO, 2001) as a measurement tool for the consequences of aphasia highlighted the usefulness and shortcomings of this document. These issues will also be discussed.

4.1 EMERGENT THEMES AND TRENDS

According to Sarno (1993), client perceptions heighten the speech-language therapist's awareness of the experiences and magnitude of the emotional devastation suffered by adults with aphasia. This study's utilization of personal accounts therefore gives valuable insight into the consequences and needs that adults with aphasia experience at different stages of the disorder.

With reference to Table 4, a broad pattern was evident through all the areas investigated, namely the emergence of participatory restrictions in the early chronic stages of aphasia (Group two) and the perseverance of these restrictions through the later-chronic stages of the disorder (Group three). Furthermore, the environmental elements of individuals also suggested a pattern where facilitating environmental attitudes may enhance the individual's immediate (short term) recovery, but environmental barriers present increasingly more restriction to the day to day participation of individuals in the chronic stages of aphasia recovery. These observations confirm the pattern of disablement

Table 4 Summary table on consequences and needs

Communication: consequences and ICIDH-2 codes			
Component of functioning	**GROUP 1**	**GROUP 2**	**GROUP 3**
	Consequence	**Consequence**	**Consequence**
Body functioning	Memory problems	Memory problems Reading problems Writing problems Fluency of speech	Memory problems Writing problems Organise thoughts before speaking
Activity	Speaking problems	Speaking problems	Speaking problems
Participation		Problems in group conversations Problems using the phone	Problems in group conversations Problems with topic maintenance Problems using the phone
Environmental	Lack of acceptance Lack of awareness	Lack of tolerance	
Personal	Subject avoids communication	Subject avoids communication	Subject avoids conversation
Communication: Needs			
Component of functioning	**GROUP1**	**GROUP2**	**GROUP 3**
	Needs	**Needs**	**Needs**
Body functioning		To improve reading, writing and stutter less	To improve reading and writing
Activity	To speak effortlessly For speech to sound organized To receive speech therapy		
Participation		To improve topic maintenance To use the telephone with more ease To cope better in group conversation	For conversation to be two-way To cope better in group conversation
Environmental	For people not to avoid talking with subject	For people to accept communication For people not to pity subject For people to be patient while talking	For people to accept communication For people to be patient while talking
Personal	Want to communicate more Want to improve speech on own Want to be more confident when speaking Want t someone to talk to about speech	Want to communicate more Want to be comfortable with own speech	To maintain hope for improved speech To be comfortable when communicating To communicate easier about personal issues

Table 4: Summary table on consequences and needs (continued)

Relationship with family: Consequences and ICIDH-2 coding			
Component of functioning	**GROUP 1**	**GROUP 2**	**GROUP 3**
	Consequence	**Consequence**	**Consequence**
Participation	Much closer now	Friction in family Marital problems Child-parent problems Lack of interest from siblings	Treated like outsider Lack of communication Can't find a wife Divorced (following stroke)
Environment	Support Acceptance	Lack of awareness Too high expectations Lack of acceptance Lack of tolerance	Lack of awareness Lack of tolerance
Relationship with family: Needs			
Component of functioning	**GROUP1**	**GROUP 2**	**GROUP 3**
	Needs	**Needs**	**Needs**
Participation	To have more interaction in the family	To improve marriage To improve relationship with children To be included in the family	For more communication in family To find a wife To be included in the family
Environmental	To be supported For family to accept subject For family to be patient	To be supported For family to accept subject For family to be patient For family to learn to deal with subject For family to respect subject	For more involvement from family For family to know what subject experiences To learn to deal with disagreements
Personal		To feel less guilty about bad relationships	To be more involved in family's lives

Table 4: Summary table on consequences and needs (continued)

Relationships with friends: Consequences and ICIDH-2 coding			
Component of functioning	GROUP 1	GROUP 2	GROUP 3
	Consequence	Consequence	Consequence
Participation		Less friends	Less friends Remaining friendships are ok Best friend also aphasic Struggle to make friends New friendships are shallow
Environment Facilitators	Support Support from aphasic friends Awareness	Support	
Barriers	Some friends look uncomfortable	Lack of awareness Friends aren't sincere in their interest in subject's health Friends appear uncomfortable	Negative attitudes Friends pity subject
Personal		Subject avoids friends	

Relationships with friends: Needs			
Component of functioning	GROUP 1	GROUP 2	GROUP 3
	Needs	Needs	Needs
Participation	For more interaction For more contact with people with aphasia	To have more friends To be included by friends	To have normal friends too Tc To make friends easier To have one close friend
Environmental	For friends to support For friends to be patient To be treated the same as in the past For friends to know subject is not dumb	For friends to be patient For friends not to pity subject For friends to be more sincere For work colleagues to show interest	For friends to respect subject
Personal		To feel less lonely	

Table 4 Summary table on consequences and needs (continued...)

Daily activities: Consequences and ICIDH-2 coding			
Component of functioning	**GROUP 1**	**GROUP 2**	**GROUP 3**
	Consequence	**Consequence**	**Consequence**
Participation	Managing daily routine Problems with employment Hobbies changed Can't socialize anymore	Managing daily routine Problems with employment Mostly house activities Can't socialize anymore Not involved in children's daily activities Can't go shopping Can't go to the post-office	Managing daily routine can't sosialize more
Coping strategies	Routine hasn't changed Keep to physical jobs Relax more	Relax more	Keep to non-communicative activities Health oriented activities
Daily activities: Needs			
Component of functioning	**GROUP 1**	**GROUP 2**	**GROUP 3**
	Needs	**Needs**	**Needs**
Activity	To practice speech everyday To have speech therapy	To continue with speech therapy	
Participation	To go back to doing old hobbies To keep busy To keep current job To relax enough	To keep busy To help other people with aphasia To have variation from house tasks To work again/have a job To socialize again	To keep busy To take part in community activities To do more communicative activities To work again/have a job To socialize again To relax enough

Table 4: Summary table on consequences and needs (continued...)

Independence: Consequences and ICIDH-codes			
Component of functioning	**GROUP 1**	**GROUP 2**	**GROUP 3**
	Consequence	**Consequence**	**Consequence**
Participation	Dependent Dependent with communication Dependent when help is requested	Dependent Relatively independent Dependent with communication	Dependent Independent Dependent with communication No more a leader
Environment Barriers		Difficult for family to let go	Family won't let go
Independence: Needs			
Component of functioning	**GROUP 1**	**GROUP 2**	**GROUP 3**
	Needs	**Needs**	**Needs**
Participation	To be independent in the future	To be left alone with people To be own person To be independent with communication	To be financially independent To do shopping on own To do socializing activities on own
Environment	Need help at the moment Need help only when requested	Spouse must learn to let subject try	For family to realize subject can do it himself For all people to let subject be independent
Personal		To be strong enough to break the routine	

Table 4: Summary table on consequences and needs (continued...)

Emotional status: Consequences and ICIDH-2 codes			
Component of functioning	GROUP 1	GROUP 2	GROUP 3
	Consequence	**Consequence**	**Consequence**
Body functioning	No emotions yet Despondent Sadness Frustration Problems with regulating emotions Depression	Sadness Problems with regulating emotions Depression	Experience little emotions Sadness Depression
Participation			Highly stressed
Personal	Fear of another stroke Feel powerless	Fear of another stroke Accepted the problem	
Emotional status: Needs			
Component of functioning	**GROUP 1**	**GROUP 2**	**GROUP 3**
	Needs	**Needs**	**Needs**
Body functioning	To have more control over emotions To be more optimistic	To have more control over emotions To feel less sad	To experience more emotions To feel less sad To feel less depressed To continue with medication for depression To have a higher threshold for frustration
Participation	To avoid too much stress	To avoid too much stress	To avoid too much stress
Personal	To not have fear for another stroke	To not have fear for another stroke	

Table 4: Summary table on consequences and needs (continued...)

Self-image: Consequences and ICIDH-2 codes

Component of functioning	**GROUP 1**	**GROUP 2**	**GROUP 3**
	Consequence	**Consequence**	**Consequence**
Body functioning	Lack self-confidence Accepted the new me Low self-image Professional self-image is low	Lack self-confidence Accepted the new me More introverted now	Accepted the new me Low self-image
Personal	Lack of acceptance of self	See self as burden See self as different from other people Feel like half a person	See self as failure See self as different person Feel dumb

Self-image: Needs

Component of functioning	**GROUP 1**	**GROUP 2**	**GROUP 3**
	Needs	**Needs**	**Needs**
Body functioning	To have more self-confidence		To have more self-confidence
Personal	To accept the way subject is now To be like used to be	To be a stronger person	To accept the speech problem To feel good about self To feel worthy

proposed by authors such as Lyon (1992), Le Dorze and Brassard (1995) and Gainotti (1997) where activity limitation (disability) is followed in later, more chronic stages by participation restriction (handicap). Following is a discussion of the most prominent emerging themes for each of the three subject groups. Thereafter, the significance of these themes for service delivery in South Africa will be discussed.

4.1.1 Emergent Themes for Group One

The participants in Group one reported varied consequences and needs for the areas of communication, family relationships, friendships, daily activities, independence, emotional status and self-image. All components of functioning as specified by the ICIDH-2 namely body functioning, activity, participation, environmental- and personal factors were captured by the personal accounts of the five participants in Group one. Following is an overview of the emergent themes for Group one, based on the data summarised in Table 4.

Of all the residual sequelae of aphasia that were investigated in this study, communication emerged as the area where the largest number of consequences and needs were reported. Penn (2000) has noted that speech and language difficulties have been rated by many stroke survivors as the most meaningful and most frustrating. Communicative difficulties and needs identified by participants in Group one appeared to be concerned with activity limitations in the form of speaking difficulties when compared to the other groups. Other investigators, although not differentiating between different stages of aphasia recovery (Le Dorze and Brassard, 1995) have also established the prominent role that speaking difficulties take on for individuals with aphasia.

Regarding communicative environmental factors, participants in Group one were more concerned with a lack of awareness about the aphasia than the other groups. Investigating possible reasons for the lack of public awareness about aphasia, Elman, Ogar and Elman (2000) conducted a Lexis-Nexis search to compare the media representation of aphasia to other health conditions (Parkinson's disease, stuttering, multiple sclerosis, autism and muscular dystrophy) with similar or lower incidence rates. These authors found that the word aphasia has been used with much lower frequency compared to other health conditions. When the word aphasia is used, it is used out of context or in association with many different etiologies. This finding substantiates that aphasia has been inadequately described and may explain why so few people have heard of the disorder (Elman, Ogar and Elman, 2000). Another need related to environmental barriers, namely the need for non-aphasic people to communicate with aphasic individuals was documented for Group one. The needs survey of the National Aphasia Association (1988) identified that the reason why people avoid communication with individuals with aphasia is because of the difficulties inherent to such communication.

Another important communicative theme that emerged from Group one is the personal need expressed for information about aphasia. Parr, Byng, Gilpin and Ireland conducted a study in 1997 in which they established that immediately post-stroke, adults with aphasia need medical information, advice and reassurance about their condition. Meeting the informational demands of individuals with acute aphasia is, according to Parr *et al.* (1997) an essential step in the process of empowerment.

The data obtained for relationships with family and friends represent the area of interpersonal relationships. The consequences and needs reported by participants in Group one for family relationships mostly encompassed environmental factors. These environmental factors entailing support and acceptance were facilitative in nature. Needs for family relationships centred around requests for the continuation of minimal environmental barriers (from family). As was the case with consequences and needs for family relationships, the majority of the consequences reported by Group one were environmental facilitators, encircling the support and positive attitudes offered by friends. The needs of Group one mainly encompassed the continuation of facilitating consequences. Le Dorze and Brassard (1995) reported that the failure to attend to the crucial issue of social relationships with family and friends in the initial recovery stages may lead to handicaps for both the aphasic person and the people with whom he/she interacts. The need for contact with individuals with aphasia also arises in the acute group of this study. Kagan and Gailey (1993), Pound (1996) and Byng, Pound and Parr (2000) suggested that support in the form of support groups is essential for individuals with acute and chronic aphasia. The emergence of this need in the acute group highlights the need of individuals with aphasia to belong to and affiliate with people like themselves already in this early stage of recovery.

Participatory restrictions related to the management of daily routine and the consequent need to keep busy manifested most prominently in Group one. Adults with aphasia discover that they have an increased amount of leisure time, resulting in unoccupied and unstructured daily routines (Parr *et al.* 1997). Attempts to participate in new activities may even highlight the activity limitations (disabilities) and resulting participation restrictions (handicaps) brought on by aphasia (Parr *et al.* 1997).

Although participatory difficulties with full-time employment and socialization manifested in Group one, these difficulties were less prominent in Group one than in the other groups. This phenomenon has been noted by other researchers (Le Dorze and Brassard, 1995), who concluded that the main priority of the person who's just had a stroke isn't his friends or his job, but to get well. Dependence featured most prominently in Group one, but at the same time, participants in Group one expressed a need for assistance/help at this stage. This indicates that these individuals recognise that they are currently dependent, but at the same time realise that they need the help and support of people around them in these early stages of recovery (Croteau & Le Droze, 1999).

The personal accounts of the participants in Group one for emotional status showed that consequences and needs at this early stage mainly entailed disorders of emotional control, as well as difficulties with range of emotions. Although both these consequences manifested in the other groups, they were observed to be more prominent for Group one. Authors such as Le Dorze and Brassard (1995) and Gainotti (1997) have also identified disorders of emotional control to be present for individuals with aphasia, but this study additionally pinpoints these types of disorders to the acute and early chronic stages of post-stroke recovery. The personal fear of having another stroke featured most strongly in Group one. Hemsley and Code (1996) documented general anxiety as a consequence of stroke. However, this study shows anxiety to be specifically related to residual fear resulting from the near death experience of the stroke.

The appreciation expressed for the church's involvement was indicative of an emotional facilitator. Easton and Andrews (2000) comment on the spiritual support people may draw upon during life changing events, noting that faith and prayer can be effective coping strategies. These authors proposed that the role of spiritual leaders is overlooked in the rehabilitation team because faith is non-quantifiable and misplaced in the traditional medical model.

Although reports of low-self image manifested in all three groups, it was most prominently reported by participants in Group one. Brumfitt (1993) states that language competency could be a primary or major condition in the establishment of a sense of self. Therefore, the loss of speech may be the major handicap in developing a changed, new identity following aphasia. A lack of self-confidence also manifested more prominently in Group one than in the other groups. Parr *et al.* (1997) reported that many people with aphasia experience embarrassment, which may lead to a lack of self-confidence ultimately resulting in restriction to active participation. The person who's just had a stroke has to compose a new body and self-image (La Pointe, 1999). They rely on the reactions of the people around them whilst doing this (La Pointe, 1999). An inappropriate response/reaction from an uninformed person may increase embarrassment, which could cause a lack of self-confidence of a person who's just had a stroke.

4.1.2 Emergent Themes for Group Two

The consequences and needs documented for Group two were wide-ranging. Responses for the areas of communication, family relationships, friendships, daily activities, independence, emotional status and self-image were classified at all levels of the ICIDH-2: impairments, activity, participation, environmental- and personal factors. With reference to Table 4, the notable patterns for the data gleaned for Group two will be discussed.

As was the case with Group one, the reports regarding communication problems were the most far-ranging of all the areas covered in this study. Although occurring in all three subject groups, consequences and needs related to impaired body functioning featured most prominently in Group two. These individuals have lived with aphasia for a longer period of time and have therefore come to know the disorder and the limitations it presents to the person with aphasia (Lyon, 1992).

Communicative participation restrictions with telephone usage and conversation, manifested for the first time in Group two. This finding is consistent with Le Dorze and Brassard's (1995) study, which reported that the communication disabilities of adults with aphasia impact on their ability to partake in group conversations.

In contrast with Group one, who reported communicative barriers related to a lack of awareness about aphasia, the barriers identified by Group two mainly encompassed intolerance and lack of acceptance of the individual with aphasia's communication. This may stem directly from conversational difficulties, as reduced ability and opportunity to engage in conversation affects the way adults with aphasia are perceived (Kagan, 1995 in Kagan, 1998).

Although documented for Groups one, two and three, the personal factor of deliberate avoidance of conversation and the corresponding need to communicate more is most prominent for Group two. Parr *et al.* (1997) stated that this is often the case with individuals with aphasia: to eventually withdraw when participation in social interaction is complicated.

Personal accounts of interpersonal relationships, as represented by family relationships and friendships reveal a change of facilitating attitudes to barrier creating attitudes. These environmental barriers cause participation restrictions within relationships with family and friends, as reported for the first time by participants in Group two. The reason for the manifestation of interpersonal participation restrictions in the chronic stages may lie in the eventual realization of the permanence of aphasia, both from the individual with aphasia and the people with whom he/she interacts, leading to despair and eventually a nonchalant attitude (Währborg & Borenstein, 1990).

Environmental barriers presented by family members of participants in Group two were intolerance, lack of acceptance and lack of awareness about aphasia, with a lack of awareness/knowledge being the most prominent of these. According to Währborg and Borenstein (1990), a non-supportive family interferes with stroke recovery, causing the individual with aphasia to undergo deterioration. These authors state that, since the family plays such an important role in the recovery process, the lack of knowledge is extremely counterproductive in the rehabilitation process.

Although the majority of the participants in Group two reported absent relationships with the community and no need to engage in such relationships, two important phenomena were noted for community relationships in Group two. Firstly, as was the case for Group one, appreciation for involvement from church and secondly mixing/blending with other individuals in the community who also suffer from aphasia. Brumfitt (1993) and Parr, Pound and Byng (2001) identify this type of behaviour (interpersonal relationships with peers with aphasia) as an essential step in developing a new post-stroke self-image.

With reference to daily activities, problems with full-time employment, socialization and managing daily routine manifested in Group two. Although the themes of full-time employment and socialization were identified for Group one as well, they featured more predominantly in Group two. The participation restrictions resulting from difficulties with socializing is a direct result of the interpersonal participation restrictions already discussed. The impact of retirement is far more extensive than generally assumed, as loss of social contacts and role changes may cause belittlement, loss of respect and ultimately causing rejection (Hermann, Johannsen-Horbach & Wallesch, 1993).

Coping strategies reflecting attempts to compensate for the communicative disability, emerged for the first time in Group two. Bury (1991) defines coping as maintaining a sense of value and meaning in life, in spite of the symptoms and effects. This implicates the individual with aphasia not just being a passive victim, but an active agent dealing with chronic illness (Bury, 1991).

Dependence was, for the first time, identified as problematic by participants in Group two. Lyon (1992) states that the loss of independence, self-acknowledgement and personal fulfilment are often related consequences of aphasia, both for the individual with aphasia and for his family. Le Dorze and Brassard (1995) also identified loss of independence as one of the major and most restrictive consequences of aphasia. The environmental barrier produced by familial overprotection was also raised for the first time by participants in Group two. According to Sarno (1997), this familial overprotection is one of the major burdens of caregivers and needs to be relieved. Therefore, not only will the individual with aphasia benefit from addressing their families' over protectiveness, but family members will also experience greater independence (Sarno, 1997).

The main consequences and needs for emotional status were sadness, depression and lack of emotional control. Depression featured more predominantly in Group two than Group one and sadness and lack of emotional control prevailed less prominently in Group two than Group one. The prominence of depression in Group two supports the findings of other authors that depression in the later stages of recovery arise due to the person's evaluation of their limitations, rather than being from an anatomic-physiological origin (Lafond, Joanette, Ponzio, Degiovani & Sarno, 1993). Although less prominent than in Group one, the fear for having another stroke still manifested in Group two.

With reference to self-image, self-acceptance featured prominently in Group two. According to Falvo (1991), acceptance is a process and, as individuals accept their condition, maximal functional capacity will be achieved. A lack of self-confidence, also identified in Group one, appeared for the last time in Group two.

4.1.3 Emergent Themes for Group Three

Far-ranging consequences and needs were retrieved from the personal accounts of the subjects in Group three. The ICIDH-2 components of body functions, activities, participation, environmental- and personal factors manifested in the personal accounts of the participants in Group three. Followed is a discussion of the emergent themes for Group three as portrayed in Table 4.

Although body functions and speaking activities were still mentioned for the area of communication, the majority of the consequences and needs entailed participatory restrictions, particularly conversational restrictions involving group conversations and topic maintenance. Conversational difficulties emerged in Group two, and was intensified in Group three. This may be explained, according to Kagan (1995 in Kagan, 1998), by looking at the social context in which conversational interchange takes place. As social relationships deteriorate, the less opportunity there is for engagement in conversational exchange, which according to Clark & Wilkes-Gibbs (1986) (in Simmons-Mackie 1998) is the primary site of human communication. There is a phenomenon in Group three where no environmental barriers were reported to restrict communicative participation.

The personal accounts of this study seem to indicate that interpersonal relationships worsen along the continuum of chronicity, as reflected by the assignment of more severe qualifiers to participatory restrictions and environmental barriers within family relationships and friendships by the participants in Group three. In addition to having fewer friends, the participatory barrier of the inability to make new friends also start to become evident in Group three. Lyon (1992) notes that, as psychosocial well-being decreases, there is evidence that reluctance about and fear of participating in life, as well as communication, follow. The barrier presented by lack of awareness about aphasia within the family also features even more strongly in Group three than Group two. Community relationships, as with the other two groups, presented with participatory restrictions where a lack of relationships with the community exists.

Data gleaned for daily activities indicate that difficulties with full-time employment and socialising feature prominently in Group three, as was the case with Group two. Problems with managing daily routine are less outstanding than was the case with Groups one and two. Instead, coping strategies, which emerged in Group two, become even more apparent in Group three.

Reports about independence indicate that dependence features less prominently in Group three than in Group two. However, the barrier presented by familial overprotection is still commented on by the participants in Group three.

For the area of emotional status, it is apparent that body functioning encompassing consequences such as sadness and lack of emotional control feature less prominently in Group three. There is however the phenomenon where depression arises as the most prominent emotional concern for participants in Group three.

Interpretation of the personal accounts of participants in Group three regarding self-image indicate personal factors entailing feelings of incompetence/failure. The process of acceptance is however reflected in the report of limited needs regarding self-image.

4.2 IMPLICATIONS FOR SERVICE DELIVERY

Reflecting on the experiences of the 15 subjects in this study, the aphasia clinician has a very prominent role to fulfil at all post-stroke stages. The role of the speech-language therapist must extend into all realms affected by aphasia including body functioning, activities, participation as well as external influences produced by the environment. Presently, the rehabilitation process is obscured by the virtually exclusive focus on the communication disorder itself (Hersh, 1998). The need for a shift towards a psychosocial model of aphasia rehabilitation is highlighted by the results of this study. A number of proposed strategies which can contribute to making the effectiveness of the services provided by the aphasia clinician tangible and meaningful to both the clients and South African health care environment, follow.

4.2.1 Communicative Impairments

The first theme to have emerged has to do with communication, as affected by the symptoms of aphasia. The recognition by individuals with chronic aphasia of where and how body impairments restrict their communicative participation follows as a result of living with aphasia and consequently learning the symptomatology of the disorder (Lyon, 1992). It is important to note that individuals with early chronic aphasia expressed needs to address these issues related to body functioning. Although much debate has taken place in recent years around issues of speech therapy, Penn (2000) states that the question of whether therapy works or not has become redundant as there is ample proof to suggest that it works. A direct need for speech therapy has been documented for individuals in the acute and early chronic group, indicating that it is still the aphasia clinician's responsibility to acknowledge this need. Pound (1998) suggests that, in a situation where the need for speech therapy exists, therapy should work toward clearly defined and negotiated goals.

4.2.2 Conversational Restrictions

The emergence of conversational restrictions versus speaking limitations in the early chronic group and the perseverance of these difficulties in the late chronic group has important implications for aphasia rehabilitation. Recently, there has been a global recognition of the importance of conversation in the social interactions of individuals with aphasia and much attention has been given to ways to address this difficulty for aphasia sufferers (Kagan, 1995; Kagan, 1998; Simmons-Mackie, 1998). Conversation, that is, successful, ongoing informational exchange, requires that all parties be able to extract mutual benefit and gratification from the communicative interaction (Grice, 1975). Due to the individual with aphasia not being sufficiently equipped to hold up their end of the "bargain", their emotional needs aren't met, identities cannot be developed and most importantly, they cannot associate with other human beings (Simmons-Mackie, 1998). It is thus clear why addressing conversation difficulties in rehabilitation is of utmost importance for the individual with aphasia.

Previously, rehabilitation efforts focused on the physical transactions defined by (Sacks, Schelgloff & Jefferson (1974) as the communicative exchange of information that takes place during conversation (Kagan, 1995). Contemporary conversational research and literature focus more on interaction during conversation, therefore addressing communication within a social context (Kagan, 1995; Kagan, 1998; Simmons-Mackie, 1998), although the goal of information exchange (transaction) is still recognized as important. A recent South African study (Band and Legg, 2001) used personal accounts to obtain insights into aphasia therapy. It was found that conversation was only partaken in as introduction or conclusion to a speech-language therapy session. Holland (1998) reports that, despite the challenges inherent in conversing with adults with aphasia, there is overall agreement amongst speech-language therapists that engagement in conversation should be one of the ultimate aims of aphasia therapy. Naturally, mutual conversation remains a problem within the context of aphasia.

Conversational techniques revealing competency for the individual with aphasia have been increasingly proposed (Kagan, 1995). "Supported Conversation for Adults with Aphasia" (SCA) is an example of a technique that is based on the idea of conversational partnerships aiming to reduce the psychosocial consequences of aphasia (Kagan, 1998). SCA involves training potential communication partners, using appropriate resource materials, and providing communication opportunities to create an environment in which people with aphasia experience the fulfilment of social interaction and conversation (Simmons-Mackie, 1998). The key for South African rehabilitation specialists is therefore to consider suitable methods to create a "conversation friendly" environment for the individual with aphasia. The importance of this aspect for aphasia rehabilitation is captured by Kagan (1998), who states that conversation has been acknowledged as the "tool" for participation in daily life and social relations .

4.2.3 Awareness about Aphasia

Addressing the issue of environmental awareness of aphasia is in line with creating an interactional environment for people with aphasia. The inability to deal with individuals with aphasia directly stems from a lack of information about the disorder. In this study, the environmental barrier posed by a lack of awareness about aphasia was projected in the data for all three groups. Unfortunately, the situation is complicated further by the fact that it is difficult for the individual with aphasia to advocate his disorder himself, as limited communication access restricts him from doing this (Penn, 2000; Chapey *et al.* 2001).

Participants of the survey conducted by the National Aphasia Association in 1988 indicated that health professionals seemed to have limited information and resources about aphasia (La Pointe, 1999). In recent years, research has been directed towards grasping the nature of aphasia, therefore making health professionals more aware of the dimensions of the disorder. This professional awareness has not been successfully projected to the public yet. This unawareness may be the result of a lack of advocacy and aphasia not being a priority for funding. However, now that the devastating long-term effects of aphasia are recognised, not only for the individual, but also for the people living with individuals with aphasia, the importance for prioritising funding for aphasia advocacy and rehabilitation becomes apparent.

Although the apparent solution to this lack of awareness about aphasia is advocacy, Pound (1998) observes that it is difficult to imagine an environment which easily accommodates the hidden influences of aphasia. But ultimately, public education and awareness are central to the changing of attitudes and prejudices. Elman, Ogar and Elman (2000) stated that the lack of awareness about aphasia causes a vicious cycle leading to less money for research, less money for services and, less empathy and understanding for people with aphasia who are trying to reintegrate themselves into the community. Elman *et al.* (2000) have looked at how other minority groups achieved awareness. They identified three methods of importance: activism, legislation and judicial action.

With regard to activism in the South African context, those affected by aphasia (stroke survivors, families, friends and professionals) must find ways to turn the media's attention towards aphasia. Elman (1998) ascribes the lack of awareness about aphasia to the fact that aphasia is an invisible and thus misunderstood disorder. Using the media to make aphasia "visible" will facilitate advocacy attempts as most people in South Africa have access to some form of media, be it television, radio, newspapers, magazines or posters (in health clinics). Depending on variables such as socio-economic status and levels of education, activism attempts should involve the South African media.

However, the trick lies in sketching aphasia to the media as a number one priority. Unfortunately, the media operate on the basis of "what will sell" (Elman *et al.* 2000). The key therefore lies in making aphasia "attractive" firstly to the media, who will then make it "attractive" for the public. In the words of veteran *Los Angeles Times* editor Robert Scheer: "You have got to find a way to make aphasia sexy". The plight of individuals with for example schizophrenia and autism has been promoted by movie productions. Through telling the story of how these disorders were acquired, diagnosed, lived- and struggled with, and eventually conquered, thousands of people not only became aware of these disorders, but developed genuine empathy for the sufferers.

Legislation is one of the key elements for achieving awareness of aphasia in South Africa. A document that strongly influences health care in South Africa is the "White Paper on an Integrated National Disability Strategy" (1997), stressing that the "cure" for disability lies in the restructuring of society. According to Mbeki (1997), South Africa is still in need for a National Disability Awareness Strategy. Thus, it will be a major problem for the government to play a role in restructuring society to know, accept and embrace aphasia. According to Mbeki (1997), all governmental sectors: Human Rights, Education and Training Human Development are central to health legislative issues. Targeting the Department of Health alone will therefore have no effect on promoting the development of awareness strategies for individuals with aphasia.

Although the need for greater awareness about disability recognised by the government, South Africa faces a reality where chronic disorders such as aphasia are not seen as priorities for the reconstruction of society that is currently taking place (Barron, Lewin, London, Rumbelow, Seager & Truter, 1996). The government's first priority is the promotion of a healthy environment by providing basic sanitation, water and waste removal (Barron *et al.* 1996). The case for aphasia is further complicated by the fact that diseases such as HIV/AIDS and TB are seen as priority when funding is allocated to specific diseases/disorders (Barron *et al.* 1996). To change this, all parties directly and indirectly affected by aphasia must take responsibility to inform the government about aphasia and it's lasting effects. Only then will disability awareness strategies, funding and research become a priority. Sarno (1997) believes that increased awareness about aphasia can be obtained by strengthening, supporting and encouraging national and regional aphasia associations to develop networks of aphasia advocacy groups in a cross-section of the community. This will allow rehabilitation specialists to reach out to new aphasic patients, their caregivers, primary-care physicians and health personnel at community level, which will in turn provide broad-based public education.

The results of this study indicate that a lack of knowledge in the immediate environment of the individual with aphasia, implicating family and friends, creates the largest barriers. Währborg and Borenstein (1990) reported three main problem areas, as experienced by the family members of individuals with aphasia: minor psychiatric disorders, interactional changes and lack of knowledge. The most prevalent psychiatric disorders are anxiety, guilt, irritability, aggression, fatigue, depression and rejection (Währborg and Borenstein, 1990). Rejection is difficult to deal with therapeutically, but as Hersh (1998) proposed, environmental barriers posed by the family may be lessened by their acceptance of the disorder, even where communicative barriers remain. However, acceptance may only follow when families grasp the nature of aphasia, suggesting once again the importance of providing support and information to family members. Therefore, addressing the problematic issue of advocacy should start with providing information and support to the people closest to the individual with aphasia. Sarno (1997) found that a long-term rehabilitation program of one year providing education to both patients and families about the nature and recovery of aphasia, led to an improvement in quality of life. The need for increased awareness amongst family members is therefore not an unobtainable goal for the aphasia clinician to be met.

Once the immediate environment of the individual with aphasia has been provided with information, awareness can be expanded into the broader community. In South Africa, the church may have an important role to play in community awareness. Several subjects in this study indicated their appreciation for the supportive role the church offered them in their post-stroke recovery. The church represents an entity that possesses considerable authority in many South African communities. Using the church as a means of increasing awareness about aphasia in the community may be another solution to the problem of advocacy.

4.2.4 Forming a New Identity

Another aspect of community life that is often overlooked is that of being a member of a community of individuals with aphasia. One of the subjects in this study briefly touched on this issue when commenting on his need to help other individuals with aphasia in his community. Sarno (1993) proposes the aspect of finding a new identity, as a member of a community of chronically disabled individuals, as a crucial component of the aphasic person's reaching an acceptable and positive level of life satisfaction. In recent years, rehabilitation approaches focusing on providing support for the individual with aphasia in the form of group therapy/sessions, have aimed to adhere to this goal of rehabilitation. These approaches have shown to have positive rehabilitative outcomes in the form of improved life satisfaction (Holland, Fromm, DeRuyter, Stein, 1996; Penn, 2000).

Due to the fact that a number of different cultures represents the South African community, a challenge is faced when the individual with aphasia seeks affiliation within a community of chronically disabled individuals. The culturally mixed participant sample of this study shows that cross-cultural aphasia experiences are common. Rehabilitation should therefor focus on the similarities that a person has with the aphasia community, regardless of their culture.

4.2.5 Support Groups

The importance of support even after therapy has ceased has been highlighted, as the psychosocial effects of chronic aphasia do not necessarily lessen with the passage of time (Kagan & Gailey, 1993). Support groups have definite potential in the current South African health system. Band and Legg (2001) identified five reasons (on the basis of personal accounts) why support groups seem to be a solution to deal with the current circumstances. Firstly, people cannot afford ongoing speech-language therapy. Thus, once discharged, support groups will enable them to continue to receive counselling, guidance and support. Secondly, support groups can be established on community level, therefore making the service accessible. Thirdly, support groups can be utilized as sources of information as required in first languages. Fourthly, health care costs can be kept to a minimum by using volunteers that involve a weekly or monthly gathering. Lastly, running support groups themselves will provide self-empowerment and opportunities for conversation. Therefore, support groups should be used to deploy community resources in order to base the person in the community and provide the person with aphasia with long-term support.

4.2.6 Coping Strategies

A facilitative environment, where the public knows about aphasia and offers support to these individuals, may lead to improved life satisfaction (Penn, 2000). This will allow the individual with aphasia to explore his strengths and weaknesses. La Pointe (1997) emphasizes the need to shift away from focussing on maladaptive processes in rehabilitation and to incorporate positive activities of adaptation and accommodation. Penn (2000) supports this statement by emphasizing that there is an expanding focus not so much on the deficit, but on the person's ability to compensate for the deficit. The emergence of coping strategies by the early and late chronic groups in this study shows that compensation is indeed one way to get around the participatory restrictions that aphasia imposes on an individual. Sarno (1997) proved that a rehabilitation service that addressed issues related to difficulties with coping (amongst other issues) led to a resultant improvement in coping skills. This has important rehabilitative implications for the individual with acute aphasia for whom no coping skills were documented in this study. Education on coping skills may be incorporated into the initial stages of information provision.

4.2.7 Participation in Daily Activities

Lyon, Cariski, Keisler, Rosenbek, Levine, Kumpula, Ryff, Coyne and Blanc (1997) stated that what every individual must face and endure to restore purpose in daily life is every bit as challenging as their struggles to cope with aphasia's more apparent core component, namely communication. The need to "keep busy" was reported in all three subject groups in this study, indicating the importance for the aphasia clinician to increase participation in daily life activities. Two other topics for daily activities that were identified as prominent difficulties in the early and late chronic groups are employment and social activities. For many individuals, purpose in life means having a job and being able to socialize/interact with family and friends (Ryff, 1989). Both these topics have received increasingly more attention in recent years in attempts to improve psychological well-being for individuals with aphasia (Angeleri, Angeleri, Foschi, Gioquinto & Nolfe, 1993; Hemsley & Code, 1996; Gianotti, 1997). Penn (2000) suggests that rehabilitation specialists should, one year after the stroke and beyond, carefully evaluate possible return to work. If such return is possible and feasible, the aphasia clinician should provide the returnee with the necessary support (Penn, 2000). However, Angeleri *et al.* stresses that the return to work or obtaining a job is not where our rehabilitative role ends. These authors emphasize the importance of the consideration of job satisfaction.

4.2.8 Social Interactions

The aphasia clinician can approach the problem regarding socialization difficulties from more than one angle. The most important methods have been discussed already. Firstly, the lack of awareness about aphasia and how to deal with a person with aphasia needs to be addressed by providing information to family and friends. Secondly, conversational strategies must be explored. Thirdly, opportunities must be offered for the individual with aphasia for joining support group activities, as this will help him/her to affiliate with a community of people like him/herself. Socialization, according to Penn (1993), should be the measure of therapeutic success.

4.2.9 Independence

Another aspect that correlates with daily activities is that of the degree of independence experienced during execution of daily routines. The results of this study indicate that the number of individuals who perceived themselves as dependent decreased from the acute to later chronic stages of aphasia. Hoen, Thelander and Worsley (1997) demonstrated that the rehabilitation of aphasic individuals had, as one outcome, an improved sense of independence, which may lead to an actual increase in independence. With newly founded independence, adults with aphasia may begin to restore control, direction, purpose and destiny to their lives (Lyon, 1992). The importance of independence as goal for rehabilitation was first recognized by Maslow (1968) who believed that successful rehabilitation should encompass the process of shifting from survival (as in the acute-stages of aphasia) to self-actualization in the chronic stages of aphasia. As seen from the results of this study, the family may be a significant barrier to the independence of the individual with aphasia. The aphasia clinician's role can therefore be twofold in the restoration of the client's independence. Firstly, the family must be instructed on how to re-align their "overprotective" helping attitudes to help their family member explore his/her independence. Secondly, the client must be taught how to master his environment (Ryff, 1989).

4.2.10 Emotional Difficulties

Depression often follow due to a variety of difficulties after a stroke. The results of this study suggest that depression seem to increase in severity along with an increase in chronicity. Although depression was categorized as a body dysfunction in this study (according to the ICIDH-2 classification system), evidence suggests that depressive alterations take place along the continuum of recovery (Parikh, Lispsey, Robinson & Price 1987; Angeleri *et al.* 1993; Herrmann, Johannsen-Horbach & Wallesch 1993). These authors indicated that depression changes from being related to impaired body functioning directly post-stroke, to a psychological reaction to participation restrictions (handicap) resulting from living with aphasia. Treatment of depression and emotional disorders remains intermittent despite its acknowledged presence and initial efforts to quantify it (Herrmann & Wallesch, 1989). Research leans towards indicating a correlation between addressing the psychosocial difficulties of individuals with aphasia and reduction in depression (Angeleri *et al.* 1993; Hoen *et al.* 1997).

Another consequence related to emotional difficulties, is the personal fear of another stroke that manifested in the acute and early-chronic groups. Although anxiety has been documented as a consequence of stroke (Hemsley and Code, 1996), little evidence could be found as to anxiety being limited to, amongst other things, the fear for another stroke. Although anxiety is such a powerful negative psychological experience, some of the subjects in this study reported relaxing more and living a slower life (incorporated into way daily routine is managed) as a compensatory strategy in order to overcome this constant fear they have. This may be a valuable tip for the aphasia clinician, as Falvo (1991) stated that coping strategies are effective when they help the individual attain emotional equilibrium, which is exactly what the strive towards more relaxation is intended to achieve (reduce fear).

4.2.11 Self-image

Low self-image was a prominent consequence of aphasia in the acute group. However, participants in the early and late chronic groups conveyed acceptance of their condition. La Pointe (1997) suggests that we view the path to acceptance of aphasia in a more positive framework. He suggests that the process to acceptance is achieved by activities that reflect adaptation and accommodation to the aphasic condition. It is therefore not strange that, in this study, the participants who exhibited positive coping strategies such as keeping to non-communicative activities and adopting hobbies related to health activities, are the ones that expressed their acceptance of aphasia. The process towards acceptance may have important implications for the rehabilitative framework, as in the initial stages, clients may be urged towards acceptance through incorporating adapted activities (coping strategies) that will bring about acceptance.

This concludes the discussion of the main themes of this study and the implications of these themes for rehabilitation. It is clear that aphasia extends beyond the realm of communication to affect psychosocial well-being and participation in life. It was further noted that certain consequential and need changes take place over time. This necessitates the shift of rehabilitative focus over a gradual period of time to foster different needs at different stages post-stroke, including personal, environmental and activity/participation issues. Following is short comments on observations made in connection with the ICIDH-2 as a measuring instrument for the population of individuals with aphasia.

4.3 DIVERSITY OF THE RESULTS

Although a number of trends within- and across groups have been noted in this study, it was evident that a certain amount of diversity co-existed with the commonalities identified. This may be due to the multi-cultural participant sample. Firstly, the sample contained white and coloured participants. Secondly, there was Afrikaans as well as English first language speaking white and coloured participants respectively. Also, the participant groups included males and females belonging to different age groups.

All of the above-mentioned factors will affect how the participants experience illness. Therefore unification of experience and thought would lock cultural accuracy (La Pointe, 1999). By recognising the diversity within and across groups, the psychosocial nature of the study is reinforced, because psychosocial rehabilitation focuses on, and is adapted to the context of each individual patient. Furthermore, because the South African population consists of a number of different cultures, the diverse participant sample is a more accurate reflection of the South African aphasic population.

4.4 COMMENTS ON THE ICIDH-2

The ICIDH-2 was used to classify the data of this study into the components provided by this document: impairment, activity, participation, environmental- and personal factors. The codes used in this study showed varied levels of descriptiveness. Following is comments on the usefulness and shortcomings of this document, based on the codes portrayed in Tables 3.1.4 to 3.7.4.

The redefinition of the components of disability from impairments, disability and handicap to impairments, activity and participation allow greater freedom and at the same time specificity in the coding of health states. The terms "activity limitation" and "participation restriction" allows the coder to consider activities against the background they occur, making it possible to code the manner in which the consequence affects functioning (e.g. limiting an activity or restricting participation). An example may illustrate this comment. Whereas problems with speaking on the phone would previously have fallen under a disability, the subjects of this study have experienced this consequence as restrictive to their participation in daily life.

The greatest difficulties were documented for the coding of environmental factors. The ICIDH-2 chapters of "Support and Relationships" and "Attitudes" were indicated to be relevant influences on the functioning of the individuals of this study. The categories within these chapters however lacked specificity. For example, consequences such as support, help and empathy all had to be coded under the code for support provided for family, friends and community respectively. The same problem arose with individual attitudes, where attitudes related to tolerance, awareness/knowledge, acceptance/rejection and overprotection (e.g. in the case of the family's overprotection causing an individual to be dependent) all had to be coded under the code for individual attitudes for family, friends and community. Therefore, although these chapters allow the coder to get an idea of whether the consequences of support or lack thereof and positive or negative individual attitudes are present, important information regarding the nature of these consequences are lost in the coding process.

Generally, the codes provided for body functioning proved to be accurate reflections of the consequences they presented. Depression presented an array of coding difficulties because the ICIDH-2 doesn't provide a code for depression. Although the ICIDH-2 only uses neutral terms (Schneider, 2002), depression has received ample attention in aphasiology showing that depression has definite negative implications for functioning and health. A number of studies have indicated depression to be the result of body dysfunction, resulting from damage to the brain following stroke (Parikh, Lipsey, Robinson & Price 1987; Herrmann & Wallesch 1993). This provides enough evidence for the ICIDH-2 to include depression under the component of body functioning.

Although the majority of consequences related to activity functions could be coded with relative specificity, some problems were encountered. For communication, the most obvious inadequacy was the provision of only one code (a330) for any consequence related to the activity of speaking (e.g. word combination problems, unorganised speech, unclear meaning of speech, problems with expression and speaking in short phrases). Although it is not realistic to expect the ICIDH-2 to provide detailed assessment measurements (codes) for all types of health states, communication does have a very prominent influence on well-being, rationalizing the need for greater specificity within the ICIDH-2 for this domain of health. For example, the coder should at least be able to specify the component of "speaking" with which the client is having difficulty, namely phonology, morphology, syntax, semantics or pragmatics.

The participatory codes that were used to describe the nature of relationships between family, friends and community at different levels proved to be suitable to describe the basic nature of the relationships with these people. As was the problem with the other codes that have been discussed so far, the use of these codes do not allow for an accurate description of where the problems lie within these relationships. It would however not be plausible for the ICIDH-2 to provide a code for every possible wrong-going in interpersonal relationships.

Another participatory area that proved to lack specificity, was the code for managing daily routine, as occurred in the mentioning of the consequences of aphasia on daily activities. Differentiation between a lack of managing daily routine and constructive management of daily routine was not possible by using "p2301". Although it can be reasoned that the qualifier will, to a certain extent, indicate whether a consequence presents a problem to the client or not, the problem of not being able to indicate the "restrictive" or "coping" nature of the consequence still persists.

Two codes from the ICIDH-2, namely that for "undertaking a single task independently" and "undertaking multiple tasks independently" made provision for consequences related to dependence/independence. Dependence however doesn't refer to the execution of activities, but to a state of being autonomous (Ryff, 1989). Therefore, these two codes aren't reflective of an individual's state of independence.

The ICIDH-2 includes personal factors as a contextual factor that influences an individual's health, but doesn't provide codes for personal factors because of the large cultural and social variance associated with them (WHO, 2001). This study illustrated that a number of personal factors for certain consequences did exhibit some agreement across the subject groups. The most important notable of these are for consequences related to self-image. Although the category of "temperament and personality functions other specified" was used to code consequences related to self-image, this is a personal factor that will manifest, in some form, across all chronic illnesses.

The second personal factor that manifested often in this study, is the deliberate avoidance of participation in activities that difficulty is experienced with, such as communicative situations and social interactions. Avoidance, according to Falvo (1991), is one of the basic coping strategies and is a consequence that can be expected from many individuals suffering from a chronic illness. In other words, certain personal factors do manifest across populations from different social and cultural backgrounds .

In conclusion, this study illustrated the usefulness of the ICIDH-2 in being able to categorise consequences of aphasia into different components of functioning. All the components of the ICIDH-2: impairment, activity, participation, environmental- and personal factors were reflected in the reports of the subjects. Furthermore, the categories provided within each component served as useful frameworks to classify the consequences of aphasia. The ICIDH-2 therefore suited the context of all participants in this study. All consequences could be coded, regardless of participant's culture. Furthermore, the codes that were not accurate descriptions of the consequences expressed by the participants were documented across all the cultures recognised in this study. The ICIDH-2 therefore proved to be a solution to problems experienced with culturally bound assessment procedures.

5. LIMITATIONS OF THE STUDY

> *"Ultimately, research designs become orchestrations of ideal arrangements, on the one hand, and constraints and limitations, on the other"*
>
> -Nesselroade & Labouvie, 1985, p. 35

The goal of this study was to investigate consequences and life needs of individuals with aphasia at different stages. Although one can draw on the principles and themes that arose from this study, the concepts may not be assumed to be generalized to all individuals with aphasia. The reason for this statement is two-fold. Firstly, the sample size of this study is relatively small. Thus, differences reflected across stages could be ascribed to individual attributes in stead of the stage of recovery. A larger sample size would necessitate the use of more empirical techniques. Furthermore, it is acknowledged that, due to the usage of verbal data, global aphasia is not represented by the results obtained from this study.

Another issue of importance is the cultural differences that may be present between the subjects in this study. For purposes of this study, the groupings were not done according to cultural differences, but time post-stroke. However, studies have shown that cultural differences do exist between individuals with aphasia from different South African cultures (Rabinowitz and Legg, 2001).

It is acknowledged that one person, the researcher, collected and analysed the data for this study. Reliability was however promoted by precise and systematic procedures and the use of the ICIDH-2 classification guidelines .

6. IMPLICATIONS OF THE STUDY

Although preliminary, the results of this study showed important trends and patterns. These emergent themes have implications on three levels: theoretical, clinical and empirical.

Theoretically, this study adds to the current body of literature that describes the impact of aphasia on different aspects of an individual's life. Also, the study supports literature that focus on the different components of disability, but illustrates that, although the lines aren't always clear between impairment, activity and participation, these components emerge at different times of the continuum of recovery. Therefore, this study supports the theoretical motivations for the adaptation of rehabilitation services according to the changes the individual with aphasia experiences, thus focussing more on social issues in the chronic stages as this is ultimately the participation restrictions implicated by the individual's aphasia. This study makes a contribution to South African aphasiology literature since other studies have not investigated the changing consequences and needs of individuals with aphasia at different recovery stages.

Empirically, the results of this study are preliminary, but further research is suggested by the emergent issues. One way to verify the results of this study is to extend this study, executing a study with the same goals on a larger population of individuals with aphasia. Included in further studies should be other types of aphasics with different cultural backgrounds. On a different level, a longitudinal study may give even more qualitative information on exactly when and how consequent changes of aphasia take place with time. Also, consequences and needs don't always correspond, urging the need to develop assessment procedures that prompt into the needs of individuals with aphasia as well, not just the consequences. The use of the ICIDH-2 as measurement tool for the aphasic population also requires further investigation.

The results of this study have many important clinical implications. The first and most prominent is the necessity for focussing on long-term service provision for adults with aphasia. The second clinical implication is the responsibility of the aphasia clinician to focus on the psychosocial adjustment of the individual with aphasia, not just in the acute, but more importantly, in the chronic stages of recovery. Related to this topic is the overwhelming lack of awareness about aphasia that needs to be addressed, both for the individual with aphasia and for his family. Thirdly, the study shows that, even though psychosocial adjustment plays such a prominent role, there is still a need indicated to focus on the remediation of linguistic competency. All the above-mentioned clinical implications must be considered in the training of aphasia therapists, both undergraduate and already qualified. A doctor does not treat a cough as an individual symptom. He rather sees it as a symptom of pneumonia, and focuses his treatment on his knowledge of pneumonia. In the same way, the aphasia clinician must be equipped with the knowledge of aphasia. The communication difficulties associated with aphasia include only one dimension of the disabilities and handicaps associated with the disorder. Only a well-trained clinician can provide appropriate psychosocial treatment for people at all stages of aphasia.

In summary, the findings of this study suggest an extension of the role of the speech-language therapist to ensure that the needs of individuals with aphasia are met, as experienced at all stages of the disorder. The necessity for focusing on the psychosocial adjustment is highlighted as well as the need to refine current aphasia therapy models.

7. CONCLUSION

"To know all things is not permitted"

- Horatius

This thesis has explored the impact of aphasia on various aspects of the lives of those who experience it, at different stages post-stroke. The needs of these individuals were also investigated at these recovery stages. Additionally, the consequences of aphasia, as perceived by the subjects, were coded according to the 2001 version of the WHO's International Classification of Functioning, Disability and Health (ICIDH-2). The resultant themes highlighted the impact of aphasia on the realms of communication, interpersonal relationships, daily activities, independence, emotional status and self-image. Individuals at different stages of aphasia experience different consequences and needs. These differences aren't always linear, but important patterns regarding activity, participation, environmental- and personal factors should be accommodated in service provision.

The continuum of recovery indicated by the results of this study may reflect a pattern of ICIDH-2 progression from body impairment in the acute stages to participatory restrictions in the chronic stages. This pattern of declining participation and increasing exclusion highlights the essential need for long-term socially-based support. The ICIDH-2 proved to be a suitable document for providing a broad description of different components of functioning of an individual with aphasia, and can be developed as a useful clinical and research tool.

REFERENCE LIST

African National Congress – Western Cape (2002). *Towards equity in Health for the* People of the Western Cape.
http://www.hst.org.za

Ahlsio, B., Britton, M.V. and Therell, T. (1984). Disablement and quality of life after Stroke. *Stroke,* 15, 886-890

Angeleri, F., Angeleri, V.A., Foschi, N., Gioquinto, S. and Nolle, G. (1993). The influences of depression, social activity and family stress and functional outcome after stroke. *Stroke*, 24, 1478-1483.

Band, L. and Legg, C. (2001). Insights into aphasia therapy: A study of client and caregiver perceptions. *A report on a research project presented to the Division of communication Sciences and Disorders*. Faculty of Health Sciences: University of Cape Town.

Barron, B., Lewin, S, London, L. Rumberlow, R., Seager, J. and Truter, H. (1996). *The state of housing, water and sanitation in the greater metropolitan area of Cape Town.* The Health Systems Trust. South Africa, Durban.

Beeke, S., Maxim, J. and Wilkinson, R. (2000). Longterm adaptation to conversation by people with aphasia and their partners.
http://www.hcs.ud.ac.uk.

Bethoux, F., Calmels, P., Gautheron, V. and Minaire, P. (1996). Quality of life for the spouses of stroke patients: A preliminary study. *International journal of Rehabilitation Research*. 19, 291-299.

Brumfitt, S. (1993). Loosing your sense of self: What aphasia can do. *Aphasiology*, 7 (6), 569-591.

Bury, N. (1991). The sociology of chronic illness: a review of literature and prospects. *Sociology of Health and Illness,* 13, 451-468.

Byng, S., Pound, C. and Parr, S. (2000). A framework for therapy interventions. In I. Papathanasion (Ed.), *Acquired neurological communication disorders: A Clinical Perspective.* London, UK: Whurr.

Chapey, R., Duchan, J.F., Elman, R.J., Gereid, L.J. Kagon, A., Lyon, L. and Simmons Mackie, N, (2000). Life Participation Approach to Aphasia: A statement of values for the future. *The ASHA leader.*

Clarke, M.S. and Smith D.S. Changes in family functioning for stroke patients and their Families. *International Journal of Rehabilitation Research,* 22, 171-179.

Code, C., Hensley, G, and Herrmann, M. (1999). The emotional impact of aphasia. *Seminars in Speech and Language*, 20 (1), 19-31.

Croteau, C., and Le Dorze, G. (1999). Overprotection in couples with aphasia. *Disability and Rehabilitation,* 21 (9), 432-437.

Easton, K.L. and Andrews, J.C. (2000). The role of the pastor in the interdisciplinary rehabilitation team. *Rehabilitation Nursing,* 25 (1), 10-15.

Elman, R.J., (1998). Memories of the ‘plateau’: Healthcare changes provide an opportunity to redefine aphasia treatment and discharge. *Aphasiology,* 12, 227-231.

Elman, R.J., Ogar, J. and Elman, S. (2000). Aphasia: Awareness, advocacy and activism. *Aphasiology,* 14, 455-459.

Falvo, D.R. (1991). *Medical and psychosocial aspects of chronic illness and disability.* Aspen.

Friedlan, J. and McColl, M.A. (1996). Social support and psychosocial dysfunction after stroke: buffering effects in a community sample. *Archives of Physical and Medical Rehabilitation,* 68, 475-480

Gainotti, G. (1997). Emotional, psychological and psychosocial problems of aphasic patients; an introduction. *Aphasiology*, 11, 636-650.

Gee, J.P. (1999). *An introduction to Discourse Analysis: Theory and Method.* London and New York: Routlegde.

Grice, H. (1975). Logic and conversation. In Cole, P. and Morgan, J. (Eds). *Syntax And semantics: Speech acts.* (pp. 41-58). New York: Academic Press.

Hersh, D. (1998). Beyond the 'plateau': Discharge dilemmas in chronic aphasia. *Aphasiology*, 12, 207-218.

Hemsley, G., and Code, C. (1996). Interaction between recovery in aphasia, emotional and psychosocial factors in subjects with aphasia, their significant others and speech pathologists. *Disability and Rehabilitation*, 18 (11), 567-584.

Herrmann, M., Johannsen-Horbach, L. and Wallesch, C.W. (1993). Depressive changes in stroke patients. *Disability & Rehabilitation*, 150, 55-60.

Hoen, B., Thelander, M. and Worsley, J. (1997). Improvement in psychological well-being of persons with aphasia and their families: evaluation of a community based program. *Aphasiology*, 11 (7), 681-691.

Holland, A. (1998). Some practical considerations in the treatment of aphasic patients. In M. Sullivan & M. Kommers (Eds.*), Rationale for adult aphasiology therapy* (pp. 167-180). Omaha, NE: University of Nebraska Press.

Holland, A.L., Fromm, D.S., DeRuyter, F.D. and Stein, M. (1996). Treatment Efficacy: Aphasia. *Journal of Speech and Hearing Research*, 39, S27-S36.

Kagan, A. (1995). Revealing the competence of aphasic adults through conversation: A challenge to health professionals. *Topics in Stroke Rehabilitation,* 2, 15-28.

Kagan, A. (1998). Supportive conversation for adults with aphasia: Methods and resources for training conversational partners. *Aphasiology,* 12, 851-864.

Kagan, A. and Gailey, G. (1993). Functional is not enough: Training conversation partners for aphasic adults. In Holland, A., Forbes, M. (EDS), *Aphasia treatment: World perspectives* (pp. 199-215). San Diego, CA: Singular Publishing Group.

Kagan, A., Winckel, J. and Shumway, E. (1996). *Pictographic Communication Resources Manual.* Toronto Canada: Aphasia Centre North York.

Lafond, D., Joanette, Y., Ponzio, J., Degiovani, R. and Sarno, M.T. (Eds.) (1993). *Living with aphasia: Psychosocial issues.* San Diego: Singular.

La Pointe, L.L. (1997). Adaptation, Accomodation, Aristos. In LaPointe, L.L. (Ed). *Aphasia and related neurogenic language disorders.* (2nd ed.) (pp265-287). New York: Thieme.

La Pointe, L.L. (1999). Quality of life with aphasia. *Seminars in speech and language,* 20 (1), 5-17.

Le Dorze, G. and Brassard, C. (1995). A description of the consequences of aphasia on aphasic persons and their relatives and friends, based on the WHO model of chronic diseases. *Aphasiology,* 1 (3) 239-255.

Leedy, P.D. (1993). *Practical Research: Planning and Design.* New York: MacMillan.

Lomas, J., Pickard, L., Bester, S., Elbard, H., Finlayson, A. and Soghaib, C. (1989). *Journal of Speech and Hearing Disorders.* 54, 113-124.

Lyon, J.G. (1992). Communicational use and participation in life for adults with aphasia in natural settings: the scope of the problem. *American Journal of Speech and Language Pathology*, 1, 7-14.

Lyon, J.G., Cariski, D., Keisler, L., Rosenbek, J., Levine, R., Kumpula, J., Ryff, D., Coyne, S. and Blanc, M. (1997). Communication partners: Enhancing participation in life and communication for adults with aphasia in natural settings. *Aphasiology*, 11 (7), 693-708.

Maslow, A.H. (1968). *Toward a psychology of being* (2nd Edition). New York: Van Nostrand.

Mbatsha, S. and McIntyre, D. (2001). *South African Health Review.* http://www.hst.org.za/sahr/2001

Mbeki, T. (1997). White Paper on an Integrated National Disability Awareness Strategy.

National Aphasia Association (NAA) (1988). *Impact of aphasia on patients and family: Results of a needs survey.* New York: National Aphasia Association.

Muller, D. (1999). Managing psychosocial adjustments to aphasia. *Seminars in Speech and language*, 20 (1), 85-91.

Neuman, W.L. (2000*). Social Research Methods: Qualitative and Quantitative Approaches.* 4th Edition. Boston and Others: Allyn & Bacon.

Parikh, R.M., Lipsey, L.R., Robinson, R.G. and Price T.R. (1987). A two-year longitudinal study of post stroke mood disorders: dynamic changes in correlates of depression at one and two years. *Stroke*, 18, 579-584.

Parr, S., (1994). Coping with aphasia: Conversations with 20 aphasic people. *Aphasiology*, 8, 457-466.

Parr, S. (2001). Psychosocial aspects of aphasia: who's perspective? IALP Congress Montreal Canada, August, 2001.

Parr, S., Byng, S., and Gilpin, S. (1997). *Talking about aphasia: Living with loss of language after stroke.* Buckingham, Ireland: Open University Press.

Penn, C. (1993). Aphasia therapy in South Africa: some pragmatic and personal personal perspectives. In Holland, A. and Forbes, M. (Eds). *Aphasia treatment: world perspectives.* (pp. 25-53). San Diego, CA: Singular.

Penn, C. (1998). Clinician-researcher dilemmas: Comments on 'Supported conversation for adults with aphasia' by Aura Kagan. *Aphasiology,* 12, 839-844.

Penn, C. and Beecham, R. (1992). Discourse therapy in multilingual aphasia: a case study. *Clinical Linguistics and Phonetics,* 6, 11-25.

Penn, C. (2000). Communication problems following stroke. *CME*, 18 (1), 35-40.

Penn, C. (2000). Clinician – researcher dilemmas: Comment on Supported Conversation for adults with aphasia: Clinical Forum. *Aphasiology,* 12, 839-844.

Penn, C. and Smollan, T. (1996). The measurement of depression in a South African stroke population. *Paper presented at the Seventh International Aphasia Rehabilitation Conference.*

Penn, C. and Vyncke, O. (1998). The Rainbow Nation: Evidence for diversity in the beliefs and perceptions about stroke and aphasia. *Wits Working papers in Speech Pathology and Audiology*, 1 (2).

Pound, C. (1996). New approaches to long-term aphasia therapy and support. *Bulletin of The Royal College of Speech and Language Therapists,* 532, 12-13.

Pound, C. (1998). Therapy for life: Finding new paths across the plateau. *Aphasiology*, 12, 222-227.

Rabinowitz, L. and Legg, C. (2001). Living with aphasia: The life needs and personal experiences of aphasic adults in South Africa: An explorative study. *A report on a research project presented to: The Division of Communication Sciences and Disorders. Faculty of Health Sciences. University of Cape Town.*

Robinson, R.G., Starr, L.B., Lipsey, J.R., Race, K, and Price, T.R., (1984). A two-year longitudinal study on post stroke mood disorders: dynamic changes in associated variables over the 1st 6 months of follow-up. *Stroke*, 15, 510-517.

Ryff, C.D. (1989). Happiness is everything, or is it? Exploration on the meaning of psychological well-being. *Journal of personality and social psychology,* 57, (6), 1069-1081.

Sacks, H., Schelgloff, E. and Jefferson, G. (1974). A simplest systematics for the organization of turn-taking. *Language,* 50, 696-735.

Sarno, M.T. (1993). Aphasiology rehabilitation: psychosocial and ethical consideration. *Aphasiology*, 7, 321-324.

Sarno, M.T. (1997). Quality of life in aphasia in the 1st post-stroke year. *Aphasiology*, 11 (7), 665-679.

Schneider, M. (2002). Personal communication via e-mail and telephone, 2001.

Simmons-Mackie, N.N., (1998). A solution to the discharge dilemmas in aphasiology: Social approaches to aphasiology management. *Aphasiology*, 12, 231-239.

Simmons-Mackie, N.N. (1998). In support of Supported Conversation for adults with Aphasia: Clinical Forum. *Aphasiology,* 12, 831-838.

Simmons-Mackie, N.N., (2001). Life Participation Approach to Aphasia: An Asha Convention, Washington DC:
World Wide Web: http://www.employees.org/raccadmin/asha2000-lpaa-handouts.html

Small, S.L. (1999). The future of aphasia treatment. *Brain and Language,* 71, 227-232

Smollan, T. and Penn, C. (1997). The measurement of emotional reaction and depression in a South African stroke population. *Disability and Rehabilitation,* 19 (2), 65-63.

Terre Blanche, M. and Durrheim, K. (Ed.) (1999). Research in Practice. *Applied method For the social sciences.* University of Cape Town Press.

Währborg, P. and Borenstein, P. (1990). The aphasic person and his/her family: what about the future? *Aphasiology,* 4(4), 371-378.

WHO (2001*). International Classification of Impairments, Disabilities and Handicaps.*
World Wide Web: http://www.who-int/icidh/brochure/whatis.htm

APPENDIX A

Information and consent form
for
Subjects participating in a research project

LIFE NEEDS ACROSS THE STAGES OF APHASIA: USING THE ICIDH-2 AS A SERVICE DELIVERY GUIDE

	
Information	Consent

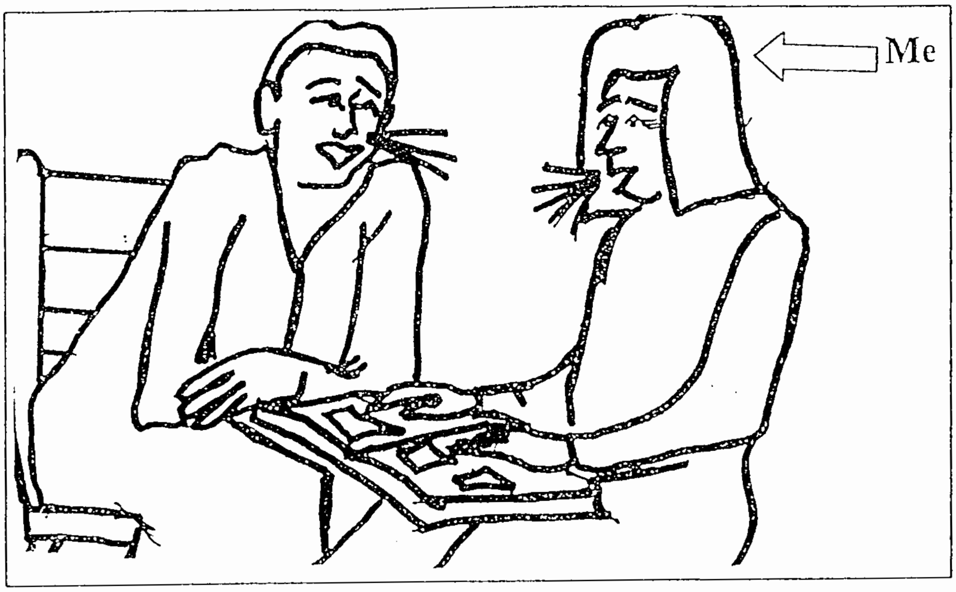
Participant________________________________

Date_______________________________________

Researcher: Julia Alberts
Home: (021) 851-3725
Cell: (083) 925-1123

My name is **Julia Alberts**

I am a **Speech Language Pathology** masters student.

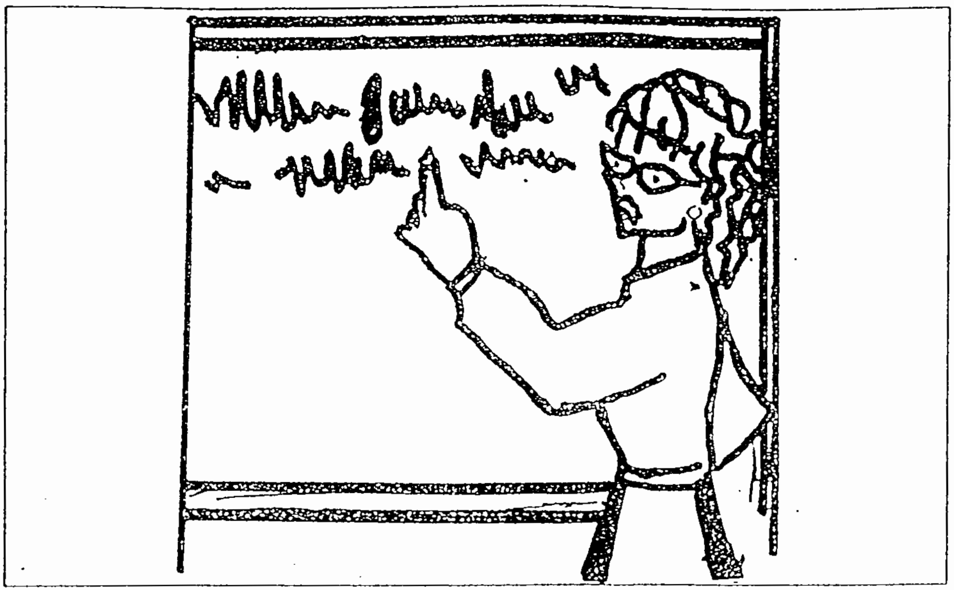


Speech therapy

I must do a **research project** as part of my degree.

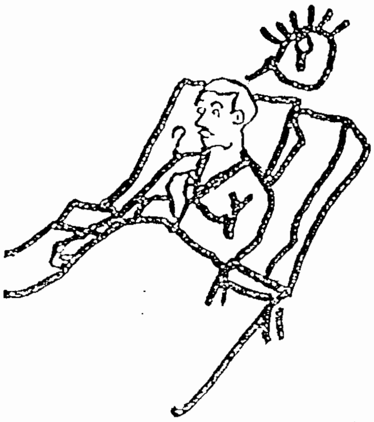
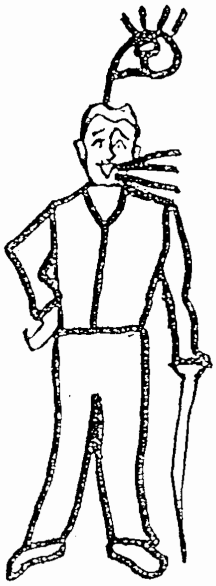
Research

Let me **explain** to you what **my study** is about.

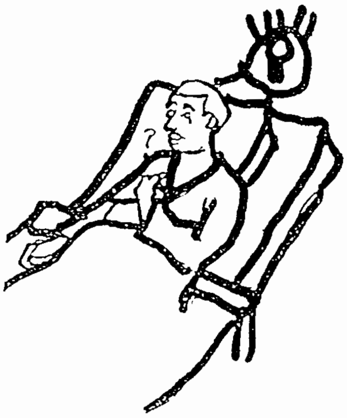
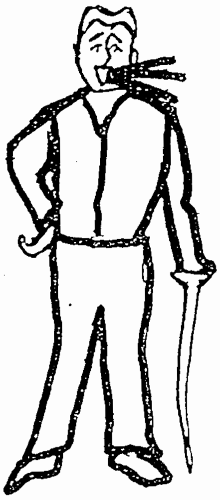
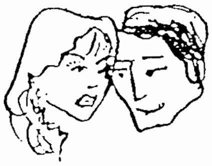


Explain

People with aphasia go through **different stages**.

		
Stage 1	Stage 2	Stage 3

At each stage, they have different **needs.**

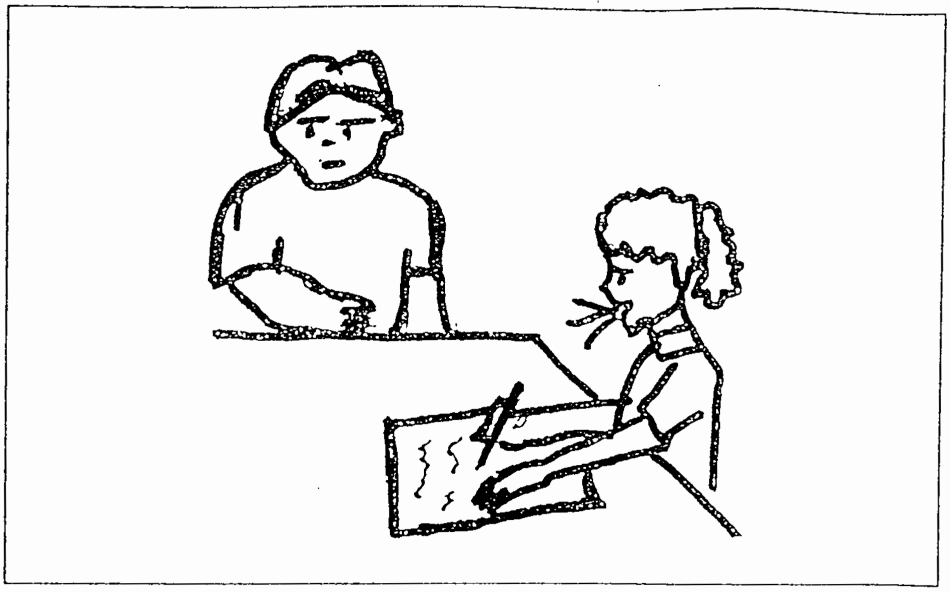
		
	Needs	
Food 	Reading 	Friends 
Medication 	Writing 	Job 
Speech therapy 	Speaking on phone 	Loved ones 
Stage 1	Stage 2	Stage 3

Different stages

I want to **determine** the exact **needs** of people at **each stage** of aphasia.

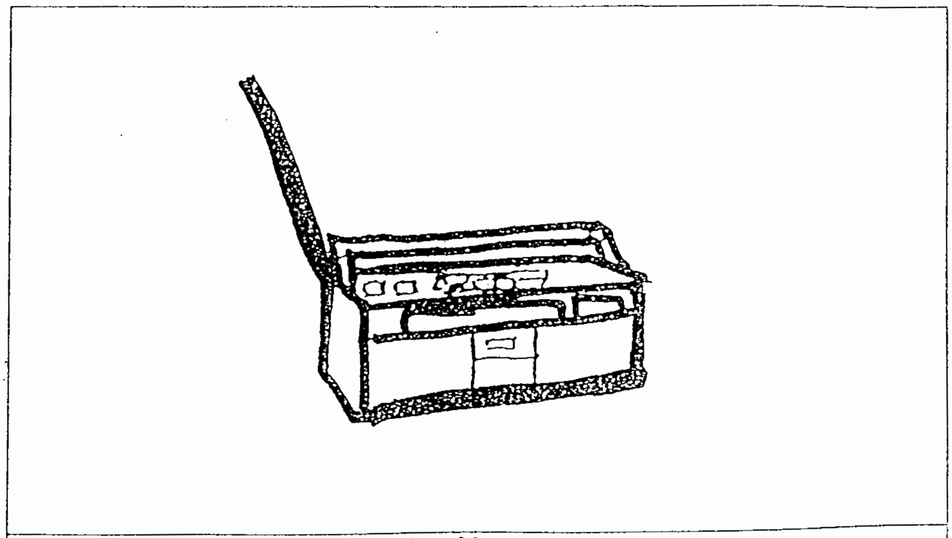
Your role in my study

I am going to **interview** you.



Interview

I will **record** this interview on **audiotape**.



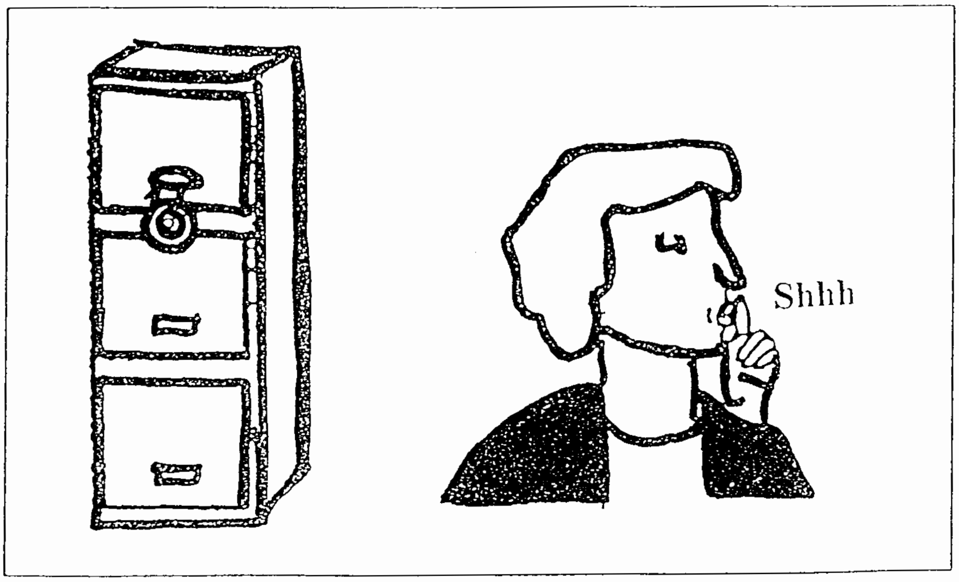
Audiotape

Record

Only the **researchers** will **look** at and **listen** to the recordings.

Listen

Everything is **confidential.**



Confidential

You **can stop** at any time.

It is **your choice.**

It is **ok to quit.**

	
Stop	Quit

Research consent

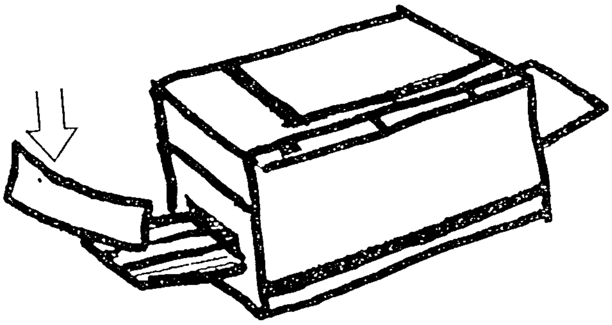
I **understand** all the **information.**

YES 	NO 
Yes	No

I **agree** to **participate** in this study.

YES 	NO 
Yes	No

I have been given a **copy** of this form.

	
Copy	
YES 	**NO** 
Yes	No

Signature of participant

Date

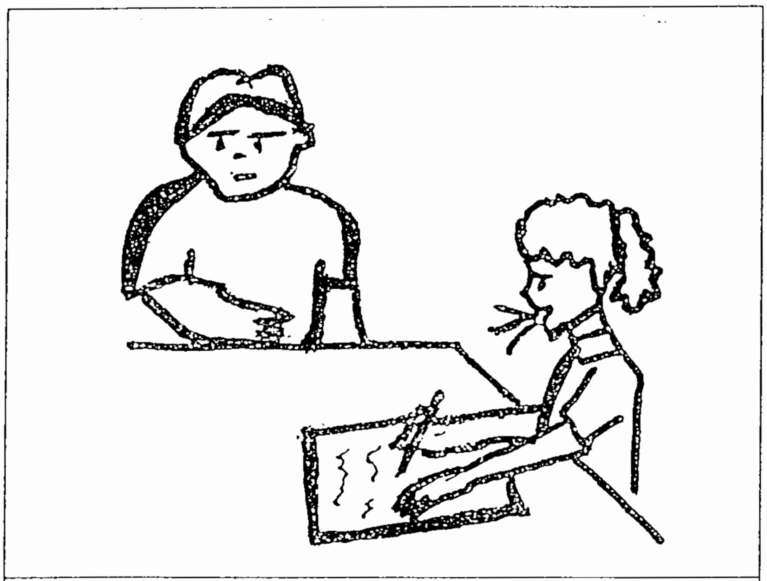
Signature of spouse/caregiver

Date

APPENDIX B

Questionnaire for interview
with
subjects participating in a research project

LIFE NEEDS ACROSS THE STAGES OF APHASIA:
USING THE ICIDH-2 AS A SERVICE DELIVERY GUIDE



Interview

Subject no.____________________________

Group no.____________________________

DATE____________________________

Part one: Biographical information

1. Name of the subject______________________________________

2. Sex *(mark in the appropriate block)*:

   male ☐ female ☐

3. Age____

4. Address____

   ____

4. Contact number____

5. Time since stroke______________________________________

6. Clinical diagnoses of stroke as confirmed by____________________

   ____

7. Type of aphasia_______________________________________

8. Severity of aphasia_____________________________________

9. Living arrangements____________________________________

Part two: Questionnaire

GETTING TO KNOW THE SUBJECT

1. Tell me about your experience of aphasia?

____

____

____

____

2. Mention the main effects that aphasia has on your life?

____

____

____

____

REHABILITATION

3. a) Do you receive any therapy *(mark in the appropriate block)*?

Yes☐ No☐

b) What kind of therapy?

____

c) How does it help you?

____

____

____

4. a) Have you received therapy in the past *(mark in the appropriate block)*

Yes ☐ No ☐

b) If yes, when?

____

____

c) What kind of therapy?

____

____

d) How did it help you?

____

____

____

CONSEQUENCES OF APHASIA

5. How does aphasia influence your communication?

____

____

____

____

6. How does aphasia influence your family relationships?

____

____

____

____

7. How does aphasia influence your friendships?

____

____

____

____

8. How does aphasia influence your independence?

____

____

____

____

9. How does aphasia influence your daily activities?

____

____

____

____

10. How does aphasia influence your emotional state?

____

____

____

____

11. How does aphasia influence your self-image?

____

____

____

____

NEEDS

12. Tell me what needs you have regarding communication (re. you and your partner)?

____

____

____

____

13. Tell me what needs you have regarding your family relationships?

____

____

____

____

14. Tell me what needs you have regarding your friendships?

____

____

____

____

15. Tell me what needs you have regarding your independence?

____

____

____

____

16. Tell me what needs you have regarding your daily activities?

____

____

____

____

17. Tell me what needs you have regarding your emotional state?

____

____

____

____

18. Tell me what needs you have regarding your self-image?

____

____

____

____

REFERENCE LIST

The researcher formulated the questions used in this questionnaire. Ideas for the questions were however obtained from results of the following studies:

Le Dorze, G. Brassard, C. (1995). A description of the consequences of aphasia on aphasic persons and the relatives or friends, based on the WHO model of chronic diseases. *Aphasiology,* 9(3), 239-255.

The National Aphasia Association. (1988). Needs survey. In: Sarno, M.T. (1997). Quality of life in aphasia in the first post-stroke year. *Aphasiology,* 11 (7), 665-679.

APPENDIX C

Guidelines for using the ICIDH-2

ICIDH-2 is a classification of human health and disability. It is systematically arranged according to levels at body, individual and society levels. At each level domains are grouped according to their common characteristics (such as their origin, type, or similarity) and ordered in a meaningful way. The classification has been organized according to a set of principles (see Appendix 3). These principles refer to the interrelatedness of the levels and the hierarchy of the classification (sets of levels). However, some categories in ICIDH-2 are arranged in a non-hierarchical manner, with no ordering but as equal members of a branch.

The following are structural features of the classification that have a bearing on its use.

(1) ICIDH gives standard operational definitions of the health domains as opposed to "vernacular" definitions of health. These definitions describe the essential attributes of each domain (e.g. qualities, properties, and relationships) and contain information as to what is included and excluded in each domain. These definitions contain commonly used anchor points for assessment so that the definitions can be translated into questionnaires, or conversely results of assessment instruments can be coded in ICIDH terms. For example, "vision" is defined as whether the person can see clearly objects at varying distance so that the severity of vision difficulty can be coded at mild, moderate, severe or total levels.

(2) ICIDH-2 uses an alphanumeric system whereby the letters b, s, a, p and e denote the components Body Functions, Body Structures, Activities, Participation and Environmental Factors. These letters are followed by a numeric code that starts with the chapter number (1 digit), followed by the second level (2 digits), and the third and fourth levels (1 digit each).

(3) ICIDH categories are organized in a "nested" approach in which broader categories are defined to include more detailed versions of the parent category. (e.g. mobility includes standing, sitting, walking, carrying items etc). The short (concise) version has two levels. The full (detailed) version covers four levels. Both short version and full version codes are in correspondence i.e. the short version can be aggregated from the full version.

(4) Any individual may have a range of codes in each level. These may be independent or interrelated.

(5) The ICIDH Codes are only complete by the presence of a Qualifier, which denotes the magnitude of the level of heath (e.g. severity of the problem). Qualifiers are coded as one or two numbers after a decimal point. Use of any code should be accompanied by at least one qualifier. Without qualifiers codes have no meaning when used for individuals or cases.

(6) A generic qualifier has been developed to describe the extent or magnitude of the problem in that construct. This is to be used as the first qualifier. It can be used for the three constructs and Environmental Factors.

(7) According to this generic qualifier, all constructs (B, A, P) and E component are coded in the same manner. Having a problem may mean an impairment, limitation, restriction or barrier depending on the construct. Appropriate qualifying words as shown in brackets below should be chosen according to the relevant classification domain:

xxx.0	NO problem	(none, absent, negligible...)	0-4 %
xxx.1	MILD problem	(slight, low...)	5-24 %
xxx.2	MODERATE problem	(medium, fair...)	25-49 %
xxx.3	SEVERE problem	(high, extreme, ...)	50-95 %
xxx.4	COMPLETE problem	(total...)	96-100 %
xxx.8	not specified		
xxx.9	not applicable		

The quantification of each qualifier as a universal scale has to be developed through assessment procedures using research. Broad ranges of percentages are provided for those cases in which calibrated assessment instruments or other standards are available to quantify the impairment, limitation, restriction or barrier. For example when no problem or complete problem is stated this may have a margin of error of up to 5%. Moderate problem is generally up to half of the time or half the scale of total difficulty. The percentages are to be calibrated in different domains with reference to population standards as percentiles.

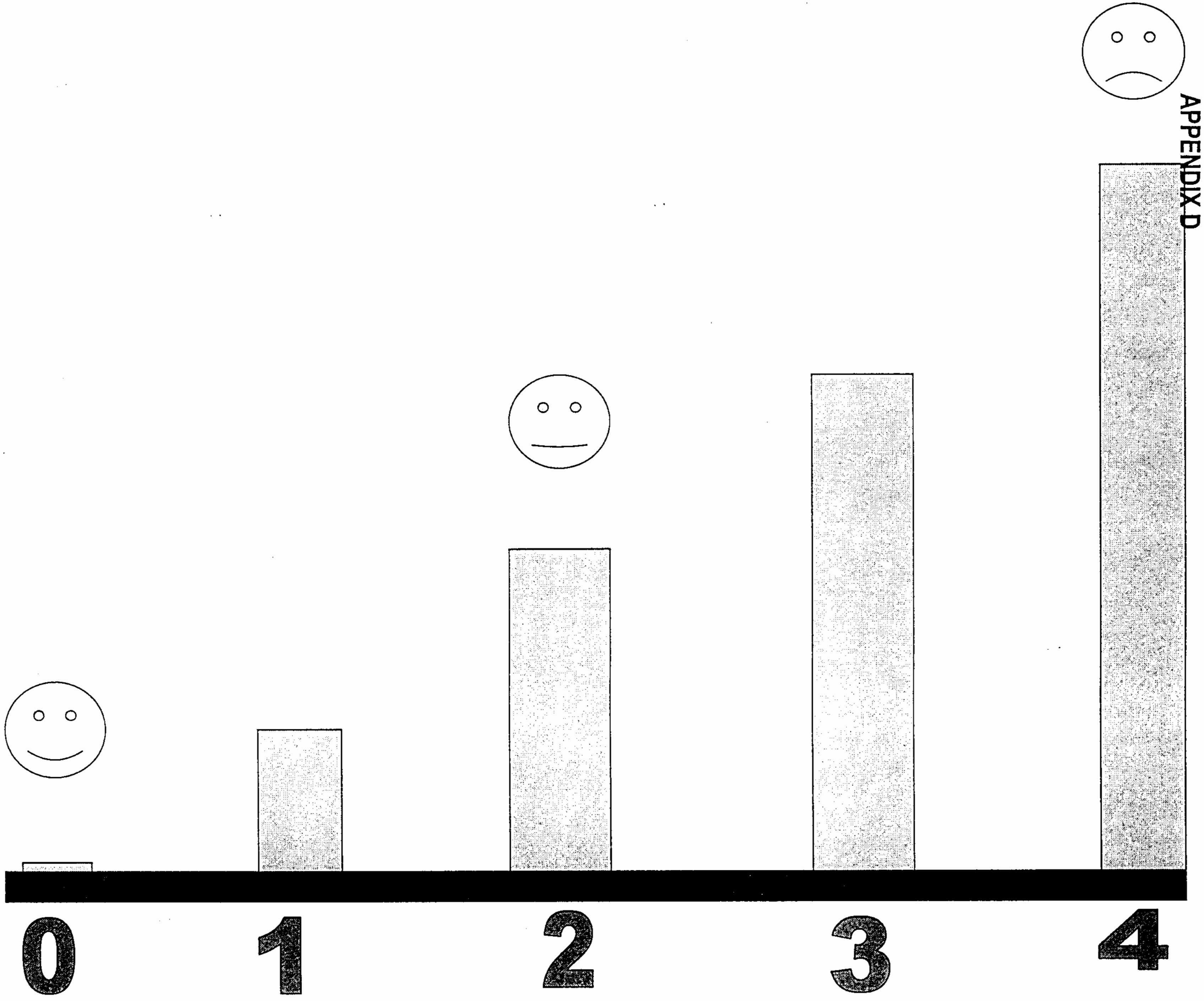
(8) In the case of Environmental Factors, this first qualifier can also be used to denote the extent of positive aspects of the environment, namely facilitators. To denote facilitators, the same 0-4 scale can be used, but the decimal point is replaced with a plus sign: e.g. e110+2. Environmental Factors can be coded as (i) in relation to each construct; (ii) without relation to constructs. First style is advantageous since it identifies the impact and attribution more clearly.

(9) Second and further Qualifiers: For different users, it might be appropriate and helpful to add other kinds of information to the coding of each item. There are a variety of potential second qualifiers that could be useful. Table 2 sets out the details of the generic qualifier for each construct and Environmental Factors as well as suggested second qualifiers to be developed.

(10) The descriptions of health domains refer to their use at a given moment (e.g. as a snapshot), however, use at multiple times is possible to describe a trajectory over time and process

(11) In ICIDH-2, a person is given an array of codes that encompass the three parts of the classification. In this way the maximum number of codes per person can be 30 at one digit level (e.g. 10 Body Functions, 10 Activities and 10 Participation codes). Similarly, at two digit level total of B, A, P codes adds up to 300. At further detail these codes can be theoretically be up to 3000, however, only some 1300 are actually filled in the long version of the classification. In real life application of ICIDH a set of 3 to 18 codes seem to be used to describe a case with three digit level precision. Generally the more detailed 3-level version is used

APPENDIX D



APPENDIX E

Example of procedure followed for data analyses, using the verbal responses of subject one, Group one

Discourse during interview

Question: "Tell me about the consequences of aphasia on your communication"?

Response: Well, the communication is like...uhm...its like...(long silence). Its like this now. Its that happening.

Prompt: Described to me what is happening now and when you talk to other people?

Response: Its like... Its like *I'm looking for what I'm saying*, you know...in there (points to head). And you just look and look, cause its not there (points to mouth)....and you cant say it like-like-like that (snaps finger).

Question: Can you show me how big this problem is for you, on this line (show patient the Visual Analogue Scale [VAS])?

Response: Yah sure, its uhm...its there (points to *three*)

Prompt: Is there any other problems you have with talking?

Response: Uhm...Its *this jumping, you know... then here then here*. I sound like..... when you go shopping without the-the-the paper, *not that I can read anymore*.

Question: And how big is the jumping around problem for you? (show patient the VAS)

Response: (shows to *two*)

Question: And reading, how big a problem is that?

Response: Uhm, lets see, uhm...its I think *three*

Analysed data

Actual Words Spoken	Summarised Words	ICIDH-2 Component	Qualifier
I'm looking for what I'm saying	I search for the right words	Body functioning: Memory problems	3
This jumping, you know...then there then there	I sound disoriented/disorganised	Activity limitation: Speaking problems	2
Not that I can read anymore	Reading problems	Activity limitation: Applying knowledge	3

APPENDIX F

RECEIVING MESSAGES (a310 a329)

a310 **Receiving spoken messages**
the ability, in a uniform environment, to comprehend literal and implied meanings of messages in spoken language, such as the ability to understand that a statement asserts a a fact or is an idiomatic expression

a315 **Receiving non-verbal messages**
the ability to comprehend the literal and implied meanings of messages conveyed by gestures, symbols and drawings, in a uniform environment, such as the ability to realize that child is tired when she rubs her eyes or that a warning bells means that there is a fire

- a3150 **Comprehending body gestures**
  the ability to comprehend the meaning represented by facial expressions, hand movements or signs, body postures and other forms of body language as well as vocalizations and sounds (e.g., moaning, screaming, or crying)

- a3151 **Comprehending general signs and symbols**
  the ability to comprehend the meaning represented by public signs and symbols, such as traffic signs, warning symbols, notations (e.g. musical or scientific) and icons

- a3152 **Comprehending drawings and photographs**
  the ability to comprehend the meaning represented by drawings (e.g. line drawings, graphic designs, paintings, three-dimensional representations), graphs, charts, and photographs, such as the ability to understand that an upward line on a height chart indicates a child is growing

- a3158 **Receiving non-verbal messages, other specified**

- a3159 **Receiving non-verbal messages, unspecified**

a320 **Receiving messages in formal sign language**
the ability to receive and comprehend messages in formal sign language with literal and implied meaning, in a uniform environment, such as the ability to understand that making chopping motions on the left forearm with the right hand means 'thank you' in Japanese Sign Language.

a325 **Receiving written messages**
the ability to comprehend the literal and implied meanings of messages that are conveyed through written language (including Braille), in a uniform environment, such as the ability to follow political events in the daily newspaper or the ability to understand the intent of a religious scripture or story

a329 **Receiving messages, other specified and unspecified**

PRODUCING MESSAGES (a330 a349)

a330 **Speaking**
the ability to produce words, phrases and longer passages in spoken messages with literal and implied meaning, in a uniform environment, such as the ability to express a fact or tell a story