

Participants' experience of the Bishop Lavis Rehabilitation Centre stroke group

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Project number: N05/02/030



Thesis submitted in partial fulfilment of the requirements of the degree
M. Phil (Rehabilitation) at Stellenbosch University

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Centre for Rehabilitation Studies

March 2007

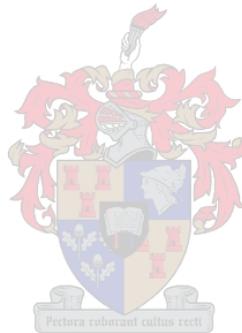
Declaration

I declare that the work submitted in this assignment is my own work, that it has not been submitted in its entirety or in any part for any degree or examination at any other university, and that all sources I have used or quoted have been indicated and acknowledged by complete references.

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Abstract

PARTICIPANTS' EXPERIENCE OF THE BISHOP LAVIS REHABILITATION CENTRE STROKE GROUP

W. de la Cornillère

M. Phil (Rehabilitation) Mini-thesis

Centre for Rehabilitation Studies, Stellenbosch University

Current emphasis for rehabilitation in South Africa remains on individual intervention within the move towards primary health care. Primary health care is the strategy that has been adopted by the South African department of health to bring access and equity in health care services. Even so, the burden of providing effective rehabilitative services with limited resources requires innovative strategies, such as the use of therapeutic groups, to address certain aspects of rehabilitation. These strategies must be proven effective. There is a paucity of literature detailing the uses of group therapy in physical rehabilitation, and particularly the use of interdisciplinary group work in stroke rehabilitation. Furthermore, evidence shows that stroke survivors feel ill equipped to return to their communities despite rehabilitation. Stroke is a major cause of death and disability in South Africa, and is a condition shown to benefit from rehabilitation. These factors led to the selection of the Bishop Lavis Rehabilitation Centre stroke group as the setting for this study, which aims to describe the range of experiences relating to attendance or non-attendance of those referred to this programme.

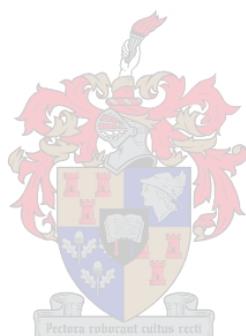
This descriptive study, employing quantitative means (to describe the demographic details of the participants) and qualitative means (to describe the experiences of participants), was conducted with twenty participants. Data was collected by means of an administered questionnaire. Following that, a focus group discussion involving six participants was used to gather in-depth information. Quantitative data was analysed with the assistance of a statistician, utilising the computer program, Statistica. The Chi-Squared, Kruskal-Wallis and ANOVA tests were used, with $p > 0.05$ showing statistical significance. Qualitative data was thematically analysed, whereby data was categorised by means of an inductive approach.

The study population consisted of 20 participants, with an average age of 59 years, of whom 15 were female and five male. The stroke group provided meaning to participants on two levels. On a psychosocial level, the phenomena of universality (identifying with others in a similar position), development of socialising techniques, imparting information and cohesiveness emerged strongly.

On the level of meaning related to stroke recovery, improvement in ability to execute activities of daily living, mobility and strength were most frequently mentioned. Transportation issues were most commonly mentioned as factors negatively influencing attendance. Staff attitude and activities of the programme were most often cited as positive factors.

Given the positive response of study participants, and the programme's ability to sustain intervention with limited resources, it was concluded that this programme has a valid place within stroke rehabilitation in Bishop Lavis.

Recommendations in terms of the group programme included investigating methods of providing transportation, providing childcare facilities and expanding the content of educational sessions. Further recommendations were to maintain the positive attitude of staff and the current activities of the programme. Frequency of group outings should also be increased and compensatory strategies for inclement weather must be explored.



Abstrak

GROEPELEDE SE ERVARING VAN DIE BISHOP LAVIS REHABILITASIE SENTRUM BEROERTE GROEP

W. de la Cornillère

M. Phil (Rehabilitasie) Mini-tesis

Sentrum vir Rehabilitasie Studies, Universiteit van Stellenbosch

Ten einde toegang tot en gelyke verspreiding van dienste te verseker fokus die Departement van Gesondheid op die verskaffing van primere gesondheidsorg. Die klem val egter steeds op individuele behandeling. Beperkte hulpbronne bemoeilik egter effektiewe diensverskaffing en innoverende strategieë soos die gebruik van terapeutiese groepe om sekere aspekte van behandeling te dek is nodig. Daar is weinig literatuur rondom die impak van groep terapie in fisiese rehabilitasie, of beroerte rehabilitasie, en die gebruik van inter-dissiplinere spanwerk in groep terapie. Dit tesame met bewyse dat persone met beroerte, ten spyte van rehabilitasie, onvoorbereid voel om terug te keer na hulle gemeenskappe, het gelei tot die studie. Beroerte is een van die hoof oorsake van mortaliteit en morbiditeit in Suid Afrika. Voorts is dit ook 'n toestand wat baat vind by rehabilitasie. Die studie fokus op die beroerte groep program van die Bishop Lavis Rehabilitasie Sentrum. Die doel van die studie is om die spektrum van ervarings van groeplede ten opsigte van groep bywoning te beskryf.

Die studie is beskrywend van aard en maak gebruik van kwantitatiewe (om die demografiese samestelling van die studie populasie te beskryf) en kwalitatiewe (om groeplede se ervaring van die groep te evalueer) metodes van data insameling. Data is ingesamel deur middel van 'n vraelys en na dit 'n fokus groep bespreking, met ses deelnemers, om in diepte inligting in te samel. Kwantitatiewe data is met behulp van 'n statistikus en die rekenaar program, Statistika, geanaliseer. Die Chi-Squared, Kruskal-Wallis en ANOVA toetse is gebruik. 'n P-waarde van >0.05 is gesien as statisties beduidend. Kwalitatiewe data is volgens tema geanaliseer deur middel van 'n induktiewe proses.

Die studie populasie het uit 20 deelnemers bestaan. Hulle gemiddelde ouderdom was 59. Vyftien van die deelnemers was vrouens en 5 mans. Deelnemers het beide op 'n psigososiale and fisiese vlak baat gevind by die groep. Op 'n psigososiale vlak het die verskynsel van universaliteit (identifisering met ander in dieselfde posisie), die ontwikkeling van sosialiseringstegnieke, oordrag

van inligting en kohesie sterk na vore gekom. Op `n fisiese vlak het deelnemers gevind dat hulle vermoë om aktiwiteite van die daaglikse lewe uit te voer, hulle mobiliteit en hulle spierkrag verbeter het.

Probleme ten opsigte van vervoer was die mees algemeenste faktor wat bywoning negatief beïnvloed het. Die houding van personeel en die aktiwiteite van die program het na vore gekom as faktore wat groep bywoning positief beïnvloed het.

Die positiewe reaksie van deelnemers en die program se vermoë om volhoubare behandeling ten spyte van beperkte hulpbronne te verskaf het gelei tot die gevolgtrekking dat hierdie program 'n definitiewe plek in beroerte rehabilitasie in Bishop Lavis het.

Aanbevelings sluit in om ondersoek in te stel na moontlike metodes van vervoerverskaffing, kindersorg fassiliteite en uitbreiding van die inhoud van die gesondheidsonderrig sessies. Verdere aanbevelings is om die positiewe houding van die personeel, sowel as die aktiwiteite van die program te behou. Daar moet ook aandag geskenk word aan meer gereelde groep uitstappies, en alternatiewe strategieë om bywoning in ongunstige weerstoestande te verbeter.



Acknowledgements

God, for being my strength and hope.

Scott Barr, for his endless patience and unparalleled love and support.

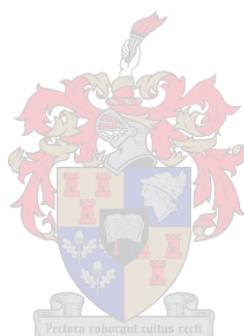
Surona Visagie, for her excellent supervision, her understanding and her patient guidance in her role as supervisor. For challenging my thinking and for being available - every step of the way.

Gené Guthrie, Peter, Liz and Jo de la Cornillère, Siegi Rabe, Ryan Rutherford and Aisha Abdulatief, for their support and generosity with time in being unpaid “research assistants”.

The Bishop Lavis stroke group, for their inspiration and willingness to share openly.

Siphokazi Gcaza, co-supervisor.

Gubela Mji, head of department.



Dedication

This study is dedicated to Rachel Nakeli (1944 - 2006), generous and selfless member of the Bishop Lavis community, who volunteered at the Bishop Lavis Rehabilitation Centre for many years and facilitated the Bishop Lavis community stroke support group with love and skill.

Key words

Bishop Lavis, community-based rehabilitation, rehabilitation, stroke, therapeutic group.

Definition of terms

Community-based rehabilitation

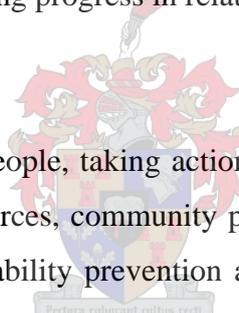
“...a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities and the appropriate health, education, vocational and social services.”¹

Interdisciplinary team approach

Type of team approach characterised by the coming together of health professionals who specialise in different areas of care, and who set common goals for client care and have regular communication regarding progress in relation to these goals.²

Primary health care

“The first level contact with people, taking action to improve health in a community”,³ with focus on maximal use of resources, community participation, affordable and accessible care, integration of all levels of disability prevention and co-ordination between health and other sectors.⁴



Rehabilitation

“Ways of helping people with disabilities to become fully participating members of society, with access to all the benefits and opportunities of that society.”⁵

Stroke

“Rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer leading to death with no apparent cause other than of vascular origin.”⁶

Therapeutic group

Setting in which several clients are treated together by one therapist as a group.⁷ The group provides a context for therapeutic intervention, where the processes of the group contribute to healing.

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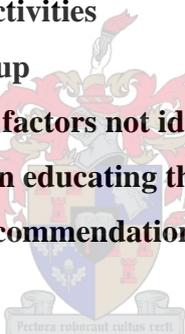
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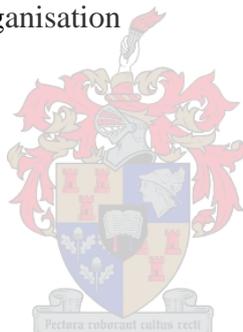


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Abbreviations

ADL	Activities of daily living
BI	Barthel ADL Index
BLCHC	Bishop Lavis Community Health Centre
BLRC	Bishop Lavis Rehabilitation Centre
CBR	Community-based rehabilitation
CHC	Community health centre
HSL	Household subsistence level
IDP	Integrated Development Plan
OT	Occupational therapist
PHC	Primary health care
PT	Physiotherapist
SIS v3	Stroke Impact Scale, version 3
WHO	World Health Organisation

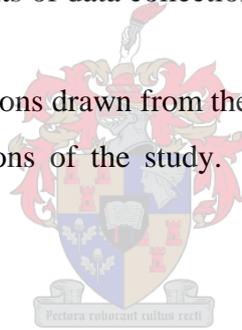


Chapter 1

INTRODUCTION AND BACKGROUND

1.1 Thesis outline

- ⊕ Chapter 1 serves as an introduction to the study. It provides the reader with the background to the study and the study setting, as well as motivation for and significance of the study.
- ⊕ Chapter 2 provides insight into the current literary context of the topic in the form of a literature review. It defines rehabilitation, gives an overview of current trends in rehabilitation, with a focus on stroke rehabilitation in South Africa, and introduces the reader to therapeutic groups.
- ⊕ Chapter 3 summarises the methodology used in the study.
- ⊕ Chapter 4 presents the results of data collection, and discusses these results in terms of the stated objectives.
- ⊕ Chapter 5 contains conclusions drawn from the study, outlines resulting recommendations, and highlights the limitations of the study. It also makes recommendations regarding future study.



1.2 Background

Within the context of South Africa as a developing nation, there is a significant burden to provide effective health care with limited resources. Rehabilitative aspects of health care are often under even more pressure, as they are not considered as high a priority as life-saving interventions are.⁴ Traditional forms of medium and long-term individual therapy programmes, whilst effective in certain contexts, are insufficient in meeting the current needs of the South African public. From an egalitarian perspective, there is insufficient manpower and resources to provide comprehensive, long-term, individual rehabilitation programmes for all clients in need thereof.⁸ Simply put – there are just not enough therapists, facilities or funds available.

It is clear that alternative means of providing rehabilitation must be investigated. This is supported by the Western Province's health plan 2010,⁹ which aims to provide ninety percent of health services – including rehabilitation services – at community level by the year 2010. Within this plan, there is a move away from the expensive, labour-intensive strategy of in-patient rehabilitation, which removes the client from their natural setting, effectively isolates them, and trains them to

cope in an environment that is often far-removed from the reality these clients will face upon discharge. The movement of resources for rehabilitation in South Africa is now in the direction of primary health care (PHC), and the associated approach of community-based rehabilitation (CBR). CBR helps to address the low level of available professional resources by involving the family, and community as a whole, in the rehabilitation process. The inadequacy of resources to meet the needs of the 82 % of South Africans dependant on the public health system cannot be ignored.⁸ It is envisaged that the approaches of PHC and CBR (discussed in further detail in Chapter 2) will be instrumental in bridging this gap.

The emphasis of rehabilitation currently remains on individual intervention, even at community level. At this point, it must be questioned whether individual treatment approaches are still the most effective means of rehabilitation. Individual treatment plans do have definite advantages, as every individual has unique needs. It seems, however, that certain aspects of rehabilitation that do not rely on one-on-one contact, may actually be enhanced within a group setting. Group programmes could, for example, be an effective method of providing health education, teaching lifestyle modification, promoting socio-emotional support, providing maintenance exercises and allowing for emotional expression. A review of the literature (refer to Chapter 2) reveals that there are, in fact, many such advantages. These include reducing anxiety, fulfilling the need to share and feel supported, overcoming dependency and guilt, increasing self-esteem, accepting change, learning new behaviours and setting realistic goals,¹⁰ amongst numerous others.

At the Bishop Lavis Rehabilitation Centre (BLRC), which forms a part of the Bishop Lavis Community Health Centre (BLCHC), one of the means used to provide rehabilitation to clients who have suffered a stroke is interdisciplinary group therapy. It is this stroke group programme that is the subject of this research project. An understanding of the functioning of the stroke group programme, and the context within which it operates, is essential to this study. Therefore, a detailed outline of the community of Bishop Lavis, the BLRC and the stroke group programme is included at this point.

1.3 The community of Bishop Lavis

Bishop Lavis was founded in the early nineteen hundreds by Bishop Sidney Warren Lavis, in an attempt to raise the poor standard of living amongst ‘coloured’ people of the Cape Peninsula. It is situated approximately twenty kilometres from central Cape Town, in the Western Cape Province of South Africa. Bishop Lavis is a densely populated, urban area – home to 23 737 people. Of these, 98 % are so-called ‘coloured’ and two percent are ‘black’ Africans. Afrikaans is the mother tongue of ninety percent of the population, with nine percent of the remainder speaking English as a

home language, and one percent speaking Xhosa. Bishop Lavis has a youthful population, with a mean age of 24 years.¹¹

Only 66 % of the economically active population (aged 15 to 65 years) of this community are employed. Approximately half of these (54 %) earn R0 - R1600 per month, thus less than the household subsistence level of R2 000 per month.¹² The dominant types of occupation in Bishop Lavis are those classified as elementary occupations, e.g. machine operators and assemblers, craft and related trades workers, and clerks. Of those unemployed, only seven percent report to be so by choice. Of the remaining unemployed, 15 % are unable to find work and 12 % are ill or disabled.¹¹

In general, education levels in Bishop Lavis are fairly low, with only one percent of the population having tertiary education. A fair proportion (41 %) of the adult population has some secondary school education and six percent have no formal schooling at all.¹¹

Extended families tend to live together in this community. Bishop Lavis is classified as a public housing area within the Cape Metropole, which means it is an area consisting mostly of council-built housing.¹² More than ninety percent of these households have access to flushing toilets, running water, and lighting by means of electricity. Most (70 %) of the houses are brick, built on a separate stand or yard.¹² Public transport is provided by the Golden Arrow bus company, Metrorail train services and minibus taxis. The vast majority of the community does not have access to private transport, and many cannot afford to use public transport. Walking therefore remains a very common mode of transport.¹² The researcher has heard many complaints from clients of the centre regarding the inaccessibility of transport systems, as well as the unsuitability of roads and kerbs for people with disabilities. Furthermore, the researcher has observed that there are no elevators in place at the local train station and there are high steps into buses and taxis. The local roads and kerbs are in a state of disrepair, with potholes and poor drainage in many areas. There is also sand and gravel surfacing in some areas of the community. Rainwater has been observed to flood the roads and entranceways to some of the houses.

The community is plagued by gangsterism and drug abuse, with a high rate of violent crime (seven murders per 10 000).¹¹

Resources in the community include: a day hospital, maternity unit, library, police station, sports centre, two old age homes, a day centre for the elderly, eleven primary schools, three high schools, various pre-primary schools and crèches, Lifeline counselling services, a youth centre, Communicare social work agency, various churches and mosques, Meals on Wheels, The Caring

Network home-based caring agency, as well as the BLRC. A shopping area is located centrally in Bishop Lavis, which includes a grocery store, hardware store, clothing store, pharmacy, butchery, fruit and vegetable market, post office as well as various smaller, specialist stores. The shopping area has been observed to be accessible by the researcher. This observation is supported by the regular sight of wheelchair and assistive device users utilising the area.

The BLCHC is a PHC facility catering for the basic health needs of this community. It operates on weekdays for eight hours a day. The service includes dentistry, psychiatry, social work, a children's clinic and a 24-hour maternity unit, in addition to general practitioner services. There are a number of private general practitioners in the area, but no private therapists. The BLRC, which provides rehabilitation to the Bishop Lavis community, forms a part of the services of the BLCHC.

1.4 The Bishop Lavis Rehabilitation Centre

1.4.1 Introduction

The BLRC provides occupational therapy, physiotherapy as well as speech and language therapy to the community of Bishop Lavis and its surrounds. It was opened in January 1994 as an academic PHC centre, and is a joint venture between the University of Stellenbosch, the Provincial Administration of the Western Cape, and the Bishop Lavis local authority. The BLRC functions as an ambulatory, out-patient unit, which operates for eight hours a day, five days a week. The project was developed with two aims in mind: to provide a comprehensive therapy service to the Bishop Lavis community, and to provide students of Stellenbosch University opportunities to gain experience in primary health care. The BLRC forms a part of the BLCHC. Although the BLRC occupies separate premises and is a joint project between the various parties, described above, service delivery is directly linked to the BLCHC. The staff of the BLRC functions as part of the BLCHC team, attending regular management and staff meetings, as well as making referrals to and accepting referrals from this establishment.

The current aims of the BLRC, as stated in the 2004 annual report,¹³ are:

- ⊕ To provide therapeutic, rehabilitative and maintenance programmes for all ages of clients, both individually and in group settings
- ⊕ To implement health promotion and preventative strategies
- ⊕ To empower the community
- ⊕ To enhance therapy services

An interdisciplinary teamwork approach is followed during rehabilitation. The core team consists of the patient, his or her family, an occupational therapist, a physiotherapist as well as a speech and language therapy student. The expanded team consists of the following members, who are based at the BLCHC: doctor, nurse, dietician, pharmacist, radiographer, sonographer, orthopaedic sister, psychiatric nurse, psychologist and social worker. It might also include the following community organisations: home-based care, old age home staff, and staff of the local day centre for the elderly.

Whilst the core team operates at the BLRC, this team is expanded as necessary by inclusion of the relevant professionals at the BLCHC by means of well-established lines of communication. For logistical reasons, it is difficult to have all members of the team present at all meetings. The professional members of the core team meet weekly to set integrated goals for new clients and discuss progress in relation to aims relevant to each client. This is after having first clarified these with the client and his/her family to ensure that a co-ordinated approach to treatment is adhered to. Joint documentation is kept, with an integrated assessment form in use.

Students of the University of Stellenbosch Physiotherapy, Occupational Therapy, and Speech and Language Therapy departments are placed at the BLRC during term times. These students form an integral part of the team as they gain their practical experience in this setting. Students are placed for six to ten weeks at a time, and can total twenty at any given time. The students have a positive impact on service delivery, as they contribute to managing the caseload as well as to programme development. On a negative front, however, the regular changing of students can be disruptive to the formation of therapeutic relationships with clients.

Conditions that are treated at BLRC include neurological and surgical (e. g. stroke, head injury, amputation, spinal cord injuries, burns); orthopaedic (e.g. vertebral and peripheral joint and muscle conditions, hand injuries, fractures and sport and work related injuries.); respiratory (e.g. chronic obstructive airway disease, pneumonia, paediatric chest conditions.); gynaecology and obstetrics and paediatric conditions (e.g. cerebral palsy, spina bifida, developmental delay, learning difficulties.) Clients are seen at the BLRC or at their home, as appropriate. Treatment programmes are individualised and, thus, vary from a few days to several months. Services rendered include management of clients on an individual basis – both at the BLRC and on home and work visits, work ability screenings, various community outreaches and a range of group programmes. The latter will be discussed in further detail as one of these groups forms the basis of this study.

There are currently eleven therapeutic group programmes running at the BLRC, which are classified by the BLRC as curative, rehabilitative or maintenance – according to their aims and duration. Curative groups operate as short-term, set courses, which are presented in a rolling fashion. Each client will attend a set number of sessions covering a spectrum of education topics related to, and exercises appropriate for their condition. After this time, clients should be in a position to self-manage the health condition in question. Examples of curative groups are the arthritis and back pain groups.

Rehabilitative groups operate over longer periods and, although goal orientated, do not follow as rigid a programme as the curative groups. They provide education, appropriate exercise, and have various other aims on a holistic level. There is a strong emphasis on socio-emotional support within these groups. Clients attend for a period of their choice, not exceeding 18 months. The stroke group is an example of the BLRC's classification of a rehabilitative group. It tends toward the task and social end of the group spectrum, having a focus on development of functional skill and social interaction (refer to 2.4.3).

Maintenance groups are groups that were established by the BLRC, and are now operating independently in the community with volunteer facilitation. Members of rehabilitative groups are invited to attend maintenance groups after their discharge from the BLRC's group programme for the purposes of ongoing support and maintenance exercises. The move from a rehabilitative group to a maintenance group is seen as part of the gradual withdrawal of rehabilitative input in order to ensure community reintegration. There is no time limit for involvement in maintenance groups.

The group programme does not replace individual intervention at BLRC. All clients are assessed individually, and an individual treatment plan is devised by the interdisciplinary team according to personal needs. A team decision is taken to invite the client to the group programme if that client meets the criteria for inclusion for a particular group.

In the following section, the management of the stroke client at BLRC will be discussed, and the stroke group programme introduced.

1.4.2 Management of the stroke client

Stroke clients referred to the BLRC are usually medically stable. They are most often referred from a CHC or a general practitioner, after having been evaluated, but not admitted to hospital post-stroke. In some cases, clients are referred from Tygerberg Hospital (a tertiary health care facility in the vicinity of BLRC) post-discharge. These clients tend to have been discharged as soon as they

are medically stable, and have seldom commenced rehabilitation. Where they have, this is usually in the form of learning transfer techniques, positioning and basic home exercises. Referrals are also received from the local home-based care agency, when these clients have not already been referred by the health care facility where the diagnosis was made. Several referrals are made by family or friends of the stroke survivor who have heard of the BLRC.

The initial assessment is carried out by the occupational therapist (OT) or physiotherapist (PT) in the presence of the primary caregiver. Thereafter, subsequent team members build on assessment information gathered until a treatment plan can be devised, based on a client-centred approach. The Barthel ADL Index¹⁴ (BI) is used as tool to provide a baseline indication of a client's level of functioning. This index is used several times during the course of treatment to monitor progress and identify therapeutic plateaus. This is not done on a regular basis, but rather according to the progress of each individual.

The client will attend individual sessions with the relevant core team members who, on occasion, combine sessions when it is to the benefit of the client. One or more home visits are carried out for each stroke client, depending on need and available manpower. If and when the client meets the group inclusion criteria, he or she is invited to attend the stroke group programme. The inclusion criteria are that the client must:

- ⊕ Have sustained a stroke, or have another neurological condition which has resulted in similar symptoms (e.g. traumatic brain injury)
- ⊕ Be medically stable or moderately stable*
- ⊕ Have one or more persistent disability*
- ⊕ Have the cognitive capacity to integrate new information*
- ⊕ Posses the physical endurance to sit for the duration of the group and participate actively*
- ⊕ Be able to manage own toileting needs, or have a carer present to assist
- ⊕ Have consented to inclusion
- ⊕ Be a client of the Bishop Lavis CHC (If not already a client when referred to the BLRC, clients are referred to the BLCHC.)
- ⊕ Have been assessed by the BLRC team
- ⊕ Have undergone or commenced necessary individual therapy

Literature¹⁵ suggests that certain criteria (those marked with asterisks above) indicate a person's readiness for rehabilitation. Other of these criteria are unique to the context of the BLRC group programme, which are subjectively judged by the therapists involved as necessary for a client to be able to derive benefit from this fairly flexible group programme. Clients are free to discharge

themselves from this programme at any stage within the 18-month time frame. This approach to group entry and exit has been chosen for its emphasis on control by the client, according to the social model of disability (discussed in Chapter 2).

Group programme inclusion is voluntary, and supplementary to other intervention. Participation in the stroke group can be concurrent with individual intervention where the client stands to derive benefit from both. However, the group programme shortens the period of individual intervention at the BLRC, and meets a range of needs that the therapists have observed are not being as effectively addressed on an individual basis.

The stroke rehabilitation group consists of weekly sessions of one, to one and a half hours. Attendance varies from eight to twenty two clients, with an average weekly attendance of 15 during the study period. The group is divided into two sub-groups, which operate concurrently. One sub-group is facilitated by an OT, and the other by a PT, or by students of these respective disciplines. After thirty minutes, the sub-groups change over.

The aims of the group are:

- ⊕ Maintenance of physical abilities – range of motion, tone normalisation, balance and endurance
- ⊕ Revision of home exercise programmes
- ⊕ Monitoring of physical status
- ⊕ Provision of a forum for socio-emotional support
- ⊕ Intellectual stimulation
- ⊕ Promotion of autonomy
- ⊕ Health education

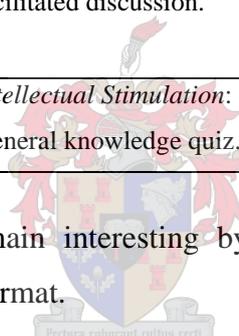
Several of these aims are the primary focus of one group per month, which are achieved by the use of a variety of leisure and social activities, educational methods, discussion groups, hemiplegic-specific exercises in supine, sitting or standing; and physical games (for example, ball games and skittles). Secondary aims are included in various sessions. These are monitoring functional status, experience and expression of positive emotion, promoting communication, enlarging life area and skill development.

After the initial one-hour programme, the sub-groups are sometimes merged for input from health professionals or students from other disciplines, which takes the form of health education. This includes a broad range of topics, such as depression and stroke, communication, and the indications and side effects of medication associated with stroke. Health promotion talks do not occur every week due to limited availability of team members. Six of these sessions were held during 2004. A typical month planner for the group may resemble the example presented in Table 1.1.

Table 1.1 – Example of stroke group planner

	<i>Physiotherapy</i>	<i>Occupational Therapy</i>	<i>Other team member</i>
Week 1	Exercise - with focus on upper limb.	<i>Creative activity:</i> Making thank you cards for carers (printing and painting).	<i>Doctor</i> Talk on prevention and management of hypertension
Week 2	Physical Games - skittles	<i>Health education:</i> Stress management	-
Week 3	Exercise - with focus on lower limb.	<i>Social:</i> Tea and snacks with icebreakers and facilitated discussion.	<i>Speech and Language Therapy student:</i> Talk on how to interact with people with aphasia.
Week 4	Exercise - with focus on trunk.	<i>Intellectual Stimulation:</i> General knowledge quiz.	-

Thus, the programme aims to remain interesting by including a variety of activities, whilst providing the security of a reliable format.



Records of the group are kept as follows:

- ⊕ A weekly attendance register provides statistics, which are reflected in the annual report.
- ⊕ Weekly sessions are planned and recorded on interdisciplinary group progress sheets (Appendix I).

Evaluation of the group occurs by means of bi-annual client satisfaction surveys that are completed by all clients attending the group (Appendix II). The results are analysed and included in the BLRC annual report. Suggestions are incorporated as far as possible in year planning.

1.5 Research problem

Group therapy is by no means a new concept. Traditionally used in the field of mental health, it is now increasingly being utilised within South African health systems. Of concern is the significant lack of literature in existence to substantiate it within the field of physical rehabilitation. Furthermore, in the South African context, there is no evidence of a published model for group

work that can be implemented to facilitate physically disabled clients through the rehabilitation process to the level of community reintegration. It seems that groups are being used to decrease cost of intervention and maximise therapists' coverage, amongst other reasons. However, without sufficient research in this area, the validity of this intervention remains in question. Perhaps, more significantly, a very valuable and effective method of intervention is being overlooked for lack of knowledge. Given the apparent advantages of group work in other settings, it would seem sapient to research this approach in physical rehabilitation as well.

The BLRC group programme is an example of a group programme for physical and psychosocial rehabilitation (refer to 1.4) that was developed in order to maximise the use of resources. The programme is perceived to have a positive impact on participants and is assisting the involved therapists to cope with the heavy caseload. However, this group programme has never been formally researched.

There are several issues around this programme that warrant investigation. For example, the researcher has observed that some members attend inconsistently. What distinguishes clients making use of this service from those declining it? Are the aims and objectives relevant for the community and users of the programme? Are activities of the programme appropriate and acceptable? What meaning does the programme hold for users? What effect do they perceive the group to have on their post-stroke recovery – physical and psychosocial? And, what effect does it actually have on an objective level, as measured by an objective outcome measure? Are these effects similar?

With such a range and number of questions it was necessary to limit the scope of this study to manageable proportions. The researcher focussed on the issue of the participants' experience of the group programme as a starting point to evaluating the effectiveness of the group, and its place in stroke rehabilitation. It is, after all, the service-user that one has in mind in developing the service of rehabilitation. This makes the concept of satisfaction with a programme central.

Understanding a client's experience of a programme can provide a starting point for gauging that client's satisfaction with the programme, and goes a long way to answering questions of effectiveness relating to that programme, as this underlies many issues around how and why a service is utilised. The satisfied client is likely to further utilise a service, and s/he may refer others to it. A study of client satisfaction will help to identify aspects of the programme that are perceived to be helpful and enjoyable, and which not. It will also assist in measuring whether or not the aims of the group are being achieved. In the case of the BLRC group programme, the issue of client

satisfaction is central to understanding why stroke survivors attend and the meaning that group involvement holds for them.

The BLRC group programme was developed based on available literature of best practice,¹⁶ experience of the therapists involved, and feedback from the clients included in the programme. But, the lack of research regarding the group programme leaves an ethical question as to the appropriateness of its use. If the use of the group programme as part of the rehabilitation of stroke survivors in Bishop Lavis is to continue, the responsible team must ask: Does the BLRC stroke group programme have a valid role to play in physical and psychosocial rehabilitation of the stroke client? This necessitates gaining an understanding of the experiences of stroke group participants relating to their participation in the stroke group.

1.6 Motivation for and significance of the study

South Africa's National Rehabilitation Policy¹⁷ emphasises the need to develop accessible and affordable rehabilitative services that are feasible within current manpower and other resource limitation. This policy highlights the need to strengthen community rehabilitation services and maximise use of available resources. A potential method of maximising resources is to make use of therapeutic groups for the purposes of rehabilitation.

There are many centres in South Africa that offer group programmes in physical rehabilitation. One of them is the BLRC, discussed above, where the researcher is currently employed as the occupational therapist.

However, many questions remain unanswered regarding therapeutic groups in rehabilitation. For example: How do group programmes impact the user? What type of client stands to derive the most benefit? What resources are required for the effective use of such a group? What factors draw or repel users from group programmes, or influence compliance? What is the ideal format for such a group? Who should be included or excluded from a therapeutic group programme? This study attempts to answer a few of these questions by exploring the meaning that stroke group involvement has to participants, and examining the factors that influence attendance of the group.

The staff of the BLRC perceive the groups to be having a positive effect on participants – both in terms of their physical recovery, and on their general motivation and well being. The staff feels that time is better utilised – and therapy enhanced – by the inclusion of clients meeting the inclusion criteria for the group programme (refer to 1.4.2) into groups. This observation has, however, not been formally researched until now.

The stroke group was selected for this study, as stroke is a prime example of a condition with lasting impairment, and resulting disability, that requires rehabilitation. Stroke rehabilitation is interdisciplinary by its nature, and is topical in South Africa, considering that stroke has been labelled the most disabling chronic disease¹⁸ and the third leading cause of death in this country.¹⁹ It is of particular significance for Bishop Lavis, given that stroke is the most common cause of physical disability in this community.²⁰

There are various treatment approaches to stroke, as discussed in Chapter 2. This study, however, aims to explore some of the issues around group therapy in stroke rehabilitation by describing the range of experiences relating to attendance or non-attendance of stroke survivors referred to the stroke group programme of the BLRC. This includes the meaning that stroke group participation has to those who attend, factors that affect attendance as well as aspects of the programme that members of the group find enjoyable or not enjoyable. Information gained through the study will, therefore, provide feedback regarding the suitability of the programme developed for the clients in question.

On a micro-scale, this study will contribute to maximising the rehabilitative potential of the stroke group programme at the BLRC. On a larger scale, a critical analysis of the stroke group programme will provide a baseline for the development and piloting of stroke and other rehabilitative group programmes in other settings. This would be of use to other PHC establishments in South Africa, particularly those serving areas with similar demographics. This potential use leaves significant scope for further study, and could lead towards establishing a group programme that can be piloted in more diverse contexts within South Africa, in order to begin the development of a model for rehabilitative group work. Furthermore, the BLRC is a unique setting in the sense that it operates as a partnership between the University of Stellenbosch, provincial government and the community of Bishop Lavis. Lessons learnt from this study will thus be useful in contributing to an evaluation of this partnership, and to issues raised in future discussions regarding the sustainability of the project.

1.7 Summary of Chapter 1

Within the context of South Africa as a developing nation, there is a significant burden to provide effective health care with limited resources. The movement of resources for rehabilitation in South Africa is in the direction of CBR, with the emphasis remaining on individual intervention. It seems that group work, whilst overcoming cost implications of individual intervention, would be useful in addressing certain aspects of rehabilitation, although little published evidence exists to substantiate it within the field of physical rehabilitation.

Chapter 2

LITERATURE REVIEW

2.1 Introduction

This chapter provides the reader with a literary context relating to the study question. It gives an overview of rehabilitation in order to set the scene for the topic of rehabilitation within the South African milieu in general, and stroke rehabilitation in particular. The chapter is concluded with a discussion on therapeutic groups and their role in physical rehabilitation.

2.2 Rehabilitation - an overview

2.2.1 Introduction

The Integrated National Disability Strategy⁵ of South Africa defines rehabilitation as “ways of helping people with disabilities to become fully participating members of society, with access to all the benefits and opportunities of that society”. It is a holistic and ongoing process, which ends only once the individual has fully reintegrated into his society. Rehabilitation has also been described as “planned withdrawal of support”.²¹ These definitions imply a graded process of support for individuals with an impairment of any sort, to a point at which that individual has achieved satisfaction with his or her ability to participate and fulfil his or her life roles.

The above definitions subscribe to the social model of disability, which sees disablement as a form of social oppression, rather than as a disease state, as is the case with the medical model of disability.²² The social model emphasises independence in terms of the degree of control that the individual has over his or her life. It is on the basis of the social model that the holistic field of interdisciplinary teamwork rests.

Team-work in rehabilitation is gaining increasing popularity. The rehabilitation team arises from the compromise between specialisation of disciplines and the need for a comprehensive approach to care when managing chronic illnesses.²³ There are various teamwork approaches, the most popular in rehabilitation being the multi-disciplinary and the interdisciplinary approaches. The interdisciplinary team approach, as is followed at BLRC, brings together members that specialise in different areas of rehabilitative care. It is characterised by regular communication and the establishment of common goals.² Theoretically, by integrating the different aspects of rehabilitative care, the team can create better treatment outcomes for its clients. A literature review by Halstead,

which was cited by Lubkin and Larsen,² concluded that team care resulted in better control of chronic illnesses, and less deterioration in clients with chronic illnesses. As a disadvantage, however, the same review found that team care also resulted in increased utilisation of health services at higher cost.

Rehabilitation can be categorised into: a) interventions aiming to reduce physical disability; and b) interventions aiming to reduce psychological and social problems.²⁴ As discussed in 1.4, the stroke group programme at BLRC aims to address both these aspects of rehabilitation. Neither of these areas should be neglected when aiming to provide a holistic programme. Reduction of the physical aspects of disability can include treatment of problems related to components of function – for example, muscle strength, range of motion and sensory retraining. It could also mean the provision of assistive devices or changes to the physical environment. The aspects of rehabilitation aiming to reduce psychological and social problems are slightly more difficult to define, and are the areas that have traditionally received less attention during the rehabilitation process.²² These are, for example, the adjustment to altered life roles, loss of self esteem, and community reintegration. This aspect of rehabilitation, by its nature, involves a variety of role players.²⁵

A key aspect of rehabilitation is, in fact, the inclusion of stakeholders other than the client and the professional in the process. These stakeholders include, amongst others, the individual's family as well as the community and the account payer. Literature supports the collaboration of all persons involved in the individual's care in order for rehabilitation to be effective.²⁶ The community should retain primary responsibility for the rehabilitation process,²⁷ given that this is where the individual will be living and that he or she must be able to function in the community in order to have completed his/her rehabilitation.

Community can be defined as a collection of people sharing an environment, recognisable as a group.⁷ In order to be part of a community, people must have certain characteristics in common that allow for identification – by self and by others. Often, people with disabilities feel they have lost their ability to contribute meaningfully in their community, and no longer feel as strongly that they have identifying links with their community.²⁵ Members of the community can help or hinder the rehabilitation process by removing or imposing a variety of barriers, including physical (such as accessibility issues) or psychosocial (such as bias and ignorance).²⁵ The community can provide a wealth of resources for individuals recovering from a health incident, which can help to buffer the effects of impairment or disability.¹⁵ The types of resources offered by the community can be classified as educational, instrumental or emotional. Educational resources include health information talks or literature. Instrumental resources include services of a practical nature – for

example, Meals on Wheels or home-based care. Emotional resources are those to be found, for example, in a group of peers able to offer support.¹⁵

One way for stakeholders to influence the rehabilitation process is by participating in policy development, from local through to national level, which determines to a large extent the face of rehabilitation in a country. In the following section, rehabilitation policies in developing nations, and more specifically, in South Africa, will be examined.

2.2.2 Rehabilitation policy trends in developing nations

It is estimated that global rates of disability stand at ten percent, with approximately eighty percent of people with disabilities living in developing countries.²⁸ Unfortunately, rehabilitation services in developing countries are very poorly developed.⁴ Perhaps this is because rehabilitation has, historically, been seen as a low priority world-wide due to the following factors:⁴

- ⊕ “Cost-benefit ratio of providing services to those with disabilities”
- ⊕ “Under-estimation of disabled peoples’ potential to achieve”
- ⊕ “Negative societal attitudes towards disability”
- ⊕ “Discriminatory practices”
- ⊕ “Absence of urgency – rehabilitation tends to focus on the chronic, non-communicable diseases or illnesses that do not pose a risk to others”
- ⊕ “Interest of biomedical practitioners focuses on improvement and cure, which is not always feasible or realistic for rehabilitation”
- ⊕ “Public policy is not influenced by those with disabilities as they represent a relatively small marginalised minority.”

However, with the increased attention rehabilitation has been receiving of late, it would seem that the relevant parties are beginning to move beyond the above factors. Strategies are now in place to address the problem of under-developed services for people with disabilities, the most important of which is PHC. The Alma Ata Declaration²⁹ of 1978 was the first international declaration underlining the importance of PHC. It highlighted the role of the community in the development and provision of health services, emphasised the importance of inter-sectoral collaboration, and prioritised those most in need of basic health care. The United Nations Standard Rules for the Equalisation of Opportunities for Persons with Disabilities followed in 1992, aiming to ensure that all people with disabilities had the same rights and obligations in their society as others.⁷ The World Programme of Action was later established in 1993, outlining actions to be taken towards the realisation of this ideal.⁷ The United Nations and World Health Organisation (WHO) have been

placing increasing emphasis on PHC and community services over the past decade, with promotion, prevention, rehabilitation, social integration and equalisation of opportunities for people with disabilities as key features thereof.⁴

Primary Health Care refers to “the first level contact with people, taking action to improve health in a community”³ and is particularly emphasised for developing nations. It focuses on:⁴

- ⊕ “Maximum use of local resources, including traditional healers and trained community health workers”
- ⊕ “Participation of the individual and the community”
- ⊕ “Affordable and accessible care”
- ⊕ “Integration of prevention, promotion, - treatment and rehabilitation”
- ⊕ “Co-ordination between the health care sector and other aspects of society, such as housing and education.”

A term strongly associated with PHC is CBR. Community-based rehabilitation was formalised in 1976 by the WHO as a model for provision of essential services and training for people with disabilities as part of the ‘Health for All’ campaign.¹ A United Nations joint position paper¹ defines CBR as follows: “CBR is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities and the appropriate health, education, vocational and social services.” It is a client, rather than professional, centred service.⁴ The ultimate aim of this approach is to integrate people with disabilities into their society.³⁰ PHC and CBR are inherently linked, as they share many of their original principles.¹ It is not difficult to see how these strategies could be used together to optimise rehabilitation.

Both PHC and CBR seem ideal solutions to the problems associated with provision of rehabilitative services in developing nations. There has, however, also been criticism. Both PHC and CBR have been accused of falling short of the ideal by using a top-down approach to gain compliance, rather than emphasising the importance of community participation, as is theoretically key.³¹

South Africa is striving towards the effective use of the systems of PHC and CBR. In the next section, the researcher will discuss health care and rehabilitation in South Africa in more depth.

2.2.3 Health Care and Rehabilitation in South Africa

At present, a two-tiered system of health provision exists in South Africa – the private and the public systems. Richer households tend to make use of private health care, whilst poorer households depend on public services. In 2003/2004, private care was provided by 66 % of South Africa's physicians to only 18 % of the population, totalling sixty percent of the health expenditure within the country.⁸ The remaining resources were allocated to public health. For the purposes of this study, the public health system will be examined more closely.

Public health care in South Africa has been faced with many challenges and has undergone radical change over the past years. In 2000, the World Health Report ranked the South African health care system as 175th in overall performance and 182nd in efficiency amongst 191 countries.³² This is not a positive reflection. The Western Cape Province now, however, has a long-term, strategic plan in place, entitled Health Care 2010.⁹ A key aspect of this plan is to develop primary-level services, community-based care and preventative care. The desired outcome of this is to improve the quality of health care, as well as to bring health expenditure within sustainable limits. The plan aims to have 89 % of acute health care contacts and 99.5 % of chronic contacts at community level by the year 2010, provided closest to where the individual resides. The plan aims to ensure that no person in the Cape Metropole has to travel more than five kilometres to access their nearest PHC facility.

The other two levels of health care provision are mentioned briefly, as they are not the focus of this study, nor of the province's health plan. Secondary health care is defined as “specialised ambulatory medical services and commonplace hospital care (out-patient and in-patient services), not including highly specialised, technical inpatient medical services”.³ Tertiary health care refers to “medical and related services of high complexity and usually high cost.”³

South Africa's national budget demonstrates commitment to the change in focus of the country's health care. There has been a significant increase in allocation to health over the past years.³³ In 2003/2004, 11 % of the Gross National Product was allocated to public health services, catering for 82 % of the population.³⁴ The previous total of health expenditure was increased by a further 11 %, bringing the total to R9, 825 billion for 2005/6. This figure is projected to increase further still. This understood, South Africa has some way to go to meet the standards of health care in developed nations.³² It must be acknowledged that South Africa is a developing nation, and therefore comprises largely of disadvantaged settings. Models of health care must take cognisance of this reality. In such settings, innovative intervention strategies are required to compensate for limited resources.³⁵

Rehabilitation forms part of PHC, which means that, in line with Health Care 2010, rehabilitation services in the Western Cape should be developed. For this development to be effective, models and methods of rehabilitation must be established – and these proven to be appropriate, necessary and accessible.³⁵ These requirements necessitate research in this field.

There are several established settings for rehabilitation, including varieties of both in-patient and out-patient settings. The move towards PHC in South Africa, however, places increasing emphasis on out-patient rehabilitation over in-patient rehabilitation. Out-patient rehabilitation is often in the form of home-based or community-based services.³⁶

Home-based rehabilitation is rehabilitation occurring in the patient's home environment. This form of rehabilitation has been shown to be feasible and acceptable to patients and their caregivers, and is now generally accepted as routine care.³⁷

Community-based care is defined as “care that a consumer can access nearest to his home, which encourages participation by people, responds to the needs of people, encourages traditional community life and creates responsibility.”³⁶ Community rehabilitation services are usually linked to CHC within South Africa. These provide out-patient rehabilitation to individuals and serve as the link between hospital discharge and full community reintegration. A major advantage of this setting is that it can assist individuals and their families through the process of rehabilitation, without the high cost of hospital care.¹⁵ This is much the same as for home-based care, but community health centres, theoretically, have added advantages for rehabilitation – such as access to an interdisciplinary team, availability of equipment and the opportunity for peer support.¹⁵ Due to manpower limitations, the concept of the interdisciplinary team is unfortunately under-developed in many of these settings.

Rehabilitation services at PHC level, such as the service provided by the BLRC, cover the entire spectrum of disability prevention from primary to tertiary. Primary prevention consists of “measures to prevent diseases, injuries, or conditions that can result in impairments or disabilities”.³⁸ This includes services such as health education of relevance to the field of rehabilitation. Primary level prevention is particularly important for the Western Cape, which has high rates of modifiable lifestyle risk factors, as well as biological risk factors for stroke and other vascular diseases. Twenty six percent of the province's population is overweight, and a further 31% are obese. The Western Cape has the highest provincial rates of hypertension, heart attack, high cholesterol levels, diabetes, asthma and arthritis.³⁹

Secondary prevention consists of “early intervention in the treatment of diseases, injuries, or conditions to prevent development of impairments”.³⁸ Whilst this type of intervention is most often initiated elsewhere, it is usually followed up within the PHC system.³⁸ It includes services such as mobilisation post fracture to prevent contracture formation, or lifestyle modification programmes for hypertensive and diabetic patients.

Tertiary level prevention interventions are “measures to limit or reduce impairments or disabilities”.³⁸ These also include the treatment of disabilities, and therefore rehabilitation.

Whilst rehabilitation within PHC has a role to play at each of these levels, the results of health promotion and disability prevention are often intangible, and in the context of South Africa’s limited economic resources, competition is strong for adequate funding for such programmes.²⁷ What type of intervention can realistically be offered within the context of limited resources of a developing nation? It would seem as if traditional individual therapy, whilst it has its definite advantages and uses, cannot be considered to be adequate as the only form of intervention offered in the context of rehabilitation at the primary level.

This study examines therapeutic groups, and specifically rehabilitative groups, as a supplementary approach to out-patient rehabilitation at PHC level, addressing primary, secondary as well as tertiary disability prevention needs. Therapeutic groups are utilised in the management of a variety of physical conditions. This study will focus on stroke group therapy, as stroke is a complex condition that requires input on multiple levels.

2.3 Stroke

2.3.1 Introduction

As mentioned in Chapter 1, stroke is a prime example of a condition requiring rehabilitation, given that it has been classified as the most disabling chronic disease world-wide.¹⁸ Literature reveals that it is the third most common cause of death in South Africa.¹⁹ In 2004, 5.6 % of deaths within the district in question in this study (Western District of the Cape Metropole), were due to stroke, making it the third highest cause of death in the district after ill-defined/unknown causes and ischaemic heart disease.⁴⁰ In South Africa, the highest incidence of stroke is amongst the so-called ‘coloured’ and Asian population groups⁴¹ and, unlike the world incidence, occurs fatally to a similar extent in men and women, with a 30 % higher incidence in men.¹⁹ Up to 72 % of those sustaining stroke in sub-Saharan Africa have low-socio-economic backgrounds.⁴² With advances in health care, the incidence of fatal stroke is decreasing, leaving an increasing number of individuals returning to the community in need of rehabilitation.⁴³

According to South Africa's National Guideline on Stroke and Transient Ischaemic Attack Management,⁴¹ non-modifiable risk factors for stroke are age (incidence doubling for each decade over 50), gender and race. Modifiable risk factors include hypertension, diabetes mellitus, smoking, alcohol use, atheroma, hypercholesterolaemia, heart disease and atrial fibrillation. Currently, there are an estimated six million hypertensive people, seven million smokers and three to four million people diagnosed with diabetes mellitus who are at increased risk of sustaining a stroke in South Africa.⁴¹ In Bishop Lavis, stroke patients have an average of 2.4 of these risk factors at the time they sustain their first stroke.²⁰ A review of literature revealed that there is generally under-diagnosis and poor control of these modifiable risk factors in sub-Saharan Africa.⁴²

Primary prevention of stroke can be achieved by addressing the modifiable risk factors mentioned above, and by having early detection mechanisms in place. Secondary prevention strategies are employed after a vascular event has occurred, and involve identifying and treating the causes and risk factors leading to that event, as well as treatments aimed at limiting the extent of the impairment. This aims to prevent a second stroke, which most often results in severe impairment. Tertiary prevention consists largely of rehabilitation⁴¹ and limiting the extent of disability.

Those who suffer a stroke are likely to experience a wide and varied pattern of impairment – from physical and functional, to emotional and cognitive. Obvious deficits include hemiplegia, incontinence, as well as perceptual, sensory, and language disturbances, cognitive loss and swallowing difficulties.⁴¹ Depression, decline in leisure and religious activities, and problems with social integration have also been shown as concerns for stroke survivors.⁴⁴ One study showed some degree of depression to be present in half the respondents in a 14-year stroke survival study.⁴⁴ Psychosomatic symptoms are also common, including exhaustion, stress, mental confusion, anxiety, irritability, and dizziness when required to work fast. These psychosomatic symptoms have been found to be more common in older than younger patients.⁴⁵ The combination of the residual symptoms of stroke make the prospects of employment bleak for many stroke survivors.²⁵

Given the high incidence of stroke, the significance of the resulting impairment and disability, and the impact that rehabilitation can have on stroke outcomes, it is a relevant condition to investigate with regard to effectiveness of rehabilitation at PHC level.

2.3.2 Approaches to stroke rehabilitation

The Neurological Association of South Africa Stroke Working Group¹⁹ established guidelines for stroke therapy in 2000, which state, “Rehabilitation and community care need to be evaluated in light of currently available resources, future vision and outcome measures. A goal-orientated, time-limited programme that enables the impaired person to reach an optimal level of mental, physical and social functioning should be the objective of therapists.” This seems to summarise the ongoing challenge for stroke rehabilitation.

There are currently several schools of thought in existence on stroke rehabilitation. Some of the great names associated with stroke rehabilitation approaches include Bobath, Brunnstrom, Clayton, Coulter, Fay, Kabat, Knott, Rood, and Voss.⁴⁶ Two separate reviews^{46,47} revealed that none of these approaches has been proven more effective than the others. It is, however, evident that stroke patients benefit from rehabilitation in general, even if the improvement is sometimes statistically small.⁴⁶ Whitelaw *et al.*⁴⁸ found significant evidence that rehabilitation improves functional outcome in strokes, and therapy-based rehabilitation has been shown to reduce the risk of stroke survivors’ deterioration in ability to undertake activities of daily living (ADL).²⁴ The conclusions of Ernst’s⁴⁶ review advocate for the use of the most cost-effective rehabilitation method available in the absence of evidence of best practice. It is also recommended that rehabilitation be commenced as soon as possible post stroke, and continue over a longer period to prevent deterioration. At the BLRC, rehabilitation is commenced as early as possible after referral (within two weeks) and is sustained for as long as 18 months by means of the group programme.

A review²⁵ of five randomized control studies showed that stroke survivors rehabilitated on specialised stroke rehabilitation units had significantly better outcome than those rehabilitated on general wards. This was particularly true for ambulation and self-care. Certain studies included in this review also found significantly decreased length of hospitalisation and increased discharge rates to own home in-patients treated in specialised stroke units. Most of the clients referred to the BLRC have not had the opportunity for treatment in a specialised unit, with some never having been admitted to hospital at the time of their stroke at all.

Both in-patient and out-patient rehabilitation can be beneficial to the stroke survivor, depending on the stage of recovery and the particular circumstances of the individual. Literature²⁵ recommends that all stroke patients should at first be hospitalised. After the acute phase of rehabilitation has passed (two weeks), out-patient rehabilitation becomes more appropriate if the patient can be mobilised in the community with reasonable effort. Due to the situation of limited resources in South Africa, this process is somewhat accelerated for stroke survivors. Home-based rehabilitation

is most appropriate when the client has significant logistical difficulties in accessing the rehabilitation centre.²⁵ Again, limited resources in this country often limit the coverage of such services. The good news is that certain studies^{37,49} have shown that early discharge with home-based rehabilitation is at least as effective as in-patient rehabilitation, and in one study,⁴⁹ it was found to be more effective in the areas of motor and functional recovery. Given the move towards out-patient rehabilitative services, this finding is positive for South Africa.

Several guidelines on stroke management exist internationally.¹⁸ The Melbourne Declaration of the Asia Pacific Consensus Forum on Stroke Management⁵⁰ states that all stroke patients should have access to rehabilitation by means of locally available and culturally appropriate resources. In the context of the South African health care system, this would seem a tall order. This struggle is recognised in the declaration. It acknowledges the inability of most developing countries to provide ideal stroke services due to the limited resources, but states that efforts should be made to reduce incidence of stroke, largely by means of risk factor modification. The declaration suggests that resources should be focused on, amongst other, developing rehabilitation services. It also emphasises the need for cost effectiveness of all aspects of stroke management, including rehabilitation and community integration.

Despite the positive effects of rehabilitation, there is often a poor outcome following stroke. This is possibly because the long term psychosocial needs of stroke survivors are often overlooked.³⁷ One study²⁶ showed that stroke survivors, although provided with in-patient rehabilitation following the stroke, often feel ill equipped to return to community living. This may be as a result of the lack of social support. It has been found⁵¹ that strong social support improves outcomes in stroke patients, particularly those with severe strokes.

The above indicates a need for an alternative type of rehabilitative input to supplement what is currently in practice. Perhaps the incorporation of structured, interdisciplinary group work to the rehabilitation programme can assist with more effective utilisation of resources and provide a basis for social support outside the family. Group therapy has been shown to be a time, and therefore cost effective method of intervention when treating the elderly. One study showed savings of between fifteen and forty percent of therapists' time by utilising group therapy.⁵² Furthermore, groups have been shown to have many positive, curative factors resting on the basis of social interaction and support. These factors are discussed in the following section.

2.4 Therapeutic groups

2.4.1 Introduction

It is within groups, both informal and formal, that we develop our sense of identity, establish roles and learn who we are.⁵³ Groups can be said to be the building blocks of society – each group sharing an identity and common objectives, and forming part of the greater whole. Thus, none of us is a stranger to groups. If groups are this fundamental to our existence, what is it that sets therapeutic groups aside from other groups and requires them to be researched and developed?

2.4.2 Curative factors of therapeutic groups

The founder of group psychotherapy for health is accepted to be Joseph Henry Pratt, an internist, who started a treatment group for tuberculosis patients in 1905.⁵³ Since then, group work has traditionally been used in the field of mental health, but research is increasingly showing its effectiveness in other fields.⁵⁴

Yalom (1985)⁵⁴ is largely responsible for laying the foundation for current therapeutic groups. He established 11 curative factors of group therapy, which he defines as “guided human experiences”. These factors are described in the sub-points below. The impact that a stroke has on the individual in each of these areas is also highlighted. However, since there is a notable lack of literature of the role that group therapy can play in stroke rehabilitation, no conclusions can be drawn. The researcher intends to compare the results of the study to these factors in order to ascertain whether the participants of the BLRC stroke group programme experienced similar phenomena on a psychosocial level as a result of their group participation.

2.4.2.1 Instillation of hope

Instillation of hope is the first phenomenon that patients experience in a group, because members of a group with common experiences act as inspiration for each other.⁵³ Instillation of hope is a major contributor to effective healing,⁵⁵ as it enables the individual to conceptualise a way forward in the face of major loss. It is this factor that maintains an individual’s involvement with therapy in order for other interventions to occur.⁵⁴

The acute loss of function associated with stroke is very traumatic. For stroke survivors facing this loss, the idea of future meaningfulness in life is exceptionally important.⁵⁶ Motivation and hope have, in fact, been described as “critical to post-stroke recovery”.⁵⁷

2.4.2.2 Universality

Universality is the phenomenon whereby members of a group find they are not alone with their problems.⁵³ The group setting provides members with the opportunity to disclose their experiences, feelings and perceptions in a safe environment.⁵³ They find acceptance and support within a group,⁵⁴ which leads them to continue to risk disclosure, leading ultimately to trust.⁵⁸

It has been found useful for medical patients to realise, within groups, that they are not alone with their medical issues,⁵⁹ as being part of a group can be a good way of inspiring adjustment to changes in health status.⁵³ A stroke results in dramatic, unforeseen changes in one's life, including lasting impairment and disability which are fairly unique to stroke survival.⁵⁶ One author⁵³ reports that stroke patients would often share their experiences of the stroke within groups for the elderly, thereby experiencing the phenomenon of universality.

2.4.2.3 Imparting information

Information imparted in groups can relate to diagnosis, or be advice from other group members or the therapist. Learning in a group context can occur either formally, by means of lectures, or informally as members share their experiences with each other.⁵³ Whilst individual intervention can be effective for formal education, it does not provide a forum for informal learning.

Literature supports that education is crucial to successful outcome in stroke survivors.⁵⁷ As mentioned previously, stroke is most often related to chronic diseases of lifestyle.⁴¹ Lifestyle adaptation is, therefore, required to reduce the risk of further strokes and subsequent disability. In addition to this, stroke patients are at risk of developing spasticity and contractures,⁵⁷ and require education regarding the prevention thereof. Stroke survivors also have the need to be educated in compensatory strategies for the execution of certain ADL.⁶⁰

2.4.2.4 Altruism

Altruism is “the practice of placing others before oneself”.⁷ A group setting provides various opportunities for one to be of service to others – from provision of advice, to practical assistance. Within groups, self-esteem is boosted by these altruistic acts of members giving of themselves, and therefore being important to others.⁵³ Altruism is a significant contributor to morale, which is a strong indicator for rehabilitation. Morale can be defined as one having a “feeling of having attained something in his life, of being useful now, and thinking of himself as an adequate person.”⁵⁶

The loss of function and role-fulfilment associated with stroke can lead to a loss of self-esteem and morale,⁶⁰ which must be addressed as part of the rehabilitation process. The need for the experience of altruism is particularly strong for those who consider themselves a burden to others, with nothing of value to offer.⁵⁴ As stroke survivors have been reported to feel this way,²⁵ altruism can be considered an important factor for them.

2.4.2.5 Corrective recapitulation of the primary family group

Yalom⁵⁴ states that group processes can simulate the original group each of us was exposed to, namely, the family. Group members explore their reactions to each other so as to repeat or heal past experiences of family interactions.

2.4.2.6 Development of socialising techniques

This factor is inherent to all groups as members learn and practice social skills, and provide feedback for each other.⁵³ Within the safety of a group setting, members are required and encouraged to communicate, which aids in the development of socialising skills.

Stroke is associated with communication difficulty – whether this be as a result of expressive or receptive dysphasia, facial muscle tone abnormalities or loss of confidence. In fact, communication difficulty may occur in as many as forty percent of stroke survivors.⁵⁷ The loss of speech associated with stroke has a profoundly negative effect on one's sense of self.²⁵ Non-verbal aspects of communication may also be affected by hemiparesis associated with stroke,⁶⁰ and loss of self esteem associated with stroke may negatively affects one's ability and desire to communicate.²⁵

The goal of rehabilitation in this regard is to facilitate the recovery of communication by various methods, including assisting patients to develop compensatory strategies, as well as counselling and educating people in the patient's environment to facilitate communication and to decrease isolation.⁵⁷

2.4.2.7 Imitative behaviours

Group members model each other and the leader, which is desirable for learning adaptive behaviour.⁵⁴ Positive behaviour within groups is encouraged by the leader, and this positive reinforcement may illicit similar behaviour in others.

2.4.2.8 Interpersonal learning

Groups help members to self-reflect on their behaviour, relationships and emotions.⁵³ Elderly people, in particular, tend to become socially isolated, and these individuals benefit greatly from the social aspects of group participation.⁵³ This is because groups provide what is often the only forum for essential feedback about interpersonal skills for socially isolated individuals. This should, then, also be a consideration for stroke survivors who tend to be elderly, and are known to experience social isolation in many cases.⁵¹

2.4.2.9 Group cohesiveness

Cohesion refers to “the degree of connectedness and closeness members feel toward each other and the value they place on the group”.⁵³ Several authors identify cohesiveness in a group by the “we-feeling” – that is, the use of the pronoun ‘we’ in group dialogue.⁵³ A cohesive group is characterised by trust, warmth, loyalty and sense of belonging. This creates an environment where self-disclosure is encouraged and risk-taking, in the form of new behaviour, is enabled.⁵³ A study by Dickoff and Larsin, cited by Finlay,⁵³ reported over fifty percent of group psychotherapy participants found mutual support to be the most useful aspect of the group. She also reports that members are more inclined to express themselves in an atmosphere of acceptance.

2.4.2.10 Catharsis

Within groups, members learn how to express their feelings freely.⁵³ Catharsis is used within the field of psychology to relieve tension and anxiety by bringing repressed feelings and fears to consciousness.⁷ This can be by means of activities used in the group context, or by interacting with others who are experiencing and expressing emotion.⁵⁴

It is very common for stroke survivors to experience periods of emotionalism,⁵⁷ whether this be as a residual symptom of the stroke, or associated with the extreme sense of loss following stroke. Depression is a common consequence of stroke,⁶¹ occurring in an estimated 25 % to 75 % of stroke survivors.⁵⁷ Anxiety is another factor seen in those surviving strokes, often co-existing with depression.⁵⁷ The loss of roles associated with stroke has also been found to cause significant emotional distress.⁵⁶

2.4.2.11 Existential factors

Members of a group begin to recognise philosophical aspects of the group.⁵³ Stroke sufferers are often confronted with their own mortality by virtue of the fact that they have sustained a major health incident.⁶² They struggle with issues such as life and death, fate and future, meaning and meaninglessness. They are further confronted by this when members of the group pass away, often due to a subsequent stroke. The group context can be a valuable forum in which members can express their thoughts and fears relating to mortality and other aspects of philosophy.⁵³

2.4.2.12 Impact of curative factors

Kriegsman and Cellota¹⁰ summarised the effectiveness of group work in its role of enabling individuals to gain information, reduce anxiety, acquire specialised training, fulfil their need to share and feel supported, overcome dependency and guilt, increase self-esteem, accept change, learn new behaviours and set new, more realistic goals. Many of these agree with the factors described by Yalom.⁵⁴

The impact of therapeutic groups holds a challenge for evaluation. Not all factors are always acknowledged by participants as having contributed to their recovery. Yalom⁵⁴ states that when patients evaluate the effects of the above curative factors on their well being, they tend to focus on the obvious and superficial factors – and are often not even aware of the deeper healing factors that are in place. One long term study, cited by Yalom,⁵⁴ stated that subjects are more likely to comment on the negative aspects of the group experience when interviewed four years after completion of treatment than they are immediately after completion of treatment. He also reminds the reader that the importance of the experiences of group work cannot be generalised, as each person places their own value on their experiences.

2.4.3 Types of therapeutic groups

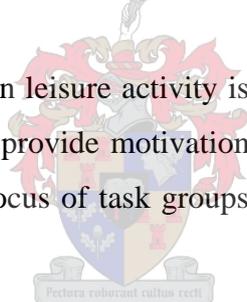
There is a wide range of therapeutic group types to suit the particular needs of the target group. Finlay⁵³ identified four types of groups that are used therapeutically in occupational therapy. She arranged these on a continuum. On the one end, she placed the individual, end product focussed group. On the other, she placed the group, and group process, focussed group. The main elements on this continuum are task, social, communication and psychotherapy. These types of groups are not mutually exclusive, but rather represent a shifting balance of focus, depending on therapeutic need. The focus of each of these groups is discussed below.

2.4.3.1 Task groups

The purpose of a task group is to develop task and functional skill. In these groups, members talk about a task, make decisions and problem-solve together. The 'doing' element is essential, and there is most often an end product involved. Leisure activities are an important element of task groups,⁵³ with typical activities including craft activities or gardening.

Task-focused interventions are often characteristic of stroke rehabilitation, given that training in self-care and leisure activities are two of the three most frequently chosen occupational therapy interventions for stroke patients, along with provision of assistive devices.⁶³ Stroke survivors have significant need to develop functional skills lost, and to learn new skills in order to compensate for areas of loss.⁶⁰ These skills include the underlying components of function needed to perform the task. (An example might be improving bilateral hand function in order to tie shoelaces.) Exercise can also be considered as a leisure activity for a task for a group.⁵³ Structured, progressive exercises have been shown to have gains beyond those attributable to spontaneous recovery in stroke survivors. These gains included improved endurance, balance, mobility motor control, strength, upper-extremity use, and aerobic capacity.⁶⁴

Literature reveals that participation in leisure activity is closely related to health status and quality of life for stroke survivors, and can provide motivation for resuming an active lifestyle.⁵⁷ Given that leisure activities are often the focus of task groups, it seems likely that task groups would be useful in stroke rehabilitation.



Task groups may also be useful for fulfilling Yalom's⁵⁴ curative group factor of imparting information. Rickheim *et al.*,⁶⁵ in their study regarding group education for diabetes sufferers, provided evidence of its effectiveness.

2.4.3.2 Social groups

The purpose of social groups is to provide opportunities for participants to experience social interaction and develop leisure interests. This is achieved by structuring group sessions in such a way as to allow members to experience social interaction they might otherwise lack the opportunity for.⁵³ Social groups are characterised by informal chatting and sharing of feelings. Leisure activities often serve as a medium for this interaction in groups,⁵³ with typical activities including playing Bingo and having newspaper discussions.

This type of group might be best used to evoke the curative factors of interpersonal learning, imitative behaviour and development of socialising techniques, discussed under 2.3.2.

2.4.3.3 Communication groups

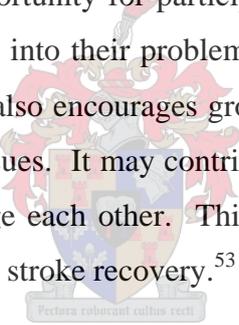
Communication groups provide a context for people with similar problems, conditions or concerns to give and receive support,⁵⁴ and provide an opportunity for mutual sharing.⁵³ This type of group can include, for example, gender-specific support groups, art groups and social skills training.

Social support, which is based on interaction with others, is an important need for stroke survivors, shown to be inadequately met by existing researched rehabilitative programmes.⁵¹ Inadequate social support is as much of a health risk as many common lifestyle factors (such as smoking, obesity and lack of physical activity).⁶⁶ As inadequate social support increases the risk of subsequent stroke in stroke survivors, it should be addressed.

Communication groups would seem suited to promote the curative factors of group cohesiveness and interpersonal learning, as discussed in 2.3.2.

2.4.3.4 Psychosocial groups

Psychosocial groups provide the opportunity for participants to express and explore their feelings, and assist them in developing insight into their problems.⁵³ This style of group provides a setting for catharsis, mentioned in 2.3.2. It also encourages group cohesiveness and gives the opportunity for members to explore existential issues. It may contribute to the instillation of hope, as members share their experiences and encourage each other. This is promoted by universality, as members share common experiences relating to stroke recovery.⁵³

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2.4.4 Characteristics of therapeutic groups

2.4.4.1 Size

There is no ideal size for a therapeutic group,⁵² given that groups vary so widely in function. Group size will depend largely on the availability of leaders, space and resources, as well as the aims of the group.⁶⁷ It is suggested, however, that closed, therapeutic groups function best with seven or eight members, with an acceptable membership range of five to ten.⁵⁴ Groups, with participant numbers between two and twenty, were found to be effective in diabetes education by Rickheim, *et al.*⁶⁵

The advantages and disadvantages of large and small groups, according to Finlay,⁵³ are outlined in table 2.1, as follows:

Table 2.1 - Advantages and disadvantages of smaller versus larger groups⁵³

	<i>Advantages</i>	<i>Disadvantages</i>
<i>The smaller the group</i>	<ul style="list-style-type: none"> ⊕ Easier for members to contribute ⊕ Greater intimacy and depth ⊕ Safer, less threatening and more predictable 	<ul style="list-style-type: none"> ⊕ Groups can become too 'stuck', norms and roles too established ⊕ Pressure on members who wish to be more passive ⊕ Less resources and energies to draw
<i>The larger the group</i>	<ul style="list-style-type: none"> ⊕ More energy, resources and creativity to draw on ⊕ Diversity of people and experiences ⊕ May be efficient use of time 	<ul style="list-style-type: none"> ⊕ Less freedom for expression ⊕ More member under-involvement ⊕ Higher numbers can be anxiety provoking and intimidating ⊕ Greater danger of cliques forming

2.4.4.2 Member selection

A guideline for selection of group members leans towards homogeneity, as members have more opportunities for solving common problems, and higher likelihood of cohesiveness.⁵³ It is also important to consider whether membership should be open or closed. The advantages and disadvantages of open and closed groups, according to Finlay,⁵³ are stated in table 2.2 as follows:

TABLE 2.2 - Advantages and disadvantages of open and closed groups⁵³

	<i>Advantages</i>	<i>Disadvantages</i>
<i>Open group</i>	<ul style="list-style-type: none"> ⊕ More practical for certain settings ⊕ Greater variety of resources available with new members providing stimulation ⊕ Group can operate with fluctuating attendance ⊕ Opportunity to work on issues of change and adaptability 	<ul style="list-style-type: none"> ⊕ Unpredictable membership makes it hard to plan and to target treatment specifically for individuals in advance ⊕ Relationships more superficial with less group cohesion and trust, less intimacy, disclosure ⊕ Sub-groups/cliques can form making it difficult for new member to be accepted
<i>Closed group</i>	<ul style="list-style-type: none"> ⊕ Group can be specifically planned and targeted ⊕ Deeper relationships occur with greater cohesion and trust ⊕ Depth of content and level of disclosure increased ⊕ More consistent and predictable 	<ul style="list-style-type: none"> ⊕ Tendency for group to get 'stuck' with members operating in set roles ⊕ May not be feasible in certain settings ⊕ Group dependent on members commitment - may have to fold if several drop out ⊕ Less opportunity to deal with change and adapting to others

2.4.4.3 Timing

Several time factors are relevant in presenting a group.⁵³

⊕ **Day and time of group**

The natural rhythms of the members, other activities they are involved in and the availability of resources for group presenters should be borne in mind when deciding on a day and time for group presentation.

⊕ **Session length**

Attention span and physical endurance must be considered when determining session length. Yalom⁵⁴ suggests one to two hours for therapeutic groups. Finlay⁵³ suggests thirty minutes to all day for activity groups, dependant on the task at hand. The most important factor related to session length appears to be consistency, and that a limit is set so that members can pace themselves and have security in knowing expectations.

⊕ **Frequency**

Frequency of groups is influenced by the type of group as well as members needs. Finlay⁵³ reports on Whittaker's (1985) recommendation that intensity, importance and continuity should be balanced. Intensity of experience will be increased with increased group frequency. Importance should not be over-emphasised as this fosters dependence. Continuity refers to the ease with which members move from one session to the next. More frequent sessions usually mean improved continuity.

2.4.5 Barriers to therapeutic groups

Despite the advantages of group work, there is literature to support that it is not suitable for everyone. The following are contra-indications for group inclusion:⁶⁷

2.4.5.1 Practical barriers

Practical barriers may include inadequate transport, lack of caregiver, and time constraints associated with decreased ability to prepare one's self for attending the group.⁶⁷

2.4.5.2 Certain personality attributes

Personality attributes unsuitable for a group include those causing the individual to contribute negatively to the development of other members of the group, or where the individual continues to model negative behaviour which influences the group. This contra-indication may also include individuals whose personalities lend them towards isolation by choice. Personal preference must be respected.⁶⁷

2.4.5.3 Particular therapeutic needs

Certain therapeutic needs must be addressed on an individual basis, for example, toileting or sitting endurance, before the individual would be able to cope with a group programme. Some individuals may never therapeutically achieve the level which allows them active or passive group involvement.⁶⁷

The Queensland government⁶⁸ identifies other factors that may prevent individuals from participating in a group situation as part of their guidelines for best practice. These are: times of the programmes, time to attend rehabilitation programmes, access and the availability of transport, financial constraints, and the number of health professionals available. They further identify factors which may impact on the individual's ability to fully benefit from their participation. These are listed as: cultural issues, co-morbidities which influence recovery/rehabilitation, work issues, language and literacy/communication barriers, physical/behavioural issues, psychosocial issues, discomfort disclosing problems in a group environment, major barriers to change, and lack of personal motivation.

2.4.6 Therapeutic groups in physical rehabilitation

There is significant literature supporting the use of therapeutic groups to achieve psychosocial aims of rehabilitation, as mentioned above. There is, however, very little evidence available for the suitability of therapeutic groups in physical rehabilitation.

The focus of Yalom's⁵⁴ model on therapeutic principles such as installation of hope, universality and mutual support resulted in this model gaining attention within the field of medical rehabilitation.⁶⁹ A meta-analysis found that interventions in these categories resulted in reduced morbidity, mortality and psychological distress in patients embarking on cardiovascular rehabilitation programmes.⁶⁹ Research also suggests that psychological intervention offered in groups may also influence compliance to treatment programmes.⁶⁹

A study by Kääpä *et al.*⁷⁰ showed that there was no significant difference between multi-disciplinary group intervention and individual physiotherapy intervention on the intensity of pain, disability, subjective working ability, sick leave taken, health care consumption, and symptoms of depression amongst subjects with lower back pain. Although this does not advocate for group work over individual rehabilitation, it does show that, in this instance, individual therapy and group therapy are comparable, with regards to outcomes, in terms of physical rehabilitation. It is interesting to note that, in the above mentioned study,⁷⁰ there was a greater improvement in general

well-being in those subjects participating in the group programme than for those participating in the individual programme.

Group work can be a tool of empowerment, if people with disabilities are involved in the process, rather than the end product being 'administered'.⁵⁴ Empowerment is a term strongly associated with rehabilitation, if we consider the end-point thereof to be a total withdrawal of support. Rehabilitation essentially seeks to assist individuals to empower themselves in all aspects of their daily life.²⁵ If group work contributes to this, it would play a role in the process of rehabilitation.

Whilst the positive effects of group work are obvious, there is a lack of literature detailing models of interdisciplinary group work in rehabilitation. Until this point, the literature has provided information pertaining to the context of rehabilitation, and more particularly, the use of therapeutic groups in rehabilitation. Focus will now be turned towards stroke rehabilitation, and the potential for therapeutic groups in this arena.

2.4.7 Therapeutic groups in stroke rehabilitation

There is a paucity of literature regarding the use of therapeutic groups in stroke rehabilitation. However, one study was found documented, which focused on the exercise component of group rehabilitation for stroke survivors. This study, by Eng, *et al.*,⁷¹ found that an eight-week, community-based exercise group programme for stroke survivors was effective in improving strength, endurance and balance of the participants, as well as their satisfaction with their physical and social performance. This study also found that adherence to the programme was improved through group cohesion.

The study used a repeated measures design to evaluate the physical outcome of 25 subjects with two baseline assessments, one post-intervention assessment, and one retention assessment by means of the Berg Balance Test, 12-Minute Walk Test distance, gait speed, and stair climbing speed.

The programme did not specifically include any psychosocial aspects of rehabilitation, but the study did attempt to measure the effects of the programme on psychosocial recovery by means of the Reintegration to Normal Living Index and Canadian Occupational Performance Measure.

This group therapy programme of Eng, *et al.*⁷¹ is significantly different from the one outlined in the current study. The former was an eight-week programme, whereas the latter allows for involvement of participants for up to 18 months. The programme outlined by Eng *et al.*⁷¹ was run solely by physiotherapists, whereas the programme in this study follows an interdisciplinary approach. Furthermore, Eng *et al.*⁷¹ evaluated by quantitative means, whereas this study employs

qualitative and quantitative means of evaluation. There are also differences between the participants of the two studies. In the former study they had an average age of 63 years, compared to an average age of 59 years in the current study.

2.5 Measuring instruments

The purpose of this study was to measure the meaning that group participation had to clients, which is subjective by nature. However, two objective measurement tools are mentioned in this study, and will be discussed here to ensure clarity of their purpose in the study.

Due to the complex nature of the lasting effects of stroke, basic classifications of functioning, such as the Barthel ADL Index (the objective measurement tool that is currently in use at the BLRC), have been found to underestimate the consequences of this condition.⁷² The BI was therefore not used as a measuring instrument in this study, except that the BI scores, as documented during the initial assessments of patients at the BLRC, was used to give an indication of severity of stroke, and to determine whether that had any impact on group attendance. Lai *et al.*⁷³ found that stroke patients, deemed recovered according to BI scores, had residual limitations of hand function, overall physical functioning, community participation and independence in activities of daily living (ADL). They found the Stroke Impact Scale (SIS), to be more effective in highlighting residual problems. Another study found this particularly true of the important area of social participation.⁷⁴ The SIS is also the only stroke outcome measure that assesses hand function.⁷⁴

The SIS is a nominal scale of eight domains, which subjectively measures strength, hand function, ADL, independent ADL, mobility, communication, emotion, memory and thinking.⁷⁴ In the current research project, the SISv3 is not used as a measurement tool to determine recovery, but as part of the questionnaire, to encourage discussion from the participants around their perceptions regarding their functioning in these different areas. Even so, scores are included with the demographic data to provide the reader with a view of the extent of disability that participants in the study experience.

2.6 Summary of Chapter 2

Rehabilitation includes interventions aiming to reduce physical disability as well as interventions aiming to reduce psychological and social problems. It involves several role players, often within a team setting. These include the patient, health professionals, family, community and the account payer.

Although there are several established settings and approaches to rehabilitation, out-patient CBR is gaining increasing status in South Africa, with its limited resources and relatively high prevalence of disability. There is a need to develop rehabilitation interventions at this PHC level, including primary, secondary and tertiary disability prevention strategies.

Stroke was explored as a condition requiring extensive rehabilitation. The literature revealed it to be a commonly occurring and highly debilitating condition both worldwide and in South Africa. There are several traditional approaches to stroke rehabilitation – none of which has been revealed to be more effective than the others. Stroke rehabilitation, as documented, has tended to be on an individual basis and has in general been shown to have a positive effect on stroke survivors. But, research has shown that stroke survivors often feel ill equipped to return to community living, mostly as a result of poor social support.

Therapeutic groups were investigated in the literature as a potential means of supplementing individual stroke rehabilitation. Yalom's⁵⁴ curative factors of the instillation of hope, universality, cohesiveness, existential factors, recapitulation of the family group, catharsis, imitative behaviour, interpersonal learning, altruism and imparting information were discussed, as well as the relevance of these factors to stroke rehabilitation.

Although the essential role of rehabilitation is acknowledged, and support of its development encouraged in literature, there is a lack of literature proposing models of stroke rehabilitation, and in particular, the use of interdisciplinary group work as part of the process.

Only one study was found exploring the effectiveness of therapeutic groups in stroke rehabilitation. There is therefore a definite need for further research in this area.

Chapter 3

METHODOLOGY

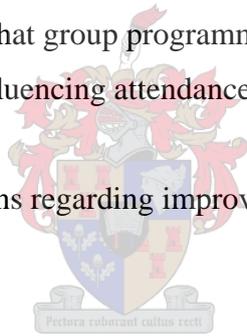
3.1 Study aim

The aim of this study was to describe the range of experiences relating to group attendance or non-attendance of stroke survivors referred to the stroke group programme of the BLRC. This was with a view to identifying ways of improving this programme.

3.2 Study objectives

The objectives are:

- (a) To describe the demographic profile of the study population.
- (b) To explore the meaning that group programme involvement has to participants.
- (c) To investigate factors influencing attendance or non-attendance of the BLRC stroke group.
- (d) To make recommendations regarding improvement of the programme.



3.3 Study design

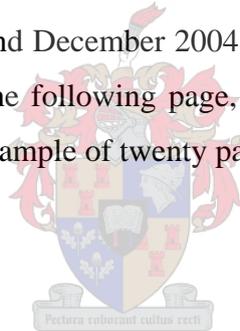
This study was descriptive – utilising qualitative and quantitative methods of data collection. A mixed method was selected for this study for the sake of complementarity. Quantitative data can be used to enhance qualitative data by broadening the reader's understanding of the population and, thereby, allows for comparison or transferability.⁷⁵ This type of design "enhances the research purposes of corroborating, elaborating, developing, and initiating understandings of social phenomena."⁷⁶ This design was applicable to this study, because the researcher aimed to gain an understanding of a phenomenon (the experiences of stroke group participants), and at the same time gain a better understanding of the demographics of the participants being studied. This would assist with the interpretation of the results obtained in the study, and increase the extent to which results could be used for elaboration and comparison in further study. The first phase of the study utilised an administered questionnaire, comprising a range of structured, semi-structured and unstructured questions, which yielded both quantitative and qualitative data. The second phase of the study had a qualitative focus, making use of a focus group discussion to gather in-depth information about the participants' experience of the stroke group.

3.4 Study setting

As discussed in Chapter 1, Bishop Lavis is home to a low socio-economic, predominantly ‘coloured’, Afrikaans-speaking community. The community has fairly low educational levels and high rates of unemployment. Within this community, the BLRC operates to offer a range of out-patient physiotherapy, occupational therapy, as well as speech and language therapy services to clients with physical and psychosocial impairments and disabilities. It is the stroke group, meeting weekly at this centre, which is the focus of this study. Participants of the stroke group are medically stable clients that have suffered a stroke, or another neurological condition - with similar symptoms to those of a stroke. They must have the cognitive ability to integrate new information, as well as the physical ability to sit for an hour at a time – irrespective of the length of time post-stroke. Stroke group attendance is voluntary. The broad aims of the stroke group are to maintain physical abilities, provide socio-emotional support and promote client autonomy.

3.5 Study population and sampling

The population for this study consisted of individuals referred to the BLRC stroke group programme between January 2003 and December 2004. Data was collected between January 2006 and August 2006. Figure 3.1, on the following page, provides a schematic representation of the population and shows how the final sample of twenty participants was determined.



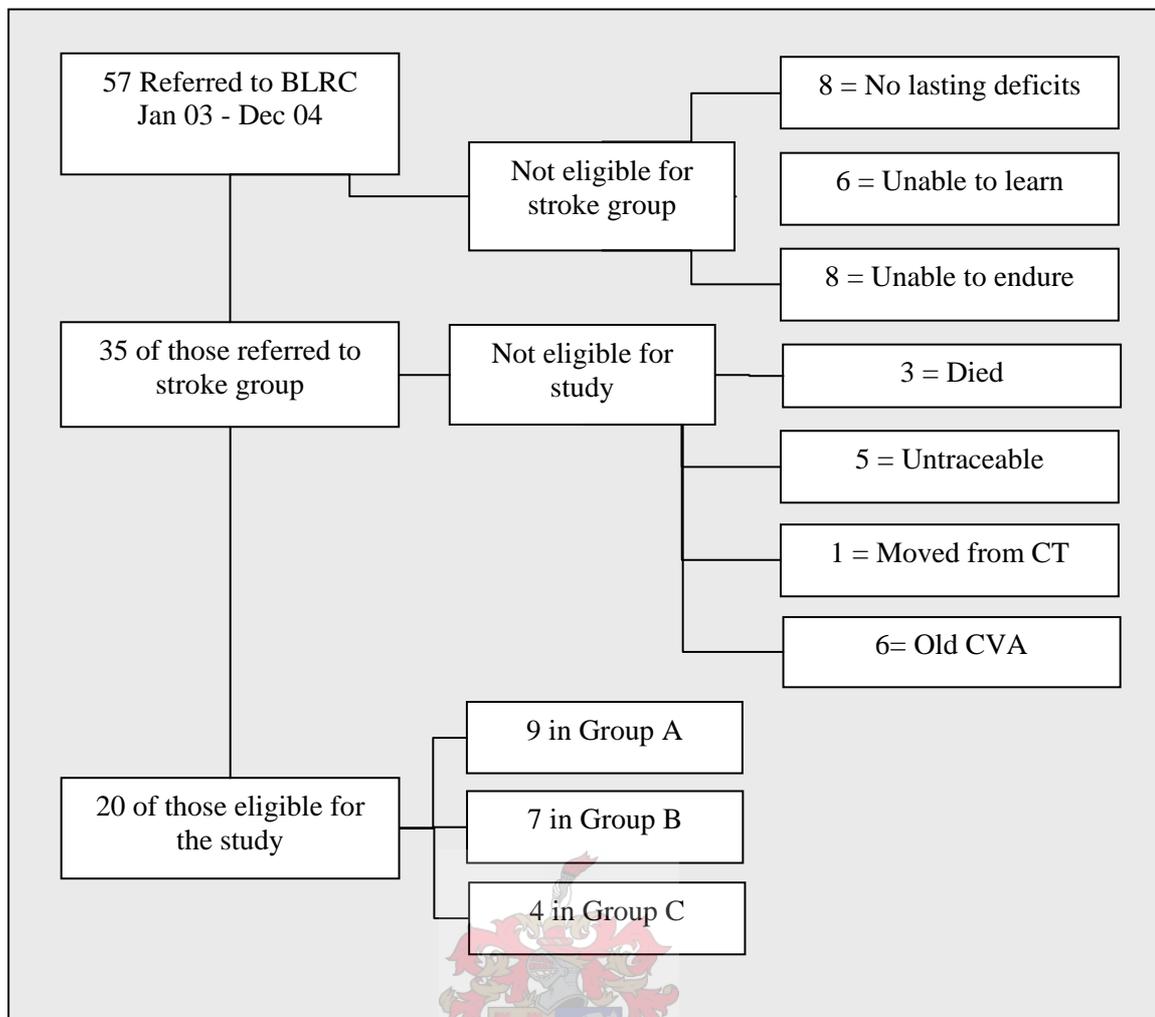


Figure 3.1 – Study population

Of the 57 clients referred to BLRC with stroke during January 2003 and December 2004, 35 were referred to the stroke group and thus were eligible for the study. Of these, 15 did not meet the inclusion criteria for the study. The remaining twenty participants were all included in the study and subdivided into the three different groups according to their attendance (refer to 3.5.3 on the following page).

3.5.1 Inclusion criteria

- ⊕ Persons who met the inclusion criteria for the stroke group programme.
- ⊕ Persons aged eighteen years or older, in order to have simplified issues of consent.
- ⊕ Persons referred to the BLRC stroke group from January 2003 up to, and including, December 2004, as this time frame would end 6 months before data collection was scheduled to begin – thus having allowed participants ample time to experience the stroke group programme. This time frame also excluded those who had been part of the stroke group prior to January 2003, which was approximately when the stroke group changed to its existing format.

- ⊕ Persons who sustained a first stroke less than 6 months prior to referral to the BLRC for rehabilitation, as during this rehabilitative phase of recovery, one would have expected to note a good rate of recovery.⁶⁰
- ⊕ Persons who were residing in the Cape Metropole at the time of data collection, in order to keep costs manageable.
- ⊕ Persons who were alive at the time of the study.

3.5.2 Exclusion criteria

- ⊕ Persons aged less than 18 years, due to issues of consent.
- ⊕ Persons referred to BLRC stroke group prior to January 2003 or after December 2004.
- ⊕ Persons who sustained a first stroke more than six months prior to referral to the BLRC, placing them in the later stages of rehabilitation by the time they join the group programme.
- ⊕ Persons who were referred to the stroke group who suffered a neurological condition with symptoms similar to those of a stroke, but did not suffer a stroke.
- ⊕ Persons who resided outside of the Cape Metropole at the time of data collection.
- ⊕ Persons who were deceased at the time of the study.

3.5.3 Allocation to study groups

The population was sub-divided into three smaller groups according to their rate and frequency of group attendance. This was done in order to allow any factors or experiences that may potentially influence attendance or non-attendance of the group to be revealed. By analysing demographic data from these sub-groups independently, it would also be possible to observe any potential differences between higher and lower attending groups.

The BLRC stroke group attendance register was used to calculate the rate and length of group attendance for all participants. Attendance rate was calculated by dividing the number of sessions attended since the client was referred to the group by the total number of sessions that were available for attendance over the period of time the participant came, which was converted to a percentage form. Duration was also taken into account, as certain participants had attended less than 4 sessions before self-discharging from the programme. Although their attendances had been consecutive, and therefore their rate of attendance was high enough for them to be admitted into the high attendance group, the short period of attendance made it impossible for them to have experienced the entire spectrum of the group programme. Therefore, both attendance rate and length of group attendance were taken into account when allocating participants to specific groups. The duration of attendance was calculated by subtracting the date the participant first attended from

the date they last attended, expressed in months. Participants were divided into Groups A to C according to the frequency and duration of their group attendance:

⊕ **Group A – Poor attendance**

These were participants that were invited to the group but had attended for less than 3 months or not at all, or who had an attendance rate of 29 % or less.

⊕ **Group B – Average attendance**

Group B comprised participants with an attendance of 30 - 59 % over a period of three to five months.

⊕ **Group C – Good attendance**

Group C comprised participants who had attended the group for a period of 6 months or longer, with an attendance rate in excess of 60 %.

3.6 Instrument design

No literature was found detailing a questionnaire designed to assess the experiences of group participants on a physical and psychosocial level in a setting of this nature. A questionnaire was thus developed as the main instrument of data collection (Appendix III). As discussed under 2.5, the SIS v3 was used as part of the questionnaire to encourage discussion around stroke recovery. The questionnaire was developed in Afrikaans, as this is the dominant language of the Bishop Lavis community. The community uses a specific dialect of Afrikaans, common to the so-called “Cape Coloured” people. Language use in the questionnaire was, therefore, made to be more appropriate to the general frame of reference of the population than true to grammatical detail. The questionnaire was reviewed by an experienced researcher and a statistician prior to its implementation. The format of the questionnaire was as follows:

3.6.1 Section A

This section was answered by all participants and yielded quantitative data for the realisation of objective (a). It comprised structured questions with predetermined response categories, aiming to gather demographic information from participants. This included background information, such as availability of transportation and caregivers, time taken to prepare for group attendance and access the BLRC, as well as costs involved and household income.

3.6.2 Section B

Section B was only administered to participants in Group A (the poor attendance group), aiming to gather information relating to objectives (c), and (d). This section comprised semi-structured and open questions with no predetermined response categories, providing both qualitative and quantitative data. It asked questions around why participants had not been attending the group –

first in an open question, and then in questions relating to categories covered in Section A and questions relating to the content of the group. Participants' were asked what they had and had not enjoyed about group sessions, if they had attended one or more. Finally, they were asked for suggestions to improve the group programme.

3.6.3 Section C

Section C was also devised to provide information towards the realisation of objectives (b), (c) and (d), but was used only with participants in groups B and C (the average and good attendance groups). The questions were different from those in section B so that the differences in attendance of the groups could be taken into account. These questions were also semi-structured and open, with no predetermined response categories, yielding qualitative and quantitative data. They were asked if any of the demographic factors in Section A had influenced their attendance, why they had attended as well as they had, and what they enjoyed or did not enjoy about the group. They were then asked if they had noted any improvement in their health or lifestyle as a result of their group involvement, and to elaborate on this topic. They were also asked to make suggestions regarding the improvement of the programme.

3.6.4 Section D

Section D was completed by all participants. It consisted of the Stroke Impact Scale (version 3) (SIS v3), which is a nominal scale providing a subjective rating of participants' physical functioning, mobility, memory and thinking, emotion, communication, hand function, personal care and other ADL (including roles and life tasks),⁷³ as discussed in 2.5. This provided quantitative data. The average scores were included in the demographic profile of the participants - Objective (a). The rationale for its inclusion in this study is that the subject population is not accustomed to providing qualitative data relating to health care because of the medical model within which they have traditionally been treated. It was hoped that the questions in the SIS v3 might assist participants in broadening their thinking around the topic of stroke recovery, and thus provide further information towards realising Objective (b). By drawing their attention to areas of recovery shown to be significant in other studies, the participants could be encouraged to explore areas of stroke recovery that they might otherwise have overlooked. This particular scale was selected as it has been found to be effective in highlighting residual problems for stroke survivors.⁷³ The SIS v3 was translated into Afrikaans by the researcher. This translation was verified by colleagues with experience in the field of stroke rehabilitation, who are first-language Afrikaans-speakers. The comprehensibility of questions was checked during the initial stages of the piloting process.

3.6.5 Section E

This section comprised unstructured questions relating to each of the nine sub-categories of the SIS v3 in order to gather qualitative information relating to these topics, and was completed by all participants. Here, participants had the opportunity to respond in more detail relating to their responses to the closed questions in Section D. Data yielded in this section contributed to realising objectives (b) to (d). They were asked, in each category in turn, whether they thought the stroke group had had an impact on their recovery in that category. If they did, they were asked to describe how. (For example, “Do you feel that your ability to move in your home and community was affected by your group attendance? How was it affected?”) They were then asked whether they felt the category of recovery had had an effect on their attendance or not. (For example, “Did your ability to move in your home and community influence your group attendance? How did it affect it?”) A final question in Section E asked what difference participants felt that stroke group attendance had made to their lives.

3.7 Piloting process

The questionnaire was piloted in two phases. Firstly, an open discussion was held with four clients of the BLRC who had sustained strokes and did not form part of the study population. Their input regarding the appropriateness of terminology and comprehensibility of the questions was requested. These clients provided verbal feedback on each question of each section, which was used to refine the questionnaire. Refinement involved substitution of several synonyms in order to make the language use in the translation of the SIS v3 appropriate to the study population.

The questionnaire was then piloted by its administration to six people currently attending the BLRC stroke group programme, who had been excluded from the study population as they had been referred to the group after December 2004. Pilot participants were asked to give feedback regarding the appropriateness and clarity of the questions in an unstructured way. They were asked to indicate any unclear questions during the administration. From this, it was established that the translation of the SIS v3 into a local dialect of Afrikaans was clear and understandable, with the exception of a few questions (1a-d and 6g), which were amended. These were all related to translation issues, where the local dialect differs from grammatical tradition (‘stroke’ was substituted for *‘beroerte’*, and ‘lot trappe’ substituted for ‘stel trappe’). Also, it was determined that questions in the SIS v3 fell within the frame of reference of this population group, with the exception of questions 4f and 4g relating to telephone use, and question 5a relating to the use of a knife and fork for eating. Some participants might not have access to a telephone, and some of the participants might be following Islam and use their hands, rather than utensils, for eating. It was

decided to keep these questions for use where applicable, with note that these questions would not yield complete data from the sample.

3.8 Data collection

Preliminary demographic data was gathered about each participant from their rehabilitation file at the BLRC between January and March 2006. This included their date of birth, date of first cerebrovascular accident (CVA), initial BI score, the hemisphere affected, gender and physical address.

The stroke group attendance register was used to determine the dates that participants were first referred to the group and when last they had attended the group. Data collected in this manner was used to establish participants' eligibility for inclusion in the study, and to provide demographic information for use in realising objective (a).

The questionnaire was administered individually to each of the participants by the researcher between June and August 2006. Data collection occurred later than initially anticipated due to service delivery factors associated with the BLRC. As the later date for data collection did not affect any of the inclusion or exclusion criteria of participants of the study, the originally selected participants were maintained as the study sample. Administration was selected over self-completion to overcome possible problems related to low literacy levels (refer to 1.4) of the study population and possible impairments associated with stroke that may have influenced reading and writing (for example, perceptual deficits and hand function limitation). The questionnaire was administered in Afrikaans to all but one of the participants, who had Xhosa as a first language. This participant was in command of both English and Afrikaans, and did not require translation services as he chose to complete the questionnaire in English. Some of the participants used English and Afrikaans interchangeably during their responses.

The researcher was known to all participants in a professional capacity prior to the study as the occupational therapist currently employed at the BLRC. She was also one of the group programme presenters. This could be seen as a disadvantage in many senses – such as potential bias that participants may have wished to please the researcher by giving favourable reports of their experiences.⁷⁷ Researcher bias also becomes more difficult to avoid. In this instance, however, the advantages appeared to outweigh the disadvantages. The researcher had already established a trust relationship with each participant, in which honest interaction had been encouraged. The researcher was familiar with participants' levels of impairment. She was, therefore, able to tailor open questions and feedback to each participant's level of ability. The researcher also had a thorough

knowledge of the cultural and social setting of the study, which allowed her to use relevant questions to probe, interpret, and ask for expansion on topics and descriptions which may not have been as obvious to an uninvolved examiner. The questionnaire administration further provided a useful opportunity for the researcher to monitor the progress being made by clients no longer associated with the BLRC, and to extend an invitation for appropriate assistance, in line with practice-based research. To reduce researcher bias, participants were expressly given permission to give their honest opinion without fear of judgement or repercussion, and they were not corrected if they said things that the interviewer believed to be wrong.⁷⁷

Questionnaire administration lasted an average of 30 – 45 minutes per participant and, where possible, was done in the presence of a primary caregiver in order to verify information and to gain additional information regarding the impact of the stroke group programme. This was particularly vital in the case of participants with obvious communication or cognitive deficits. Thirteen of the questionnaires were administered at the participants' homes, and seven at the BLRC. Those administered at the BLRC were done so on a day that the participant in question was to attend the BLRC, and thus resulted in no additional cost to the participant. Interviews were by appointment, which were made in advance telephonically.

The primary method of data recording for open questions was tape recording. Full transcripts of the recordings were made for analysis. Note taking, capturing the main concept of responses, was employed as a secondary method. This was a fail-safe to be utilised in the case of technical failure. In the instance of this study, however, all open questions were successfully recorded and could be transcribed. Non-verbal elements such as hesitation, pauses and crying were included in the transcripts. The transcripts were not corrected for grammar, nor word choices amended, for sake of preserving the full meaning and feeling of the responses. Transcripts were not translated before analysis.

3.9 Data analysis

3.9.1 Quantitative data

Quantitative data gathered from the participants' BLRC files and Sections A and D of the questionnaire were entered into a Microsoft Excel spreadsheet, where they were analysed with the assistance of a statistician utilising the computer program, Statistica. Tests used to determine whether there were significant differences between subgroups with regards to any of the quantitatively measured phenomenon were the Chi-squared test, ANOVA and Kruskal-Wallis tests (when the data was not normally distributed). A p-value of > 0.05 was seen as statistically significant in all tests. (Refer to Chapter 4 for specific tests used to obtain specific results.)

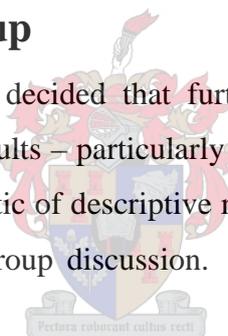
3.9.2 Qualitative data

Qualitative data gathered in Sections B, C and E of the questionnaire were analysed by means of thematic analysis.⁷⁷ An inductive approach was followed, meaning that themes were allowed to emerge from the data, rather than pre-determined categories being used.⁷⁷ The researcher has command of both the Afrikaans and English languages and was, therefore, able to analyse the data in its original language. Data was transcribed from the tapes by the researcher, which involved listening to the tapes whilst typing and reading the transcripts numerous times, to check for accuracy. Accuracy was further verified by research assistants listening to the tapes whilst reading the transcripts. The researcher then read the transcripts several times before beginning analysis.

Raw data was arranged into basic categories with the assistance of a word processor. These categories were identified as the categorisation occurred, with themes emerging being allowed to shape and define the categories.⁷⁷ The categories formed at this stage of analysis provided a framework in which to group the phenomena, and were later refined and integrated.

3.10 Phase II – Focus group

By this stage of the study, it was decided that further methods of data collection should be employed in order to enhance the results – particularly around the meaning that group participation had to participants. As is characteristic of descriptive research, further in depth data collection was conducted in the form of a focus group discussion. This second phase of data collection and analysis is outlined below.



3.10.1 Sampling

In order to ensure a variety of experiences,⁷⁸ participants for the focus group were selected through the entire range of study participants, from those who attended poorly to those who attended well. Two participants from each of groups A - C were selected for participation in the focus group. Two participants were randomly drawn from each of Groups A – C. This was done so that the researcher could not contribute bias to the study by selecting participants who had particular views of the group, and so that each of the subgroups could be represented in the focus group. They were contacted and asked to participate in the focus group discussion. All six participants consented to participation; however, one participant in Group A was unable to attend on the day due to illness. The focus group ultimately consisted of six people, as it included the primary caregiver of one of the participants. The caregiver had been present with her husband during each of his group attendances, as his cognitive impairment as a result of the stroke affected his memory. She was included in the focus group due to her experience of the group in question, as well as her ability to provide details of her husband's experiences that he may have forgotten.

3.10.2 Data collection

The focus group was held at the BLRC on 20 September 2006. As suggested by literature,⁷⁸ it was held in a room generally used by the stroke group, and at the time that the group was usually held. Warm drinks and snacks were served to create a relaxed atmosphere, and participants were reimbursed for any travel expenses.

An interview schedule (Appendix IV) was used to guide the focus group discussion. Questions were structured around the results emerging from the first phase of data collection. Several broad topics were identified for exploration during the discussion. These were: meaning, stroke recovery, group activities, issues of interaction, factors influencing attendance, and recommendations. Questions were developed around these themes, and possible prompting categories were noted. The interview schedule was very loosely structured in order to take full advantage of the peer interaction opportunity and not to stifle discussion that may have arisen.⁷⁸ The focus group discussion content was recorded and fully transcribed.

3.10.3 Data analysis

A content analysis was done on the transcript of the focus group. Data was coded into categories along the lines of themes identified during the preliminary data analysis process. This was done with the assistance of a computerised word processing programme, in which numerical codes were assigned to emerging categories. The numbered sections of text were then grouped together into themes, and further refined into sub-themes. Patterns were then sought that corroborated or deviated from the identified themes. Attention was also given to the dynamics of the focus group, specifically the nature of the interaction between the participants. This was done by including nonverbal elements of the focus group in the transcript, and including a description of the tone with which certain comments were made, as well as the response of other participants, in the discussion which follows in Chapter 4.

At this stage of the analysis the researcher noted several similarities between themes that had emerged and certain of the factors cited by Yalom as being characteristic of curative factors of groups. For the purposes of discussing the themes, those that emerged were compared to these factors described by Yalom. Not all of the themes that emerged were similar to those identified by Yalom, but all were included in the results as they were noteworthy findings of this study, and contribute to the description of the experiences of participants in this study.

3.11 Trustworthiness of qualitative data

Qualitative data should be tested for trustworthiness. That is to say: What is the truth value of the study? To what extent can the findings of this study be applied to other studies? Would the findings of the study be replicated should the study be repeated? Is the study free of excessive influences of bias? In order to deem a study trustworthy, credibility, dependability, confirmability and transferability must be established. Methods of establishing credibility are prolonged and varied field experience of the researcher, the keeping of a field journal, triangulation, member checking and peer examination. Methods of establishing dependability are a dependability audit, the dense description of research methods, step-wise replication and code-recode procedures.⁷⁹ Confirmability is ensured by use of a confirmability audit, reflexivity and triangulation. Transferability can be ensured by dense description and by comparing the sample to the greater population.⁷⁹

The researcher employed certain of these techniques - specifically: the detailed demographic description of the population and study setting to aid the reader in judging applicability to other populations, thus to ensure transferability, varied methods of data collection (questionnaire and focus group), peer examination, by means of a colleague checking the thematic analysis of data from transcripts, and meticulous record keeping forming an audit trail which could be followed by other researchers. In spite of this, more could have been done to ensure the trustworthiness of the study. This may have included member checking and reapplication of the code procedures. Due to manpower, time and resource restriction, this was not possible. This is a limitation of the study.

3.12 Reliability and validity of quantitative data

The self-developed part of the questionnaire was not tested for reliability or validity, which is another limitation of the study. The SISv3 was tested for both validity and reliability and was found both valid and reliable.⁷⁴ Reliability of the SIS v3 was determined by evaluating internal consistency with the Cronbach [alpha] for each domain scale. Criterion-validity was assessed by examining Spearman Rank correlation coefficients, and discriminant validity assessed by comparing mean scores for each domain to the previously proven valid) Rankin scale.

3.13 Ethical considerations

3.13.1 Protection of participants' interests

As the study was qualitative in nature, participants were not assigned to particular groups by the researcher. Each participant determined his intervention status by his own choice to attend or not attend the stroke group. As the researcher did not impose or withhold intervention, there was no question of this study jeopardising a participant's recovery.

3.13.2 Confidentiality

Participants were assigned a number as they were included in the study population. The number was used as reference from that point forward in all documentation, including questionnaires and data tables. Participants were informed of this prior to their consent to participate. Participants were informed that findings of the research may be published, but that confidentiality would be maintained. They were assured that information gleaned from this study would be used for the sole purposes of this research project, and would not be disclosed to third parties for other purposes. All tapes and transcripts were stored safely, where they could not be accessed by unauthorised persons. Computerised data, tapes and transcripts did not contain the names of participants – only their assigned participant codes.

3.13.3 Informed consent

Informed consent was considered to have been gained once a participant or their representative had understood and signed a copy of the document termed, 'Information and informed consent document' (Appendix V). Prospective participants were informed of the study aims and objectives, as well as the requirements of participation during the study. Participants were asked to read the consent form. If the participant was unable to read, the form was read to him/her, or translated from English to Afrikaans by the researcher as necessary. A translator would have been employed for translation to other languages should this have been necessary, but all participants were in command of either English or Afrikaans. The participant or his representative, the researcher and a witness signed the document to verify that the information had been correctly and completely conveyed. Participants were given the opportunity to ask questions relating to the study and their involvement. The researcher further clarified their understanding by asking them to recap the main points conveyed to them and summarise the expectation of their involvement in the study.

3.13.4 Approval

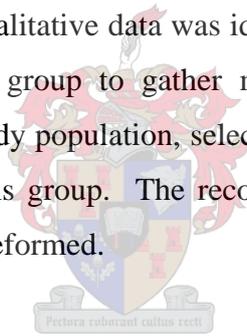
Approval for the study was gained from the Committee for Human Research, at the University of Stellenbosch, prior to commencement of data collection (Project number: N05/02/030).

3.14 Summary of Chapter 3

This is a descriptive study, employing qualitative and quantitative means. It was conducted with the study population of those invited to attend the stroke group programme at the BLRC between January 2003 and December 2004. All participants in the study population were used as the population size was small, with only twenty participants meeting the inclusion criteria.

The study was carried out in two phases. The first phase made use of a questionnaire, developed by the researcher, in the dominant language of the area. This was individually administered to each of the participants, after it had been piloted and refined. Where possible, questionnaires were administered in the presence of a primary caregiver. The questionnaire comprised a range of structured, semi-structured and unstructured questions aiming to gather information to realise each of the five stated study objectives. Responses to closed questions were entered into a Microsoft Excel spreadsheet and analysed with the assistance of a statistician. Open questions were fully transcribed and thematically analysed.

At this point, the need for further qualitative data was identified, leading to the second phase of the study. This consisted of a focus group to gather more in-depth information relating to the objectives. Five members of the study population, selected by stratified random sampling, and one primary caregiver participated in this group. The recorded content of the focus group was fully transcribed and a content analysis performed.



Data is presented in the following chapter as a narrative, using 'voice' to demonstrate themes. Where necessary, these direct quotes were translated into English, but were also presented in Afrikaans for the full benefit of readers in command of this language.

Chapter 4

RESULTS AND DISCUSSION

4.1 Introduction

Chapter 4 outlines the results obtained during this study, which are presented according to the study objectives. Firstly, the demographic details of study participants, as determined by the quantitative results, are presented. This is done in terms of general factors (gender, age and employment status), stroke related factors (laterality of stroke, Barthel Index score and SISv3 score) and according to factors which may have influenced their ability to attend the group (cost of transportation, presence of caregiver and time involved for physical preparation).

Secondly, the meaning that stroke group involvement had to participants is described in terms of the psychosocial effect it had, and then according to the impact that participants felt the group had had on their recovery from stroke. Psychosocial effects included the installation of hope, universality, imparting information, development of socialising techniques, imitative behaviour, cohesiveness, and self esteem. Recovery in stroke-related areas included improvement in ability to execute activities of daily living, strength, mobility, thoughts and memory, communication, mood and emotion, and hand function. Finally, the factors that participants reported to have affected their attendance are discussed, and their suggestions for improving the programme outlined.

Results are both quantitative and qualitative in nature, and are presented in an integrated fashion to answer the stated objectives. A discussion around each objective is also included. Part of the discussion includes narrative examples of statements relating to each topic. Quotations are in their original language and, where appropriate, are translated into English as well. The chapter concludes with other findings of interest from the study that were not previously identified as objectives.

4.2 Demographic profile of the study population

4.2.1 General

4.2.1.1 Gender

Of the twenty study participants, 15 were female. There was no statistical difference between gender distribution per group (Chi-Square test; $p = 0.43$). A complete breakdown of the gender of the participants according to study subgroups is shown in figure 4.1.

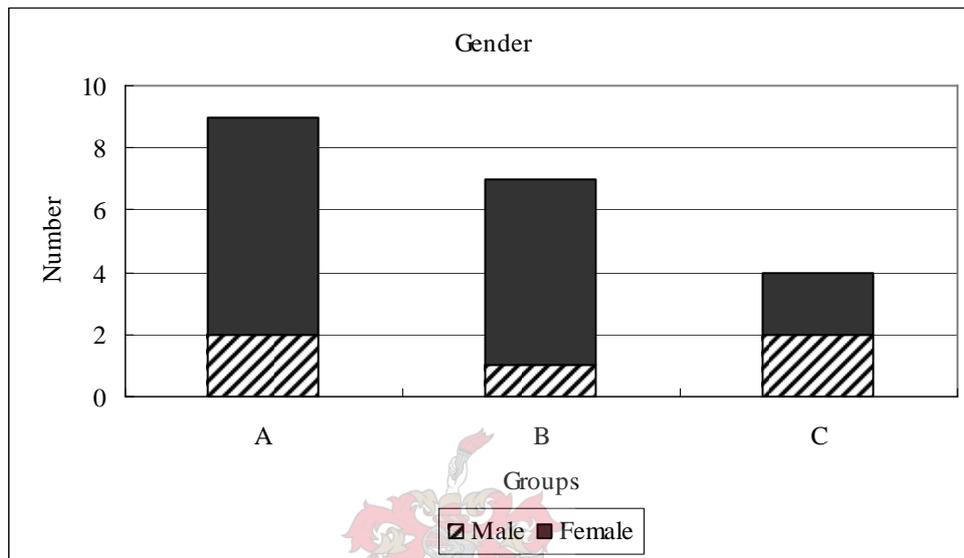


Figure 4.1 – Gender distribution

The higher number of females in the study population does not relate to the expected higher incidence of stroke amongst males, as highlighted in the literature review.¹⁹ It relates to a degree with the profile of stroke patients in this community sketched in 2003, which found 54 % of stroke patients to be female, compared to 46 % male.²⁰ The larger proportion of women could mean that males in this area who sustained strokes either had a higher rate of mortality, or did not meet the inclusion criteria of the stroke group as result of being either too severely or too mildly impaired.

4.2.1.2 Age distribution

Lack of significance in terms of age across the groups was proven by means of an ANOVA test ($p = 0.73$), and confirmed with a Kruskal-Wallis test ($p = 0.71$), as the residual values were not normally distributed. Figure 4.2 demonstrates that Group B had the widest range of ages of the study groups (ranges are depicted by the Y-bar line, with the bars depicting average age of each group).

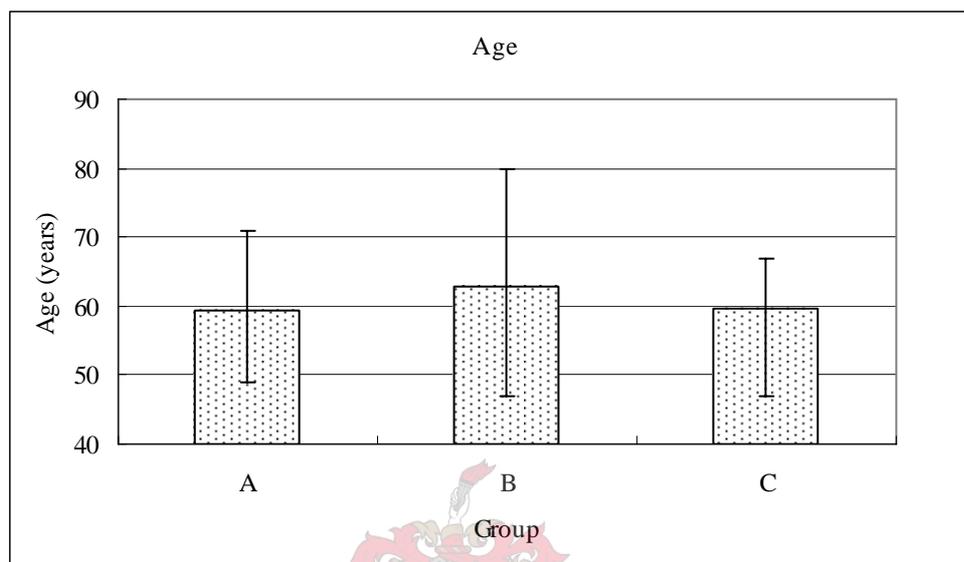


Figure 4.2 - Average age

The average age of participants was 59 years, which was similar across all groups. This was an interestingly low average age, given that risk of stroke doubles for each decade over fifty.⁴¹ However, findings were consistent with a study carried out in 2003, which found that fifty percent of the population of stroke survivors studied in the community of Bishop Lavis were younger than 60 years.²⁰ Findings also correspond to the relatively young age of the onset of stroke in sub-Saharan Africa.⁴²

The population of Bishop Lavis is fairly youthful, as mentioned in Chapter 1. This is the trend for sub-Saharan countries given the increasing rate of HIV/AIDS.⁴² This factor may also have an effect on the younger average age of stroke onset. Alternative possible explanations for the younger than expected average age of the population is the higher mortality rate of older persons sustaining stroke,⁴² along with the co-morbid conditions rendering older persons unsuitable for group inclusion (for example dementia).⁶⁷ The high rates of diseases of lifestyle recorded for the Western Cape (refer to 2.2.3) may also have resulted in more people sustaining strokes at a younger age.

4.2.1.3 *Employment status and household income*

None of the participants was formally employed, although one took care of a grandchild and another of an adult disabled daughter without remuneration. All but one was in receipt of a social grant in the form of an old age pension or disability grant. It was not possible to determine household income in absolute terms, therefore, this cannot be compared to the Household subsistence level (HSL) discussed in Chapter 1. However, the number of adults with income per number of adult household inhabitants was calculated as a guide. This ratio is reflected in Figure 4.3. This figure includes the participant as well as any other household members receiving a social grant. Groups were similar in this regard (Kruskal-Wallis test; $p = 0.38$).

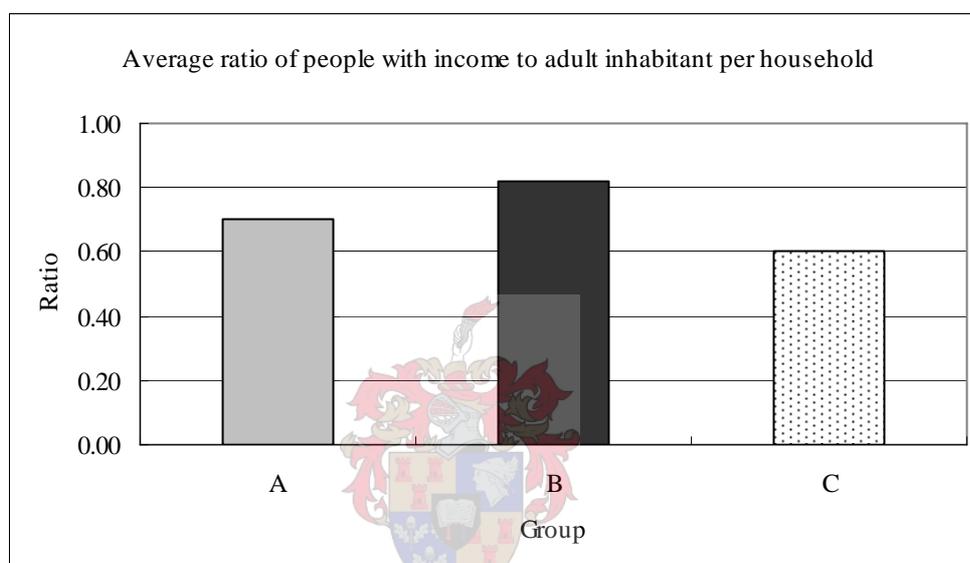


Figure 4.3 – Average ratio of people with income to adult inhabitant per group

4.2.1.4 *Ethnicity and language*

All but one of the study participants was ‘coloured’, which is reflective of the ethnicity of the vast majority (98 %) of the Bishop Lavis population (refer to 1.3). These participants all had Afrikaans as their first language, which is also reflective of the general population, of which 90 % are Afrikaans speaking (refer to 1.3). The remaining participant was a Xhosa-speaking, ‘black’ African – this being the second most common ethnic group of the community.

4.2.2 Stroke-related factors

4.2.2.1 Laterality

In total, nine study participants had sustained a left-sided CVA, and eleven a right-sided CVA (refer to Figure 4.4). This represents a fairly even distribution of laterality, which is expected in stroke survivors.²⁰

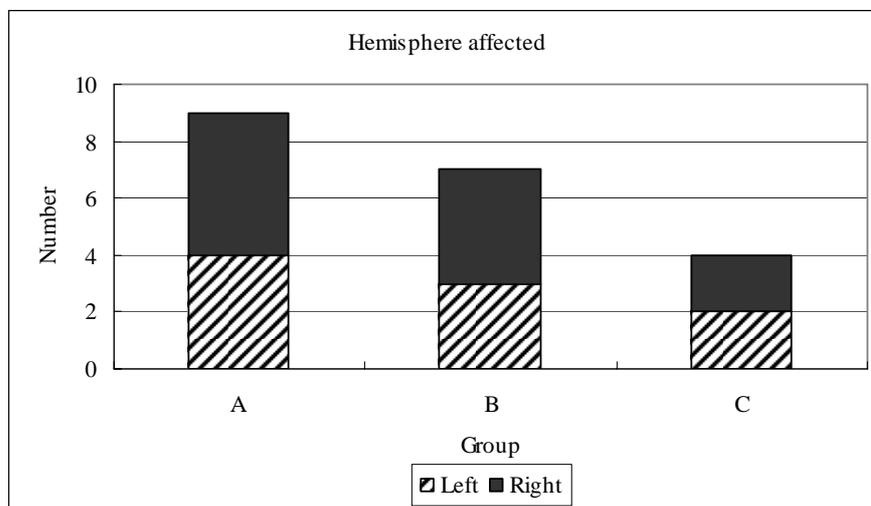


Figure 4.4 - Hemisphere affected

4.2.2.2 Barthel ADL Index score

The average BI score of participants at initial assessment upon admission to the BLRC was 13.5 out of a possible 20 (See Figure 4.5).

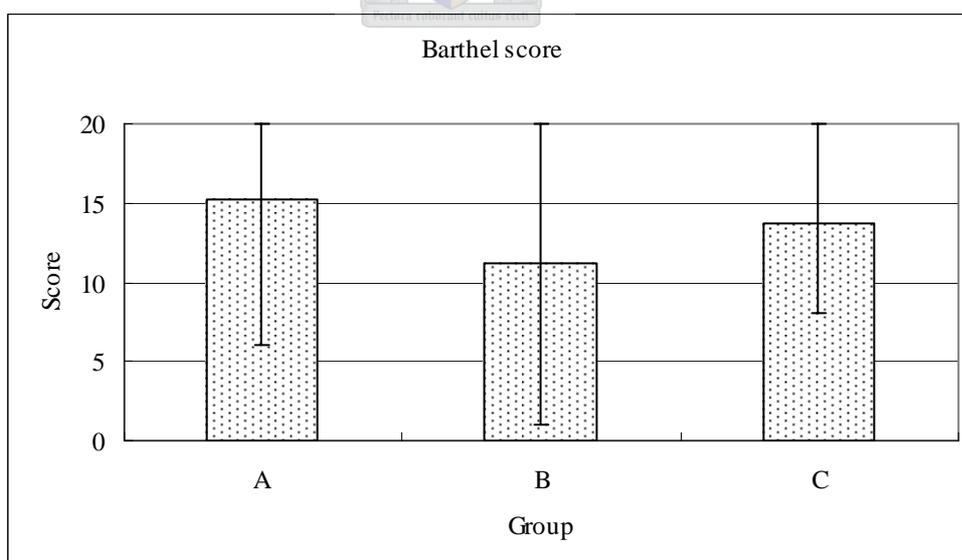


Figure 4.5 - Barthel ADL Index

This rating of ADL functioning provides an indication of the severity of functional impairment participants experienced at the outset of their rehabilitation. Note that this BI score was not intended to measure progress in this study, but only to give an indication of the severity of

functional limitation of each group in order to test a possible theory that the severity of stroke may distinguish one group from another in terms of their attendance. However, there was no statistical difference between the average BI score for each group (Kruskal-Wallis test; $p = 0.45$), although the low attendance group, Group A, had slightly higher scores than the higher attendance groups. The lack of significance disproves the possible theory that those with higher levels of functioning find less benefit from the group, and therefore have lower attendance rates. From this data, it appears that severity of stroke does not significantly affect attendance of the stroke rehabilitation group.

4.2.2.3 SIS v3 scores

Although the main purpose for the use of the SISv3 in this study was to enhance qualitative data as described under 3.6.4, an added advantage was that it also gave participants’ subjective ratings of their recovery from stroke at the time of the study. Figure 4.6, below, depicts these average scores, according to the eight different categories of the SIS v3.

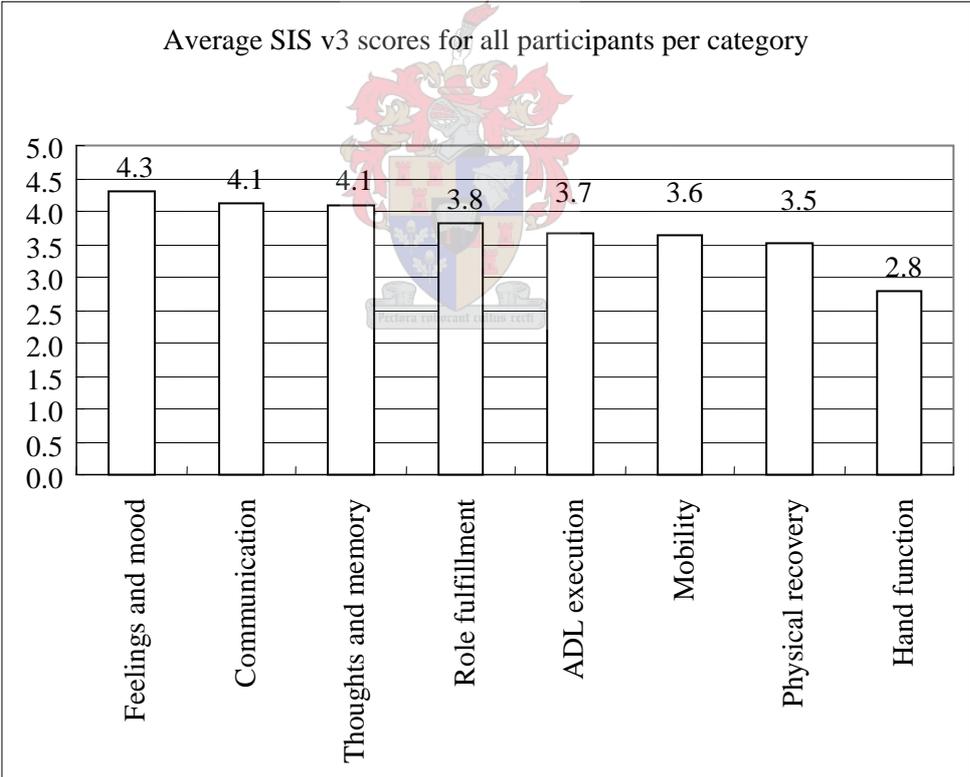


Figure 4.6 – SISv3 scores

Categories were scored between a low of 1, and a high of 5. Each category consisted of several questions that are scored separately (See appendix III, section D). Averages were obtained by adding the total scores for each participant in each category, and dividing these by the number of participants who had completed the category of questions.

Note that average scores have been used rather than total scores, as some questions were not applicable to certain of the subjects, so had to be excluded from the analysis. Also, there are no baseline scores available. Thus, the rate or amount of recovery cannot be determined. However, these scores provide information regarding residual impairments and areas of biggest residual loss at the time of the study.

Feeling and mood (question D3 in the questionnaire) showed the lowest level of subjective residual impairment, whilst hand function (D7) showed the highest level of subjective residual impairment. It is clear from the literature that hand function often recovers poorly after stroke.⁸⁰ It is of interest to note that other areas showing poorer subjective recovery rates are also related to the physical i.e. physical recovery (D1) and mobility (D6). One explanation for this finding might be that all these areas are equally affected by a stroke in the left or right hemisphere, while communication (D4) and thoughts and memory (D2) all high scorers as well as feelings and mood, the highest scorer are not equally affected by a stroke to either hemisphere.⁶⁰

4.2.3 Factors relating to stroke group attendance

4.2.3.1 Mode of transport

The most commonly used method of transport to access the BLRC was walking, which was expected as it is the most commonly used means of transport in the community (refer to 1.3). This was followed by attendant-propelled wheelchair use (refer to Figure 4.7).

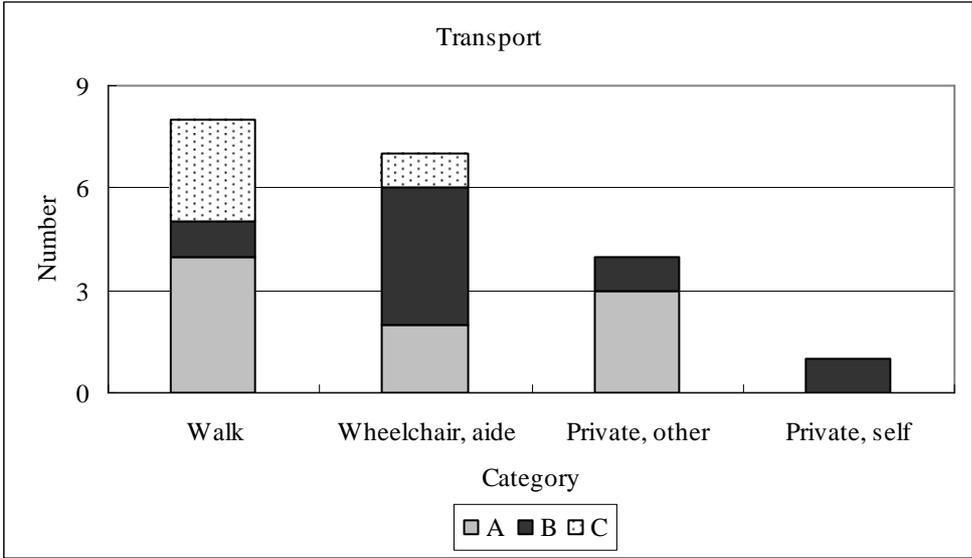


Figure 4.7 - Transport used to access BLRC

Comparatively few people made use of private transport. This may well be as a result of the cost involved in utilising private transport in this low socio-economic area, as cost is obviously absent in the case of walking, and only sometimes involves remuneration for those pushing wheelchairs.

4.2.3.2 Cost of transport

Figure 4.8 shows that 16 participants (80 %) incurred no cost in accessing the centre, with only two paying more than ten Rand for transport.

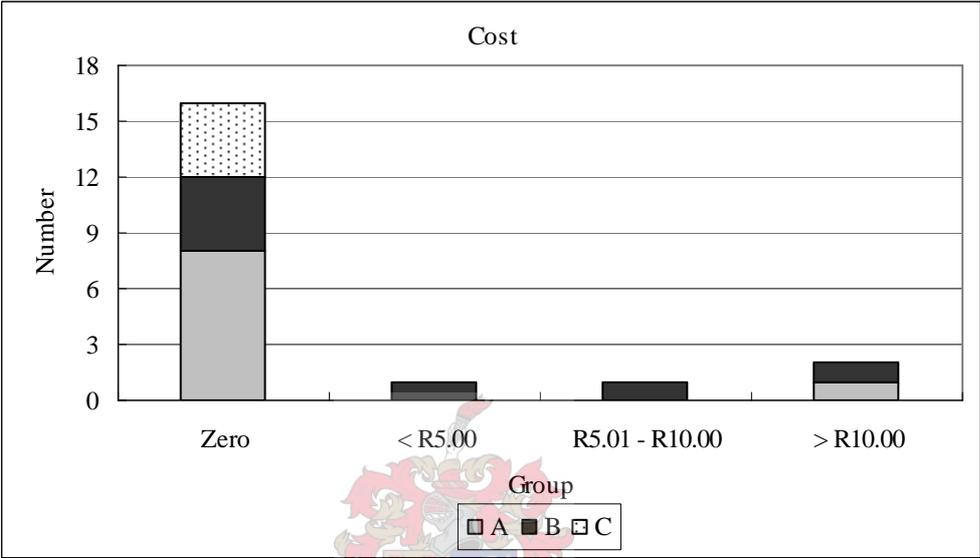


Figure 4.8 - Cost incurred in accessing BLRC

There was no significant difference between the subgroups with regards to transportation cost. Thus, the cost of transportation was not related to group attendance. Walking is possibly the most common use of transport given the financial limitations of the population in question, rather than because of choice. Although participants were able to access the BLRC by walking or wheelchair, it was not possible to measure the difficulty encountered with this arrangement. With improved finances, some participants may have chosen to use alternative methods of transportation.

4.2.3.3 Physical preparation

Most participants were usually able to prepare themselves and access the BLRC within one hour (refer to Figure 4.9) with or without assistance (as was available and needed), which seems a reasonable time frame.

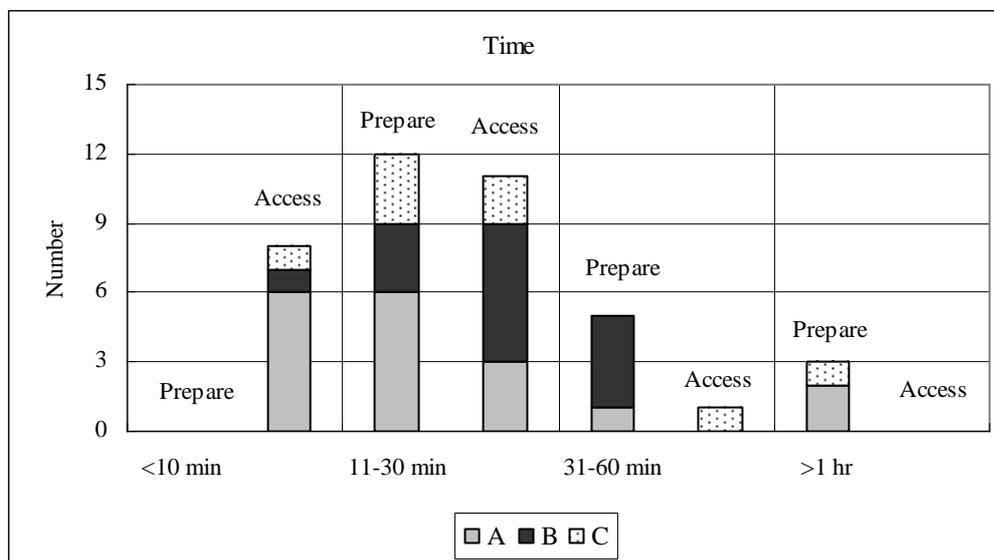


Figure 4.9 - Time taken to prepare for and access group

4.2.3.4 Presence of caregiver

Half the participants attended the group alone, and half with a companion. Five of the participants were always alone at home during the day. Three of these were in Group B and two in Group A. A further two participants were often alone during the day, one in each of groups A and B. The other participants all had an immediate family member present during the day, with one exception in Group B having a paid carer. None of Group C (high attendance group) was without a full time carer, which may have made it easier for them to attend the group.

4.3 Meaning that group programme involvement had to participants

In the context of this study, 'meaning' was understood to signify the value or significance that participants attached to group involvement. The construct was thus measured in terms of the participants' reasons for involvement and what they felt they gained from their involvement. They were additionally asked to describe how they felt involvement in the group programme had impacted their lives.

This topic was addressed only with those who had attended the group for enough time to have experienced the full range of group activities, and therefore could not comment on these. No data was yielded in this section from Group A, who all reported insufficient attendance to have an

impression of meaning that group attendance would have provided. This group was, therefore, omitted from this section of data analysis. The responses from groups B and C were analysed together as no significant demographic differences had been found between them. Additionally, these groups were very small (refer to Figure 3.1), so themes could not be established within the separate groups.

4.3.1 Meaning related to psychosocial outcomes

4.3.1.1 Introduction

From the inductive approach used, the following themes initially emerged: Cohesiveness; Universality; Support; Installation of hope; Self esteem; Imparting information; Imitative behaviour; Development of socialising techniques. Each of these will be described with *verbatim* quotes to demonstrate the theme.

It was not one of the study objectives to determine if Yalom's⁵⁴ curative factors can be related to group therapy for stroke patients, and questionnaires were therefore not structured to this effect. Upon reflection, however, it became clear that the themes identified by the researcher bore similarities to those earlier identified by Yalom,⁵⁴ which were discovered by the researcher in the literature after data collection had ended. The themes were, therefore, grouped were appropriate, according to Yalom's curative factors.

Not all of Yalom's⁵⁴ curative factors were evident from the data collected. Yalom,⁵⁴ himself, described this phenomenon (mentioned 2.4.2.12) whereby people are not always aware of the effects of all these factors. As the questionnaire was not structured to illicit responses around any of Yalom's⁵⁴ factors in particular, those that occur on a subconscious level did not necessarily emerge. These issues were not specifically probed in the focus group, as Yalom's factors had not yet been identified by the researcher as having possible links.

Where a response could relate to more than one of the curative factors of groups, the researcher has selected the most appropriate category per response, and has made reference to other relevant categories.

4.3.1.2 Instillation of hope

It was clear from the following quote how important a role the group played in this regard.

⊕ “O, dit het ‘n baie, baie, baie verskil gemaak! Want die mense by die sentrum was baie goed vir my. (Die arbeidsterapeut) het my geïnspireer. En (die fisioterapeut) ook. En ek het daarvan afgeneem om te doen wat hulle sê. Ek het bygewoon die stroke klubs en

Dinsdae het ek kom leer om 'painting' en goed te doen en dit het my alles opgehelp tot ek vandag is wat ek is vandag.”

- ⊕ *“Oh, it made a very, very big difference! Because the people at the centre were very good for me. (The occupational therapist) inspired me. And (the physiotherapist) as well. And I decided from there to do what they said. I attended the stroke groups and on Tuesdays I came and did painting and things, and it all helped me to become what I am today.”*

The above example shows how important the curative factor of instillation of hope is, as it leads to sustained attendance and encourages compliance and, therefore, increases the likelihood of successful rehabilitation. The following quote further illustrates this point:

- ⊕ *“...ek vorder beter omdat ek gereeld oefen want ek oefen soos (die terapeute) vir ons geleer het elke week.”*
“...I am improving more because I exercise regularly, because I exercise like (the therapists) taught us every week.”

Others expressed the concept of hope less directly:

- ⊕ *“Daai vrou daar anderkant (volunteer at community stroke group) het 'n terapie altans gedoen twee weke terug en sy kan nie glo nie die arm raak nie seer nie. Is miskien outomaties lam... 'lammerig'. Maar hy sal maar bykom. Ek doen elke dag my oefeninge.”*
“That woman there on the other side (volunteer at community stroke group) did some therapy two weeks ago and she can't believe that my arm doesn't get sore. It might be lame. But it will come right. I do my exercises everyday.”

Findings from focus group discussion provided a good example of group members acting as inspiration for each other, which, as discussed in Chapter 2, is part of the power of a group to instil hope in the individual. This is illustrated in the following quote of one participant speaking to another:

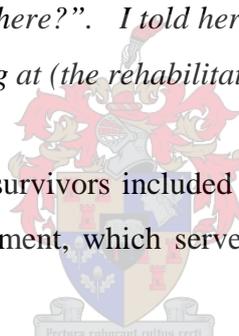
- ⊕ *“ 'n mens moet op! Jy moet 'try' en jy moet uit daai stoel uit. Jy moet sê, 'hier wil ek nie lê nie!'. ”*
“A person must get up! You must try and you must get out of that chair. You must say, 'I don't want to lie here!'. ”

This factor was further demonstrated in the focus group as participants shared their stories of success with each other. The focus group beautifully illustrated the meaning gained from seemingly small successes, which gave hope for greater things. It was very encouraging to note that the focus of attention of the group participants was on their achievements and successes, rather than on their limitations and short-comings.

- ⊕ “Nou ‘n kort tydjie toe ek na my dogter toe gaan in Mitchells Plain. Maar hulle sê, ‘Mammie kan nie gaan nie want die kar vra te duur – die trein vra ‘cheaper’.” Toe sê ek, ‘stoot my Netreg Stasie toe met die ‘wheelchair’.’ Hulle het my gestoot, en daai steppies gaan mos so op? Ek het dit geklim! Ja, op en af. Toe ek nou daar kom, toe vra my dogter vir my, ‘Hoe kom Mammie hier?’ Ek sê, ‘Ek het met die trein gekom’, en sy was verbaas! Toe sê ek haar ek het alles geleer by die terapie, ja.”

“Now a little while later I went to my daughter’s in Mitchells Plain. But they said, “Mummy can’t go, because the car is too expensive – the train is cheaper”. So I said, “Push me to Netreg Station in the wheelchair. They pushed me, and those stairs, that go up like that? I climbed them...Up and down. When I got there my daughter asked, “Mummy, how did you get here?”. I told her I came by train, and she was surprised! So I told her I learnt everything at (the rehabilitation centre).”

The results indicate that the stroke survivors included in this study experienced the instillation of hope associated with group involvement, which serves to motivate them and to encourage their participation in rehabilitation.



4.3.1.3 Universality

Participants identified their diagnoses as a uniting factor. They felt that other group members were able to understand their situation, and, therefore, experienced a sense of security within the group. As was expected from the literature,⁵³ the feeling of safety, stemming from universality, provided opportunity for disclosure. Statements made to this extent during the questionnaire administration, included the following:

- ⊕ “Ek hou van tussen die mense wees. Almal ly aan die selfde ding, so ons verstaan mekaar. Ander mense sal nie verstaan nie.”
“I like being amongst the people. Everyone suffers from the same thing, so we understand one another. Other people wouldn’t understand.”
- ⊕ “Dis lekker om te deel met ander mense wat in die selfde situasie is as ek.”
“It’s nice to share with others in the same situation as myself.”
- ⊕ “Ek voel ‘safe’ saam met hulle.”
“I feel safe with them.”

⊕ “Ons kan lekker gesels. Ek voel ‘at ease’.”

“We can chat nicely. I feel at ease”

This phenomenon was again highlighted in the focus group:

⊕ “...Want ons het mekaar geleer ken ... ons het mekaar verstaan wat daar ge te doen gewees het, het ons gedoen... as die persoon se... kyk ons het mos miskien die ou lam armpie. Dan hang hy mos. Dan sê die persoon, ‘nee wat soek daai armpie onder die tafel? Sit hom bo-op die tafel!’. Die groep het baie, baie gehelp.”

“...Because we got to know one another... we understood one another. What there was to do, we did... if the person’s... See, now perhaps I have a lame arm. Then it hangs. Then another person would say, ‘No, what’s that arm doing under the table? Put it on top of the table!’. The group helped very, very much.”

It is evident from the above that involvement in the group programme contributes to participants’ experience of universality, which results in security and leads to disclosure. This can contribute to group participants’ ability to cope with the often dramatic life changes they face as a result of their stroke.

4.3.1.4 Imparting information

Both formal and informal learning occurred in the context of the group, and had meaning to study participants. The word ‘leer’ (learn) appeared frequently in the response transcripts of the medium and high attendees, as well as during the focus group. The concept of the group as a forum for imparting information arose eight times during questionnaire administration. On a formal level, this learning was in the form of health related talks by therapists.

⊕ “Die geselsies. Ons was baie lief vir die geselsies. Daai het vir my baie geleer. Want ek kan altyd vir die anders gaan vertel, ‘ons het vandag oor dit gesels’, en dit was goed.”

“The talks. We really loved the talks. Those taught me a lot. Because I could go and tell the others, ‘we spoke about that today’, and it was good.”

More important, perhaps, was the informal learning that occurred as group members shared their experiences, aided by the sense of universality discussed above.

⊕ “Die gesels - dit het goed gegaan, dan kan jy gesels en jy kan luister na daai een se siekte of sy probleempie, en so kan jy nou leer van daai.”

“The discussion went well, you could talk and you could listen to that one’s illness or problem, and you could learn from it.”

This phenomenon was again highlighted in the focus group, by the same quote used to illustrate universality above.

- ⊕ “want ons het mekaar geleer ken ... ons het mekaar verstaan wat daar ge te doen gewees het, het ons gedoen... as die persoon se... kyk ons het mos miskien die ou lam armpie. Dan hang hy mos. Dan sê die persoon, ‘nee wat soek daai armpie onder die tafel? Sit hom bo-op die tafel!’ Die groep het baie baie gehelp.”

“Because we got to know one another... we understood one another. What there was to do, we did... if the person’s... See, now perhaps we have a lame arm. Then it just hangs. Then someone would say, ‘No, what’s that arm doing under the table? Put it on the table!’ The group helped a lot.”

And by the following statement as well:

- ⊕ “Dit help mekaar... nou, ek sal sê ons is in dieselfde posisie. Ek het ‘n stroke gehad en jy het ook ‘n stroke ‘gehet’. Ja, ons kan mekaar raad gee. Ek het die geleer by die (rehabilitasie sentrum) en ons het so gemaak - probeer jy dit ook nou so. Ons kan mekaar bemoedig.”

“It helps one another... Now, I’d say we’re in the same position. I had a stroke, and you’ve also had a stroke. Yes, we can give each other advice. I learnt this at the (rehabilitation centre) and we did this – now you try it too. We can encourage each other.”

Given that education is crucial to successful outcome in stroke,⁵⁷ and the fact that there is increasing emphasis on prevention in the management of stroke,⁴ it was very positive to note that the group programme appears to be achieving its aims in this regard. One of the aims (refer to 1.4) of the stroke group programme is health education. It was, therefore, positive to note that participants perceived improvement in their knowledge to be attributable to their group involvement.

- ⊕ “Ek dink ek ken meer as wat ek destyds geken het. Ek het meer geleer as wat ek destyds geleer het. Daar’s baie dinge waarvan ek nie geweet het wat ek nou weet.”

“I think I know more now than I knew then. I’ve learnt more now than I learnt then. There were a lot of things I didn’t know about then that I know now.”

- ⊕ “En was dit ook nie vir hulle nie sal ek nie geweet het wat ek nou weet nie.”

“And if it wasn’t for them I wouldn’t know what I know now.”

From the above, it was evident that the stroke group was a useful context for formal as well as informal learning, and, in the important area of education, contributed to positive outcome for stroke survivors.

4.3.1.5 *Development of socialising techniques*

The high incidence of communication difficulties associated with stroke, as discussed in the literature review, was also found in the study population. According to the SIS v3 responses, 58 % of the participants experienced at least ‘some difficulty’ with communication. The perceived role of the stroke group in improvement of communication was mentioned several times by the participants. The participants’ responses showed that group members had the opportunity to practice their communication skills – both verbal and non verbal – within the group and that it provided them with the opportunity to participate, and thus to socialise. Some examples of responses follow:

- ⊕ “Ek raak dan so ‘excited’ as (die fisioterapeut) of (die arbeidsterapeut) vir my sê, ‘jy gaan nou praat vandag’. Ek het baie goed daar bygekom. Die kommunikasie – dit is lekker saam met groepies te wees en ‘join’ en almal daai.”

“I get so excited if (the physiotherapist) or (the occupational therapist) says to me, ‘you’re going to talk today’. I came right there. The communication – it’s nice to be with small groups and to join in and all of that.”

- ⊕ “(Die kommunikasie) verbeter vanaf ek hier is, want ek kan nie altyd gepraat het nie. En ek lees ook baie beter.”

“(The communication) is improving since I’ve been here, because I couldn’t always speak. And I also read much better.”

From the above, it was evident that the opportunity to practice and develop communication and socialising skills was important to the study participants, and that the group provided a useful forum for this.

4.3.1.6 *Imitative behaviour*

There was an example of the curative factor of imitative behaviour being expressed. In this example, the participant referred to the imitation of therapists’ attitude.

- ⊕ “Ja, die terapie groep het (die arbeidsterapeut) en (die fisioterapeut) – almal, daai ‘patience’. Daai geduld. En hulle leer vir ons ook dit. Hier leer jy geduld. Jy leer geduld by hulle.”

“Yes, the therapy group, the (occupational therapist) and (the physiotherapist) – everyone, that patience. And they teach it to us as well. You learn patience here. You learn patience from them.”

4.3.1.7 Cohesiveness

Cohesiveness was mentioned as an important aspect of group therapy to them. The meaning that participants found in belonging to a group was expressed in both direct statements to this end, and also in “we-statements”, where the participants made statements of belonging by the use of the pronoun ‘we’. Several of the sentiments expressed demonstrated the trust, warmth, loyalty and the sense of belonging that are so characteristic of a cohesive group. For example:

⊕ “Ek geniet die ‘saamheid’ van die groep. Ek mis dit as ek eendag nie hier is nie. Ek is al gewoond.”

“I enjoy the togetherness of the group. I miss it if I’m not here one of those days. I’m used to it by now.”

⊕ “Want ek is baie opgewonde as ek moet kom. Ek ontmoet mos die span en ons gesels en ons lag.”

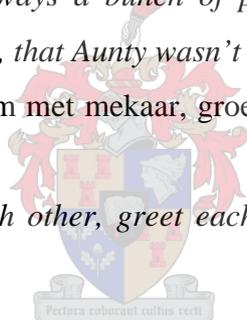
“I’m very excited if I must come. I meet the team and we talk and we laugh.”

⊕ “As ons kom is ons altyd ‘n klomp groepe en ons mis gou een uit. En sê ons, ‘haai ‘jine’, daai ‘aunty’ was nie hier nie’, of so.”

“When we come we’re always a bunch of people, and we quickly notice that one is missing. And we say, ‘gosh, that Aunty wasn’t here’, or something.”

⊕ “Soos ons mense praat saam met mekaar, groet mekaar, so ek voel vriende saam met die mense.”

“As the people talk to each other, greet each other, so I feel that I’m friends with the people.”



Cohesiveness also featured as a theme during the focus group conversation.

The literature revealed the strong need for support for stroke survivors, who are often isolated. The stroke group plays a role in preventing isolation:

⊕ “Ek geniet die mede pasiënte en die oefeninge. By die huis is ek geïsoleer.”

“I enjoy the fellow patients and the exercises. I’m isolated at home.”

Furthermore, the cohesion experienced within the group lent itself to opportunities for support. In the focus group, one participant made this comment when expanding on another participant’s response that talking to each other in the group setting was helpful:

⊕ “Want dit bring jou af van die stroke en al dinge wat jy in jou gedagte gehad het... Dit help, ja dit help baie.”

“Because it takes you away from the stroke and all the things that you had on your mind... It helps, yes, it helps a lot.”

Another participant added:

⊕ “En jy dink nie jys verlam nie as jy gesels met mense nie.”

“And you don't think you're paralysed when you speak to the people.”

There was general agreement from the group with this statement.

These statements are clearly indicative of a group that experienced a sense of connectedness, with a feeling of warmth towards one another and a sense of belonging, as is characteristic of a cohesive group. Yalom⁵⁴ includes the value that members place on a group in the definition of cohesion, mentioned in Chapter 2. All aspects of the definition of cohesion were present in the BLRC stroke group, according to the responses of study participants.

4.3.1.8 Self-esteem

Although this is not identified as a curative factor by Yalom,⁵⁴ self-esteem was a theme that emerged strongly in both questionnaire administration and focus group discussion. It has been included in this section, as the psychosocial effects of group involvement should not necessarily be limited to those identified by Yalom.⁵⁴

From the questionnaire, there was evidence of boosted morale.

⊕ “Ek voel so lekker!”

“I feel so good!”

⊕ “Wat jy nie kan gedoen het nie het jy nou gedoen met ‘n plesier en jy voel... voel gelukkig.”

“What you couldn't do before, you now do with pleasure and you feel... feel happy.”

There were also several mentions of people feeling adequate, self-sufficient and able to make a contribution. For example:

⊕ “Ek wil my eie dinge doen want ek bly alleen by die huis met die kinders. Ek doen nog steeds my eie werk in die huis. Ek gaan na [die winkel].”

“I want to do my own thing because I live alone at home with the children. I still do my own housework. I go to [the shops].”

⊕ “Ek borsel self my hare en my tande. Alles doen ek self. Ek trek my aan.”

“I brush my hair and teeth myself. I do everything myself. I dress myself.”

A more positive self-esteem and boosted morale can be linked to Altruism. Literature reveals altruism to be a contributor to improved self-esteem.⁵³ It also states that overcoming the feeling of being a burden to others and considering one's self a person of value with something to offer is

attributable, at least in part, to altruism.⁵⁴ It was also clear from the discussion around ‘imparting information’ that the members of this group offered advice to one another. This, according to Yalom,⁵⁴ also contributes to the experience of altruism. Although no conclusion can be drawn that participants experienced altruism in the group, it was evident that they experienced some of the effects of altruism.

4.3.2 Meaning in terms of improvement in stroke-related areas of recovery

4.3.2.1 Introduction

From the data collected from questionnaire completion by Groups B and C, as well as from the focus group, it became evident that much meaning was derived from improvement in areas relating to recovery from stroke, which participants attributed to their group involvement. Participants placed value on the fact that they were now able to do things that they were previously unable to do. The areas of improvement have been grouped according to the sections of the SIS v3, which highlight the main areas of stroke recovery.⁷³ The themes identified included activities of daily living, strength, mobility, thoughts and memory, communication, mood and emotions and hand function. A discussion of some of these themes follows.

There are different prognoses for the various areas of recovery post stroke. For example, hand function is known to have a poor outcome in many instances.⁸⁰ Compensation can, for example, be made for mobility and ADL deficits, which cannot be made for thoughts and mood. Also, certain of the areas of loss of function are more universal to stroke survivors than others. For example, most would suffer a degree of loss of strength, whilst fewer are likely to experience communication difficulties. The remaining level of difficulty experienced in each category can, therefore, not be calculated in absolute terms, but it does serve to broaden the understanding of the post-stroke experience of the population in question. It may also help to explain the meaning that participants associate with the different areas of post-stroke recovery.

4.3.2.2 Activities of daily living

The highest reported improvement was in the area of improved ability to perform ADL. Participants expressed their advances in these areas with enthusiasm and pride, demonstrating the meaning that these activities, and subsequent role-fulfilment, had to them. It was interesting to note that, although improvement in ADL functioning was not a direct aim of the stroke group, it remained a method of measurement of successful outcome for most of the participants, and participants attributed meaning to it. All of the activities referred to were either of a self-care or domestic nature.

Some of the comments around the topic of ADL were as follows:

- ⊕ “Ek kan vroeg opstaan, ek kan my was en aantrek en almal die kan ek doen... ek kan my werkies doen by die huis.”

“I can get up early, I can wash and dress myself and all of that... I can do my jobs around the house.”

- ⊕ “Ek kon nie opgewas het nie, ek kon nie geveë het nie, ek kon nie my bed opgemaak het nie. Al daai dinge. Ek borsel self my hare en my tande. Alles doen ek self. Ek trek my aan.”

“I couldn’t wash up, I couldn’t sweep, I couldn’t make my bed. All those things. I brush my hair and my teeth. I do everything myself. I dress myself.”

ADL was also emphasised as an important area of improvement, attributed to group involvement, during the focus group discussion. Although the activities that were mentioned could be closely associated with role-fulfilment, there was no specific mention of this by participants.

The average score on the SIS v3 for the category of ADL was 3.7, indicating that ADL were on average ‘a bit difficult’ for participants (refer to Figure 4.6). The average score for self-care tasks was 3.9 (closest to 4 – ‘a bit difficult’), and for domestic tasks 3.1 (closest to 3 – ‘quite difficult’). Heavy home maintenance tasks – such as vacuuming and gardening – remained the most difficult for participants, who rated 2.5 on average (between ‘quite difficult’ and ‘very difficult’). The importance of the execution of ADL to participants was highlighted by the fact it was so frequently mentioned as being a positive effect of the group, despite it scoring relatively poorly on the SIS v3.

4.3.2.3 Strength

Another commonly reported area of improvement was in strength.

- ⊕ “Ja, en my bene begin te sterk raak... My hand ook. Elke keer was dit pap, nou is dit sterk.”

“Yes, and my legs are beginning to get stronger... My hand too. It was always weak, but now it's strong.”

- ⊕ “Toe ek begin het was ek maar baie swak. Ek het baie, baie gedoen. Die ‘stroke’ groep het my baie lewe gegee wat ek kan beweeg en so aan.”

“When I started I was very weak. I did a lot. The stroke group gave me a lot of life so that I could move and so on.”

⊕ “Dat ek kan staan lank op die been. Ek kan my arm ‘move’, ek kan dit vorentoe en agtertoe sit. Groot verskil!”

“That I can stand on the leg for a long time. I can move my arm, I can put it forward and back. Big difference!”

The average response for participants on the SIS v3 (See figure 4.6) was 3.5, indicating that participants felt they had, on average, ‘a bit of strength’, or ‘moderate strength’ in their affected arm, hand, leg, and foot.

4.3.2.4 Mobility

Only four participants reported mobility in the home and community to be ‘not at all difficult’ on the SIS v3 (See figure 4.6). The remaining participants experienced varying degrees of difficulty – particularly with walking fast (50 % of participants reporting this to be impossible). There were, however, many comments attributing improvement in mobility to stroke group involvement. An example is as follows:

⊕ “Die groep het my gehelp om te stap. Want ek kon nie loop het nie. Ek wou nie in die rystoel gewees het nie.”

“The group helped me to walk. Because I couldn't walk. I didn't want to be in the wheelchair.”

Whilst walking is crucial for most, it becomes even more so when walking is one’s dominant mode of transport. As discussed previously (refer to 1.4), this was the case in this community, and for the study population in particular (refer to 4.2.3.1).

4.3.2.5 Thoughts and memory

According to the SIS v3, participants experienced, on average (rating 4.1), only ‘a bit of difficulty’ with their thoughts and memory (See figure 4.6). The greatest amount of difficulty was noted around the ability to think quickly (average rating of 3.1 – ‘quite difficult’). The impact of group participation on thoughts and memory was not mentioned spontaneously by participants. However, when this topic was raised during the SIS v3 section of the questionnaire, it emerged that participants noted improvement at this level, which they attributed to group involvement.

⊕ “(Die geheue) verbeter omdat ek kan nou dinge wat gesê word, dinge wat gedoen word, ek kan alles onthou.”

“(The memory) is improving because I can now remember things that are said, things that are done, I can remember everything.”

⊕ “Hulle help ons baie. Baie met die gedagtes saam. Hulle weet dat ons gedagtes nie elke dag die dieselfde is.”

“They help us a lot. A lot with the thoughts. They know that our thoughts are not the same every day.”

4.3.2.6 Communication

Improvement in communication emerged as a theme. This category on the SIS v3 (See figure 4.6) is closely related to Yalom’s⁵⁴ curative factor of development of socialising techniques (refer 4.3.1.5).

4.3.2.7 Mood and emotions

Several participants mentioned improvement in their mood and emotions. Words used to describe mood included ‘*plesierig*’ (pleasurable), ‘safe’ and ‘*tevrede*’ (satisfied). Members attributed their improved mood to their participation in the group programme. The SIS v3 quantified participants’ ratings of their mood and emotions in terms of how often they experienced certain negative and positive emotions. On average, the participants scored 4.3 for this category, meaning that they only occasionally experienced negative moods and emotions (See figure 4.6). Most of the participants reported that they smile everyday.

4.3.2.8 Hand function

Although several mentioned that their hand function had improved as a result of their group attendance, a few mentioned that it had not improved at all. Hand function was the lowest scoring section of the SIS v3, with an average of 3 (See figure 4.6). This means that, on average, study participants experience ‘quite a bit’ of residual difficulty in terms of hand function. Hand function is known to have a poor outcome in post-stroke recovery,⁸⁰ so this was not a surprising result.

4.4 Factors influencing attendance or non-attendance of the BLRC stroke group

The data gathered from each of the three groups did not vary sufficiently to warrant their individual analysis towards the realisation of this objective. The findings are, therefore, presented below in an integrated manner.

4.4.1 Positive influence

The meaning that the stroke group has to participants, as discussed in 4.3, can be considered to have positively affected their attendance. In addition to this, the following themes emerged:

4.4.1.1 Personnel

The comments made indicate that the style of group facilitation was important for the success of the programme. It appeared that the skill of the group facilitator to encourage attendance and compliance was a key factor.

- ⊕ “Net (die terapeute se) vriendelikheid al klaar trek vir jou om te kom. Dis nomer een.”
“Just (the therapists’) friendliness alone draws you to come. That’s number one.”
- ⊕ “Dit was altyd ‘n plesier om vir (die arbeidsterapeut) te ontmoet, en vir (die fisioterapeut). Hulle was bedagsaam, vriendelik en mens se hart het eintlik uitgegaan. Hulle was... hulle weet om met jou te praat, te gesels. Daar’s baie dae, as ek by die huis is, dan dink ek ‘aai, ek wonder wat maak (die arbeidsterapeut)’.”
“It was always a pleasure to meet (the occupational therapist) and (the physiotherapist). They were thoughtful, friendly and one’s heart actually went out. They were... they know how to talk to you, to chat. There are many days, when I’m at home, that I wonder, ‘what’s (the occupational therapist) doing now?’.”

This sentiment came through even more strongly in the focus group discussion, in which participants alluded to the consistency and approachability of staff.

- ⊕ “En nooit een dag of een week wat ons gekom het ek gesien (die fisioterapeut) se gesig is suur of (die arbeidsterapeut) se gesig is suur nie. Altyd die vriendlikheid, altyd die vriendlikheid wat ‘n mens trek... Dit wat ‘n mens so vry voel – vry om met hulle te praat as jy vir hulle iets wil vra... Ja, en hulle sal nooit vir jou afjak nie – daai is so wonderlik. Nee, daai is so inspireerend, ja, ja.”
“And not one day or one week that we came did we see (the physiotherapist) or (the occupational therapist) with a sour face. Always the friendliness, always the friendliness that attracted one... That’s what makes one feel so free – so free to talk to them if you wanted to ask them something... Yes, and they would never break you down you – that’s so wonderful. No, that’s so inspirational, yes, yes.”
- ⊕ “Baie mense kom en kom en kom want hulle die ‘dinges’ hierso kry... sê maar hulle kry die liefde hier [agreement from other members of group]. Want as hulle (die arbeidsterapeut) se stem hoor dan ‘smile’ hulle. Dit het ek opgelet.”

“Many people keep coming and coming and coming because they get something here... let’s say they get love here [agreement from other members of the group]. Because when they hear (the occupational therapist’s) voice, they smile. I’ve noticed that.”

The emphasis on staff attitude was not unexpected, given that interpersonal aspects of health care provision form an important part of client satisfaction. Research has revealed assurance and empathy to be the third and fourth highest ranking quality dimensions, respectively, in satisfaction with human service programmes.⁸¹ Both of these dimensions are related to staff attitude towards, and interaction with, the client. Assurance refers to politeness and friendliness of staff, and describes whether or not staff is considerate and knowledgeable. Empathy refers to the staffs’ attempt to understand the perspective of the client, and to provide individualised attention.⁸¹ From the responses of clients, highlighted above, it would appear that they were satisfied with these dimensions of service delivery at the BLRC stroke group.

4.4.1.2 Activities

There were several comments regarding the overall content of the programme on an activity level. However, certain activities stood out above the others as being favourites among the participants. These are discussed below.

4.4.1.2.1 Exercises

Exercise was the activity reported to be enjoyable by the most participants in response to the questionnaire. This was also true for the focus group, where several participants listed exercise amongst their favourite activities of the group. The exercise component of the group was the most consistently appearing activity of the group, occurring weekly during the physiotherapy aspect of the group programme. This might account for it receiving the highest number of positive responses. Other activities are repeated on a monthly basis (or less frequently) and can, therefore, be considered as minor activities of the group. Another possible reason for exercise rating so highly is its perceived effects on weakness, mobility and ADL - these being areas on which participants place high value.

A few of the participants also mentioned continuing at home with the exercises that they were taught in the group. This was positive, as one of the aims of the exercise component of the group was to encourage home programme compliance and self-management.

⊕ *“Die oefening, want wat ek hier leer kan ek weer oor gaan doen by die huis.”*

“I can go and do the exercises that I learn here at home.”

This point was raised again during the focus group

- ⊕ “Dan gaan ons huis toe, dan gaan doen ons daai selfde ding. Ja, dan gaan doen jy daai selle ding daar en ek het dit - so baie goed.”

“Then we go home and we go and do the same thing. Yes, then we do the same thing there - and I did - so many things.”

4.4.1.2.2 Games

Fewer participants commented on the games element of the group. However, those that commented did so with non-verbal indication of excitement and joy. The competitive element of games appeared to be the most enjoyable for participants.

- ⊕ “Ons speel baie mooi games. En nou en dan, dan wen jy. Dat ons vanoggend gehad het, dan sê jy, ‘BINGO!’ ...ek het amper gewen! Amper gewen. Ja, ek gaan eendag... die een langs my... dis baie lekker.”

“We play very nice games. And now and then you win. The one we played this morning, you say ‘BINGO!’... and I almost won! Almost won. Yes, I will one day... the person next to me... it’s very nice.”

In addition to distraction from their problems, these activities provide opportunities for fun and relaxation.

- ⊕ “Ja, (die speletjies) is lekker... ons speel en lag!”

“Yes, (the games) are nice... we play and laugh!”



4.4.1.2.3 Health education talks

Participants attributed improvement in knowledge, as mentioned in 4.1.3.4, to health education talks. They identified the activity as having meaning, as well as the outcome thereof.

- ⊕ “Die geselsies. Ons was baie lief vir die geselsies. Daai het vir my baie geleer. Want ek kan altyd vir die anders gaan vertel, ‘ons het vandag oor dit gesels’, en dit was goed.”

“The talks. We loved the talks very much. Those taught me a lot. Because I could always go and tell the others, ‘today we spoke about that’, and it was good.”

The topic was also raised during the focus group, where the effects of the health education talks were described by one participant as follows:

- ⊕ “Ja, my mind... maak jou mind ope. Dan kan jy beter dink en jou woorde beter sê.”

“Yes my mind... opens my mind. Then you can think better and say your words better.”

4.4.1.2.4 Relaxation

Relaxation activities, in the form of relaxation therapy, were enjoyed by participants. This participant described her perception of the process of relaxation therapy as follows:

- ⊕ “En wat ek ook baie van gehou het as (die arbedsterapeut) vir ons ingeroep het, dan moet ons doodstil sit en mens kry elk een ‘n kussing ... ‘n kussing, ja. Nou moet ons sit en ons se oe toe maak, en dan speel die musiek ...”

“And what I also liked a lot was when (the occupational therapist) called us in, and then we must sit very quietly, and each person gets a cushion... a cushion, yes. Now we must sit and close our eyes and then the music plays...”

4.4.1.3 Structure

Positive comments relating to the structure of the group were made. These focused on the consistency of the format, as well as the variety of the programme.

- ⊕ “Daar’s elke week ‘different’ goed wat ons gedoen het. (Dit) was baie goed gewees om verskillende goed te kom leer.”

“There were different things that we did every week. (It) was very good to come and learn different things.”

4.4.2 Negative influence

4.4.2.1 Transportation

Most of the responses relating to this objective were around difficulties associated with accessing the centre. This was consistent with the literature,^{67,68} citing practical barriers (of which lack of transportation is one) as a barrier for group involvement. This theme appeared the most strongly - with transport difficulties being related to either financial constraints or absence of an appropriate attendant to propel their wheelchair. Examples are as follows:

- ⊕ “Ek het nie weg gebly nie... Daar is niemand om vir my in te stoot nie.”

“I didn't stay away... there was no one to push me here.”

- ⊕ “Ek het nie altyd geld om vir mense te vra om my te neem nie. En ek kan nie op my eie hier af gaan nie.”

“I don't always have money to ask people to take me. And I can't go down from here by myself.”

The focus group discussion also revealed that access-related issues were the main cause of absenteeism.

- ⊕ “Die groep het baie vir my beteken, ek kan dit weer sê, want ek verlang altyd so om te kom, maar ek het geen een om my tot hier te bring.”

“The group meant a lot to me, I could say it again. Because I always miss coming, but I don’t have anyone to bring me here.”

Participants commented on the high costs of transportation when having to ask for lifts from friends and neighbours (approximately twenty to thirty rand per trip). Very few of those attending pay more than ten rand per trip, so it was assumed by the focus group that those with no alternative but to pay the high rates stay away. Those who were able to walk, or who were within reach of the BLRC by attendant propelled wheelchair, and who had an attendant available, accessed the BLRC by these means (refer to 4.2.3.1). This agrees with the demographic findings of the population of Bishop Lavis in general as well.

4.4.2.2 Family responsibility

One participant cited family responsibility, in the form of caring for a grandchild, as her reason for non-attendance. Another reported this responsibility in the form of caring for her child with disabilities. These informal work issues are also included in the literature as barriers to group inclusion.⁶⁸

4.4.2.3 Weather

Wet weather was given as another reason for non-attendance. This may be because the drainage systems of the area are insufficient, leading to flooding of the road in front of the BLRC in heavy rains. This occurs several times each winter. Paving and road surfaces in the area are also in a state of disrepair (refer to 1.3), which result in difficult and muddy travel in wet weather. Stroke group members with mobility limitations (the majority of the group participants) are also slower, and, therefore, may become very wet if attempting to access the BLRC on foot, or by wheelchair, in wet weather. The low socio-economic status of the area may also mean that people cannot afford to buy appropriate rainwear.

4.4.2.4 Emotional/personal

Low levels of motivation for participation in all activity, which included group attendance, were also reported as a reason for absence. This agrees with the literature stating that lack of personal motivation serves as a barrier to group involvement.⁶⁸ It was also consistent with the increased rates of depression and decreased participation in social activities that are often characteristic of stroke.⁴⁴ One participant reported to be experiencing a personal crisis that limited his ability to attend.

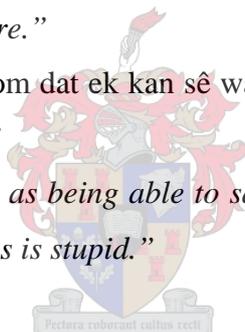
4.4.2.5 Personnel

The dislike of receiving therapy from students, and the involvement of volunteers, was also cited as a reason for poor attendance. Participants felt that the presentation of exercises was inconsistent as they were presented by a wide variety of people over the course of time. Over the course of 18 months, the stroke group would be exposed to seven teams of students. This is a high level of turnover of group presenters, but is inevitable, as part of the terms of the agreement between Stellenbosch University and the Department of Health (refer to 1.4).

4.5 Recommendations regarding improvement of the programme

Of the high and medium attendees, Groups B and C, none reported anything they did not enjoy about the group. Responses were positive. Some examples are:

- ⊕ “Ek het gehou van alles wat gedoen is. Ek was een honderd persent tevrede.”
“I liked everything that was done. I was one hundred percent satisfied.”
- ⊕ “Ek kan nie eintlik sê daar is niks lekker nie, want alles wat ek hier doen geniet ek.”
“I can't actually say there was anything about the group that I didn't enjoy, because I enjoy everthing that I do here.”
- ⊕ “Ek het nog nie so ver gekom dat ek kan sê wat nie reg is nie. Die een wat nie tevrede is met daai oefeninge is dom.”
“I haven't yet gotten as far as being able to say what's not right. The person who is not satisfied with those exercises is stupid.”



Few direct suggestions for improvement were forthcoming. From those given, no trend could be established.

One suggestion was that there should be more consistency between the exercises presented by the various students and therapists involved with the group.

- ⊕ “Die studente doen nie almal dieselfde oefeninge nie en dit gaan jou verwar. Wat ek eintlik bedoel, wat ek wil probeer sê - hulle moet nou net almal die selfde doen. Want leer ons dan baie meer daar uit.”
“The students don't all do the same exercises and that will confuse you. What I actually mean, what I'm trying to say - they must all just do the same exercises. Because we'll learn much more from that.”

Another suggestion was that another centre such as the BLRC should be established so that more people could be helped.

- ⊕ “Hulle moet maar nog ‘n sentrum opsit. Die selfde wat hulle... die vriendelikheid van die personeel wat daar werk, en nog mense kies om nog meer vir die mense te kan sê wat moet hulle doen... want ons is so baie mense.”

“They must erect another centre. The same as they... the friendliness of the staff that work there, and choose more people to be able to tell the people even more what they should do... because there are so many of us.”

Expansion of the topics for health education talks was suggested. A specific request to provide more information regarding pain was made.

- ⊕ “Kan daar nie ‘n student wat met die arm pyn of die been pyn - wat nou daai studente wat nou daar in leer - ek dink hulle moet eintlik meer in kom vir die mense te verduidelik hoekom pyn jou been en so, of hoekom sal jou been styf is en so.”

“Can't a student who is learning about arm pain or leg pain - I think they should actually come to explain to the people more often why your leg pains and so, or why your leg is so stiff.”

More group outings were suggested.

- ⊕ “Meer uitstappies. As... mense hier bymekaar kom, en ‘n mens kan nou uitgaan - oor twee maande gaan ons na soontoe – na ‘n plek toe. Ons besluit nou watter plek nou saam... Op die oomblik gaan ons net een keer in ‘n jaar uit. Meer uit gaan – die mense geniet dit om uit te gaan.”

“More outings. If people could get together here, and then go out - in two months time we're going there – to such a place. We'd decide where to go together. At the moment we only go out once a year. Going out more - the people like going out.”

Two participants, who were attending the community stroke rehabilitation group at the time (having recently completed eighteen months at the BLRC stroke group) suggested more exercise at the community group.

- ⊕ “Daar onder by die dinges daar, oefen ons nie baie nie... Daar’s nie genoeg oefeninge daar nie. Net hier.”

“There, at that other place, we don't exercise a lot... There is not enough exercise. Only here.”

⊕ “Man, ek dink nou, ons sit ‘n bietjie baie stil. Ons sit ‘n bietjie baie stil. As hulle iets kan maak soos bal speel of so.”

“I think we sit a bit too still. We sit very still. If they did something like playing ball games or so.”

There were no suggestions for improvement from the group of low attendees (Group A), all of whom stated there was nothing they did not enjoy about the group.

⊕ “You know, I think the way you’re going on now, it will make anybody a pleasure to go there. I can’t give advice what experience I have, that excellent group.”

In-depth exploration of these topics in the focus group revealed no further suggestions. The group provided an overwhelmingly positive response, and could not contribute even one suggestion, despite prompting. Some of the focus group participants had made some of the suggestions mentioned above in their questionnaire completion. When asked about these particular suggestions, they provided no further information. This may mean that the focus group applied a form of peer pressure. The other alternative for the failure to provide suggestions is that changes to the programme may have been made during the time lapse between questionnaire completion and focus group (approximately six months). Although there had been no major changes to the group in this time, the centre does continually strive to improve its standards of care. Therefore, some smaller changes may have occurred. There have been group outings arranged to Table Mountain, the Planetarium and Kirstenbosch Gardens, for example.



The focus group was asked about factors pertaining to the organisational level of the group – specifically size of the group, day and time, as well as duration and frequency of sessions. There was general satisfaction regarding these factors, although a few participants did feel that sessions could be longer.

From the averages of participant’s scores on the SIS v3 (See fig 2.6), it has been identified that participants experience the highest level of residual deficit in the areas of hand function, physical ability and mobility. These areas could perhaps receive increased focus during the group rehabilitation process. It must, however, be noted that these are the areas in which stroke survivors are most likely to experience residual difficulties,⁸⁰ and so will not necessarily be improved by increased attention. Interestingly, these areas of recovery coincide with certain participants’ recommendations of increasing the exercise component of the group.

4.6 Other results

One of the benefits of qualitative studies is the opportunity for the emergence of data not originally aimed for. In the case of this study, two interesting themes emerged from the focus group that have not been mentioned thus far. These results do not have direct bearing on the study objectives, but are interesting and potentially useful observations, and have, therefore, been included.

4.6.1 Personal responsibility for rehabilitation

A strong theme of individual motivation and the importance of taking control of circumstances, as well as responsibility for one's own rehabilitation, were revealed. This was a most encouraging observation, as it indicates that the particular population was accepting the social model of disability, and was taking over the leading role in their own rehabilitation. This is a welcome shift from the previously observed reliance on health professionals within the historical medical model.

- ⊕ “En nog ‘n ding – dan moet jy jou eie kant bring... Jy moet jousef kan gehelp het. Hulle het jou gehelp met alles, maar jy moet jousef kan gehelp het.”
“And another thing – then you must play your part. You must help yourself. They helped you with everything, but you must have helped yourself.”
- ⊕ “Dit hang baie van ‘n mens se mind af. As jy wakker skrik, dan dink jy, ‘wat gaan ek doen vandag.’.”
“It depends on one’s mind. When you wake up, you think, ‘what am I going to do today’.”
- ⊕ “Daar’s altyd iets nuuts en jy leer baie daar uit as jy net notisie neem – notisie neem daarvan.”
“There’s always something new and you learn a lot from that, if you just take notice – take notice of it.”

4.6.2 The role of the community in rehabilitation

As discussed in Chapter 2, the community should retain primary responsibility for the rehabilitation process. The focus group discussion highlighted several inadequacies in the community in fulfilling this role. Firstly, a perceived inadequacy in meeting the support needs of the stroke group participants and their caregivers was highlighted. This was found lacking on an instrumental level as well as on an emotional level. It was demonstrated by the following comment that was made by an elderly lady, with an above knee amputation, who cares for her husband who had recently sustained a second stroke:

- ⊕ “Die twaalfde het hy die stroke gehad, en toe het ek nou vir die hele maand gesukkel alleen met hom. Want ek dink toe ek kan hom heen toe bring, maar nou weer die ‘gesukkelry’ met die trap en almal daai. Met die gevolg dat ek maar met die help van die Here self probeer, en die ‘neighbours’ gevra om te help en so aan. En gelukkig het sy

skoonsuster vir my ‘n kommode geleun en dit - dit kon ek gebruik het om vir hom... maar ek moet hom help daarop en ek moet hom help met alles...”

“He had the stroke on the 12th. And then I had to struggle alone with him for a whole month. Because I thought I’d bring him here again, but there again was the struggle with the steps and so on. With the result that, with the Lord’s help, I tried on my own. I asked the neighbours to help and so forth. And, luckily, his sister-in-law lent me a commode – and I could use that to... but I have to help him onto it and I have to help him with everything...”

The comment demonstrates the determination of caregivers, and provides hope that when caregivers seek assistance, it is at times forthcoming. However, it would seem that more could be done to preempt this type of situation. This couple should have been identified by the health care facility in question as in need of assistance from other community resources – for example home-based care and Meals on Wheels. They should also have been referred to the BLRC, where a home visit and the provision of assistive devices may have been arranged. Referrals would have been accepted by the BLRC from any person in the community – including a doctor, the client himself, or a neighbour.

The perception of the group was that support was lacking for many stroke survivors.

⊕ “Almal staan mos nie mekaar by soos ons families ons bystaan. Baie mense worry nie met jou nie, jy moet kyk na jou self. Nou lê hulle maar daar.”

“Not everyone supports each other like our families support us. Many people don’t worry about you, you have to look after yourself. So now they just lie there.”

A further inadequacy was shown through several mentions of the inaccessibility of the community because of physical barriers. These included stairs at stations and inaccessible public transport systems. In this sense, the insufficiency of basic services in the community is hindering the rehabilitation process (refer to 5.3.1).

Societal attitude arose as another barrier to rehabilitation. The potential of people with disabilities often being underestimated was mentioned in Chapter 2 as a reason for the low prioritisation of rehabilitation. This phenomenon was highlighted by two participants.

⊕ “Dit maak my dan hartseer. Soos wat hulle doen, kan ek nie volgens hulle nie. Hulle sê ek kan niks doen nie En ek sê, ‘ek was maar ‘n ‘nurse’, want dink julle dan’.”

“It makes me sad. What they can do, I can’t do according to them. They say I can’t do anything. And I say ‘I used to be a nurse, what do you think?’.”

⊕ “Nou, party mense dink mens kan nie onthou nie. Maar jy kan onthou wat gesels gewees het en wat gesê gewees het.”

“Now, some people think a person can’t remember. But you can remember what was spoken about and what was said.”

Perhaps the mind-shift in this area has yet to occur in the community of Bishop Lavis. Given the high incidence of disability in this area, it would seem a priority to effect changes in this regard.

4.7 Summary of Chapter 4

The overall demographic profile of the study population is similar to the general population of Bishop Lavis in terms of ethnicity, language and most common mode of transportation, but it differs in average age, given that the study population is older than the average population of Bishop Lavis, and younger than the average age of stroke survivors. There is little notable difference between each of the three sub-groups in terms of demographic profile.

The stroke group provided meaning to participants on two levels. The first was a psychosocial level, which was explored according to Yalom’s⁵⁴ curative factors. In this area, universality, development of socialising techniques, imparting information and cohesiveness emerged strongly. The second level was meaning related to improvement in areas of stroke-related recovery, discussed according to subsections of the SIS v3. Here, improvement in ability to execute ADL, mobility and strength were most frequently mentioned.



Transportation issues were revealed to be the most commonly mentioned factor limiting attendance of the stroke group at the BLRC. Of all the participants, only one reported staying away because of negative associations with the centre and group. All other reasons were related to logistical issues and environmental barriers. The problems relating to group attendance were common to all three participant groups, whether high or low attendees.

Very few suggestions were forthcoming regarding improving the group programme. These will be discussed in more detail in Chapter 5.

In addition to the above information emerging around the stated objectives, other points of interest also emerged. These were around the empowerment of participants to take personal responsibility for their rehabilitation, and the role of the community in the rehabilitation process.

Chapter 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter brings the study to a close with the conclusions drawn from the data collected and from the literature reviewed. Based on these conclusions, recommendations are made with regards to improvement of the stroke group programme. Limitations of the study are highlighted and recommendations regarding further study are made.

5.2 Conclusions

5.2.1 Meaning that the stroke group has to participants

It emerged that the BLRC stroke group was positively experienced by the majority of the study participants. The programme held meaning to participants on two distinct levels:

Firstly, the group was meaningful on a psychosocial level, which largely corresponded to the curative factors of groups identified by Yalom.⁵⁴ Although it was not a study objective to compare the experiences of group participants with these curative factors, the possible link between these factors and stroke recovery, suggested by the literature, was explored. It became evident that the curative factors of instillation of hope, imparting information, universality, development of socialising techniques, and cohesiveness were experienced by the study population in the group context. From the comments made by participants, it can be concluded that this was a cohesive group, with members experiencing warmth and trust. This warmth and trust create an atmosphere of acceptance, necessary for effective sharing. The process of disclosure was further aided by the participants' experience of universality within the group – knowing that they were not alone with their problems. The afore-mentioned factors resulted in the group being an effective forum for imparting information – both formally and informally. Members particularly placed value on the opportunity to learn from each other. The group also provided a context for the development of socialising techniques, which was especially meaningful to those with communication difficulties.

Secondly, the group held meaning for the participants by virtue of the improvements that they noted in their own abilities. The most frequently mentioned improvements, attributed to group involvement, were in the ability to execute ADL – particularly in the areas of self-care and domestic tasks. Other areas of improvement noted were in strength and in mobility, as well as in thoughts and memory.

It can be concluded that stroke group involvement had meaning to participants, and that they perceived their group involvement to have had positive effects on their post-stroke recovery on both a physical and a psychosocial level.

5.2.2 Factors influencing group attendance

Factors which positively and negatively influenced attendance were identified.

Attendance was positively affected by the favourable attitude of staff members, who were described as friendly, inspiring, up-building, and approachable. Other positive factors identified were the activity programme – particularly the exercises, health education talks, and the games. The variety of the programme, together with the consistency of the format, was also stated as a positive factor.

Attendance was, to a large extent, negatively affected by issues related to transportation in this low socio-economic community. These issues included: limited availability of suitable transportation; limited availability of caregivers to push wheelchairs; and limited ability to afford transportation costs. Family responsibility, as well as personal circumstances, also had a negative effect on group attendance. This was also true for adverse weather conditions – specifically, wet weather. On a personnel level, attendance was negatively influenced by inconsistency in the style of exercise presentation by the various students and staff members.

5.2.3 General conclusions

The aims of the stroke group programme, as mentioned in Chapter 1, are as follows:

- ⊕ Maintaining physical abilities – range of motion, tone normalisation, balance and endurance.
- ⊕ Reviewing home exercise programmes
- ⊕ Monitoring physical status
- ⊕ Provision of a forum for socio-emotional support
- ⊕ Intellectual stimulation
- ⊕ Promotion of autonomy
- ⊕ Health education

All of these aims emerged as having had meaning for the study participants. From this, it can be deduced that the stroke group programme, in its existing format, is achieving its aims and that these aims are appropriate for the clients involved. However, the question of whether the BLRC stroke group is useful as part of the solution to the problems facing stroke rehabilitation in South Africa, as a developing nation, remains. Based on the following factors, the author suggests that it is:

- ⊕ The stroke group – with its emphasis on self management and empowerment – is congruent with the social model of disability, which is gaining increasing popularity within the medical field.²² As mentioned in 2.2.1, the social model of disability emphasises the degree of control held by the individual, which places him/her in the centre role for his/her health care. Responses of participants indicate their empowerment, and resulting acceptance of responsibility for their rehabilitation, which shows their movement towards the social model of disability. Certain of the participants made reference to this being, at least in part, due to their involvement with the group.
- ⊕ Involvement in the stroke group programme can span 18 months, after which clients have the option of attending the community stroke support group. This time frame was selected by the involved therapists in the absence of definitive literature regarding the use of therapeutic groups for stroke rehabilitation. Literature shows the most motor recovery occurring within one year post stroke, although functional recovery can continue for years.⁶⁰ After initial, more intensive, individual rehabilitation, the BLRC stroke group programme aims to help maintain participants' achieved levels of physical and psychosocial functioning. This is in line with the literature⁴⁶ stating that a sustained approach to intervention reduces deterioration in stroke survivors. This sustained intervention is not possible on the level of individual intervention due to resource constraints. Participants acknowledged that this role was fulfilled by the group programme when they attributed long term improvement and maintenance of abilities to their involvement with the group. Rehabilitation is a dynamic process. Within the group programme, individuals can also be monitored and referred for further individual intervention or to secondary or tertiary rehabilitation services, if necessary.
- ⊕ The stroke group is locally available and culturally appropriate, as is required of stroke rehabilitation strategies by the Melbourne Declaration of the Asia Pacific Consensus Forum on Stroke Management,⁵⁰ and of rehabilitation in general by South Africa's National Rehabilitation Policy.¹⁷ Although it is well documented that there are cultural

differences in perceptions of post-stroke disability and rehabilitation,⁸² it is not a simple task to determine whether or not interventions are culturally appropriate.

The Conceptual Framework for the Provision of Culturally Competent Services in Public Health⁸³ outlines several systems that need to be addressed in order to ensure the cultural competence of a programme. These include the context, the organisation, service delivery, and the client and his/her family. This framework states that, amongst others, a service is culturally competent where the client has an influence on service delivery, where members of staff have a positive attitude towards working with culturally diverse clients, and where service providers have a good understanding of their own cultural background, and can acknowledge that other cultures may be different from their own. It also requires having a culturally diverse staff, ongoing capacity to gain information on the population's culture, and flexibility in policy and procedures.

Many of these criteria are met by the BLRC, which has a culturally diverse staff and strives towards understanding the cultural group it serves. This understanding is achieved by means of a close interaction with clients, their families, and volunteers from the community. Clients influence service delivery by their participation in satisfaction surveys, which are acted upon to improve the programs of the BLRC on an ongoing basis, made possible by the flexibility of the BLRC's programmes. Given that the study participants approved of the activities of the programme, as well as of the staff attitude, it is concluded that this programme is culturally appropriate to the population it serves. The importance of this must not be underestimated, as one's culture defines how one lives socially – not just as an individual – and shapes the identity of that individual.⁸⁴ By understanding a client's worldview, a therapist is better able to understand their behaviour and to motivate them.

- ⊕ The stroke group fits the profile of PHC services, which requires maximum use of resources, participation of the patient and the community, as well as affordable and accessible services, which integrate all levels of disability prevention.⁴ It is evident from the findings of the study that the participants are actively involved in the group programme through their role in the informal imparting of information. The sense of responsibility that participants have towards each other, and the encouragement they draw from each other, is demonstrated by the strong cohesiveness and the sense of universality of the group. Members are actively involved in the development and sustainability of the programme by means of their completion of bi-annual satisfaction surveys. They report to be benefiting from strategies of disability prevention, on various levels, that are offered

within the group programme – from primary intervention (offered through health education), to tertiary (by means of rehabilitative exercises). The community is also involved in the BLRC's group programme, with volunteers assisting in group-facilitation, and family members and carers of clients attending health education sessions periodically. The community also supports the BLRC in organising and executing annual events – such as the BLRC Big Walk, and the Christmas party.

- ⊕ The stroke group also aligns with the Western Cape Province's 2010 health care plan to focus services at community level – providing basic level services for more people, rather than specialist services for the minority.⁹ The group programme undoubtedly reaches more people than the same number of therapists could reach on an individual level. The positive response of participants to the programme indicates that this basic level of service is, at the very least, acceptable to them.
- ⊕ The stroke group is a stepping-stone in a complete rehabilitation process, in which there should be a graded withdrawal of support – as is required by definition of rehabilitation.²¹ All stroke clients referred to the BLRC first receive individual intervention, which is later combined with, and then retrograded to, less intensive intervention that is provided by the group programme. Thereafter, intervention is further graded to a community support group, facilitated by volunteers. One participant mentioned that she no longer felt she needed the group intervention, and was, therefore, able to self-discharge. Other participants referred to their increasing responsibilities that kept them from attending the group programme regularly. This is positive, given that the final outcome of successful rehabilitation is the full reintegration of the individual into his or her community, which includes the fulfilment of relevant roles. The above examples highlight the ability of the group programme to allow for graded withdrawal of support in rehabilitation.
- ⊕ Given the participants' positive response to the group programme, and its ability to save time and money, it would seem an appropriate supplement to individual therapy. The literature suggests the use of the most cost-effective method of stroke rehabilitation in the absence of conclusive findings around the superiority of any particular approach. The stroke group can certainly be considered a treatment option in this case, as those involved perceive the group to be effective in both physical and psychosocial aspects of rehabilitation.⁴⁶
- ⊕ The literature³⁵ calls for innovative rehabilitative strategies which are appropriate, necessary, and accessible. The BLRC stroke group appears to be well on its way to achieving these strategies.

- ⊕ Finally, if motivation and hope are, indeed, critical to stroke recovery,⁵⁷ then the BLRC provides an excellent forum for stroke rehabilitation, given that the global impression of the group participants is positive, optimistic, hopeful, and inspired. These are the ingredients for sustained involvement in rehabilitation services and programme compliance.

5.3 Recommendations

5.3.1 Access-related difficulties

The BLRC, together with its clients, has a role to play in advocacy for the rights of people with disabilities. One of the aims of the BLRC is the empowerment of the community. It is fitting, then, that the BLRC should empower the disabled people of this community to take action in this vital area of community integration. The study can be used as an advocacy tool to this end.

Innovative strategies are required to overcome the access difficulties (such as inaccessible transport systems and the poor state of roads) that face stroke group participants, as well as others with disabilities, in this community. Access-related difficulties are a large-scale problem, and require an integrated approach. It is, therefore, recommended that the municipal council of the Bishop Lavis area be approached with regards to the use of these findings as part of an Integrated Development Plan (IDP). An IDP requires a municipality to take the existing, and needed, resources into account to develop the necessary infrastructure and services in a community. The IDP aims for municipal districts to devise long-term development strategies, based largely on the needs identified by relevant communities' themselves.⁸⁵ As such, the findings of this study should be welcomed by the Bishop Lavis municipality.

This approach should be taken in collaboration with the local health committee, as well as with the relevant disabled persons' organisations, as the difficulties experienced by the BLRC stroke group participants are likely to be universal to other people with disabilities in this community. In collaboration with these organisations, problems can be prioritised before submission to the municipality. These problems would, ideally, include: addressing the difficulties associated with inaccessible transport; and the poor state of roads and paving in the area.

5.3.1.1 Transport

In addition to the above, there are other possible, alternative, solutions to the problems associated with transportation:

- ⊕ 'Dial-a-ride', a transportation service for people with disabilities, is available to people in this community. However, the BLRC has lodged several complaints, on behalf of their

clients, for waiting times for lifts in excess of four hours. In its current state of operation, this service cannot be recommended as a viable solution for the transportation needs of this group. This study can be used to make recommendations with regards to extending and improving this service – and particularly regarding the acquisition of additional funding for the service, given that a need has been identified in this area.

- ⊕ The Department of Health can be approached to extend the availability of patient transportation services. This should be motivated on grounds of the increased resource allocation to PHC facilities. A disabled-accessible service would be required. This option, however, does not encourage the integration of services called for by the philosophy of PHC and CBR, and so is not the solution of choice.
- ⊕ A better option, perhaps, would be for the community to approach The Department of Transportation with regards to the improvement of the accessibility of public transport vehicles and train stations. Should these services become more inclusive, the necessity for specialist services for people with disabilities would be diminished. This would assist in removing environmental barriers, hereby decreasing disability in this community as a whole, whilst benefiting the stroke group as well.
- ⊕ The above recommendations are on a large and long-term scale. On a more immediately feasible level, the BLRC should aim to create a pool of volunteers who can push people to the centre in their wheelchairs. The BLRC already has an extensive network of volunteers who are managed by the staff of the centre. This pool could be further expanded, with existing strategies of sustainability applied, to meet this identified need.

Issues of volunteer sustainability in this low socio-economic community have largely been overcome by the BLRC staff seeking to understand each person's motive for volunteering, and then attempting to meet their needs by appropriately matching the person to the task. Volunteers are encouraged to expand their skills at the BLRC, and so are provided with regular supervision and informal skills training. This helps to sustain the volunteers' interest in their work, and can increase their employability in the long-term. It is considered a success when a volunteer leaves the BLRC for paid employment where they are able to utilise some of the skills they have acquired. New volunteers often approach the BLRC to offer assistance, and so the cycle continues. Although the BLRC is not in a position to financially compensate the volunteers, they are acknowledged in numerous ways. Volunteers are nominated for awards, taken on outings (for example, to Table Mountain), given small gifts, and treated to special meals at the BLRC during the year.

5.3.1.2 Weather-related difficulties

An alternative strategy suggested to overcome access-related difficulties due to wet weather is:

- ⊕ The sourcing of rainwear at an affordable rate for stroke group members. This can include raincoats, plastic boots and waterproof wheelchair capes. The BLRC is not unaccustomed to requesting donations. The acquisition of these items can form part of the BLRC's ongoing aim to meet the rehabilitative needs of the community. Attempts can be made to source these items from local factories. Additionally, organisations can be approached for cash donations to this end.

5.3.2 Childcare facilities

An informal system of child-minding should be established at the BLRC to tend group members' dependant minors whilst they participate in the group. This service should be free-of-charge, and could be run by volunteers, who are appropriately referenced and trained

5.3.3 Health education

The stroke group programme has created an effective environment for imparting information. Given the increased emphasis on preventative care, it would seem an ideal opportunity to involve a greater number of the health care team in educating the group members. This would aid in providing a greater variety of topics, as was suggested by one member. A survey should be conducted to ascertain the interests of the stroke group around health topics, as well as to identify areas of insufficient knowledge. Further opportunities can be created for peer learning. For example, group members can be invited to lead discussions around topics within their frame of reference, or to share testimonies of their post-stroke experience.

5.3.4 Focus of input

Greater attention can be paid to those areas on the SIS v3 in which participants expressed the greatest amount of remaining difficulty. It must be borne in mind that certain of these aspects are known to have poorer outcome – particularly hand function. However, an increased emphasis on weight bearing and bilateral hand use, as well as other strategies to address hand function could be trialled in order to ascertain whether they have a positive effect. Possible strategies for improving hand function, that can be incorporated in a group setting, based on the Bobath technique, are incorporation of the affected hand in bilateral activities, by using the protective extension reaction, and by application of specific neurodevelopmental techniques of tone normalisation.⁸⁶

Other areas that would benefit from increased attention, according to the SIS v3, are physical strength and mobility. This would indicate an increased emphasis on exercises during the group programme, which coincides with the activity most frequently cited as enjoyable and beneficial by the group. This aspect of the group already enjoys a substantial amount of attention, so it is doubtful that further expansion in this area would have further effect. It could, however, be researched in future to ascertain if increased exercise in the group context has an effect on strength and mobility of participants.

5.3.5 Personnel

The attitude of staff should remain positive. This must be achieved by existing staff modelling the desired attitude and interaction style to all new students, volunteers and paid staff who become involved in the programme. The impact that staff attitude has on the attendance of group participants should be highlighted to the staff in order to encourage ongoing positive attitudes. Strategies must be put in place to monitor the consistency of exercises presented by students in order to ensure that group participants experience security during group sessions, and that they are comfortable in the knowledge that they can perform these exercises correctly at home.

It is imperative that all role-players clearly state their own, and understand each other's, needs and expectations. Negotiations must be undertaken by Stellenbosch University, the BLRC and its clients, with regards to the role of students at the BLRC. A valuable forum for such negotiations would be an annual general meeting at the BLRC. Such meetings are not currently held. A recommendation of the study is, therefore, to schedule such meetings in order to promote communication between all stakeholders, and to clarify needs and expectations.

5.3.6 Group outings

The frequency of group outings must be increased, as this is a good opportunity to highlight accessibility issues in Cape Town, increase the life-area of participants, and to create further opportunities for the development of socialising techniques. It is also a good opportunity to address attitudinal barriers by increasing awareness of disability. It is recommended that a minimum of two group outings be held per annum for the stroke group.

5.3.7 Group structure and activities

The current structure and activities of the group should be maintained, given that the participants responded positively with regards to the existing programme.

5.3.8 Community stroke group

The Bishop Lavis community stroke group is an extension of the BLRC stroke group programme. Its volunteer facilitators are trained and supervised by the staff of the BLRC. The suggestion for increased exercise in the community stroke group has already been effected since the data collection phase of this study, when new volunteers took over the facilitation of this group. Volunteer training has included more input regarding the importance of exercise, and the format of the community group is now more in line with the format of the BLRC stroke group.

5.3.9 Facilitation of curative factors not identified by participants

The aims of the stroke group programme can be amended to ensure that they cover the spectrum of Yalom's⁵⁴ curative factors. In this study, there was limited evidence of altruism, catharsis, recapitulation of the family group, and existential factors. This is possibly because no specific probing was done into these areas. However, as these have been shown as curative factors by Yalom,⁵⁴ they warrant attention within the existing group programme. In some of these factors, the assistance of team members with specialised, psychological training may be required. The mental health team at the CHC should therefore be invited to give input into the stroke group programme.

5.3.10 The role of the BLRC in educating the community

The role of the community in stroke rehabilitation remains to be developed in terms of creating opportunities for stroke survivors and eradicating barriers. Buffers (as discussed 2.2.1), in the way of instrumental, educational, and emotional resources must be developed. Stroke group participants experienced the underestimation of their abilities by others, which is a societal attitude that must be overcome. As this issue emerged as being of importance to several of the participants, it could become a project of the stroke group to raise awareness of environmental barriers in Bishop Lavis, as well as to attempt to de-stigmatise disability. A project of this nature could help in the process of empowerment, as well as in providing a task through which key aims of the group can be achieved. It could also be an excellent opportunity for students based at the BLRC to gain experience in an advocacy role.

5.4 Limitations of the study and recommendations for further study

- ⊕ This study provided a generally positive evaluation of the participants' experience of stroke group involvement. Yalom⁵⁴ comments that negative experiences of group involvement sometimes only emerge years after involvement with a group has ceased. This study involved people with current, or recent, involvement in the group programme.

It is, therefore, recommended that a follow-up study be conducted with the study population in order to re-evaluate their experience of stroke group involvement after approximately four years, as was done in Yalom's⁵⁴ study. A possible problem around this recommendation is the high mortality rate of stroke survivors. During data collection, it also proved difficult to trace people no longer associated with the group programme, due to them moving away, and there being underdeveloped formal communication systems in the community. Given that the study population is already small, these factors might yield too few possible study participants after that sort of time period has elapsed.

- ⊕ This study has limited use in terms of generalisability. The study population has placed their own values on their experiences. Therefore, what is true for this population cannot necessarily be considered important for other populations. Whilst results could be extrapolated to other communities with comparable demographic profiles, it is recommended that other group programmes in differing contexts be studied to determine the meaning that group involvement has to them.
- ⊕ The study population was relatively small. This meant that little could be statistically proven in terms of significance, due to large margins of error. This was an unavoidable situation for the study, but perhaps can be overcome, in future, by the application of an alternative study design, should the research question be different. For example, the qualitative aspects of this study can provide a foundation for further quantitative study, which uses the themes that have emerged to form the research hypothesis. The data collected from the study participants was fairly repetitious, suggesting that a larger population would not necessarily provide more extensive results. The implication of this is that the sample size was appropriate for the study, despite its relatively small size.
- ⊕ Yalom's⁵⁴ curative factors, and the impact that certain of these had on group participants, was identified late in the study. As it was an emergent study design, this factor is not necessarily a limitation. However, it is recommended that with further study, a questionnaire be developed around Yalom's⁵⁴ curative factors in order to identify the extent to which the remaining factors are experienced by the members of a stroke group.
- ⊕ The researcher was very closely involved with the study population. As discussed in Chapter 3, and in line with practice-based research, this factor was used to advantage. It must, however, be borne in mind that this can also be a limitation, in as much as it is a potential source of bias. Participants may have wished to please the researcher by giving favourable reports of their experiences. Researcher bias also becomes more difficult to

avoid. A recommendation is that the research be repeated with an uninvolved examiner in order to ascertain whether or not the results correspond.

- ⊕ A limitation of the study is that no in-depth interviews were conducted, and only one focus group discussion was held. This limits the depth of information obtained. Also, no member-checking was done, so the interpretation of results is not necessarily accurate. Purposive sampling was not used in selection of participants for the focus group, which may also be considered a limitation.
- ⊕ Data was collected almost exclusively from the client, and took little cognisance of the client's family. Although primary caregivers were present during eight administrations of the questionnaire, and one formed part of the focus group discussion, more could be done to understand the perspective of this important set of stakeholders in future research around this group programme.
- ⊕ The community of Bishop Lavis has low education levels (refer to 1.3). The study population is, therefore, also likely to have had low education levels. Low education levels often translate to a limited ability for abstract thinking.⁸⁷ The data provided may, therefore, have been limited by the limited ability of the population in question for reflective thinking. However, the fact remains that the participants in this study have had a particular experience because of their group involvement. This may, or may not, have been influenced by their limited ability for abstract thinking. This experience may, or may not, be drastically different from the experience of those with more advanced ability for abstract thought. The recommendation would, therefore, be for further study of group programmes, attended by people from a community with higher educational levels, in order to determine their experiences of a group programme.
- ⊕ This study has tended to focus on the psychosocial aspects of group involvement, as these are more exclusively attributable to the group programme. Physical aspects of rehabilitation are more often confounded by external variables. This situation can be overcome by the application of alternative methodology to future study around the group programme. A case-control study, for example, could be executed.
- ⊕ It is recommended that further study be undertaken with this stroke group programme in order to address some of the remaining questions around the effectiveness and appropriateness of its use, raised in Chapter 1 (refer to 1.5). For example, an objective assessment of progress made in terms of stroke recovery, comparing those attending the

group with those not attending, would reveal useful data around the effectiveness of the group programme.

- ⊕ It is strongly recommended that stroke groups of similar and different format be developed and researched at other CHC's in the Western Cape. The data yielded from these programmes, together with the results of this study, can then be used to make recommendations regarding the modification of existing group programmes and the development of new group programmes. This will contribute to the optimal use of stroke groups, within rehabilitative programmes, at PHC level in the province.

5.5 Summary of Chapter 5

Group members experienced meaning on both psychosocial and physical levels from their group participation. Of the factors influencing attendance, the positive attitude of the staff was mentioned most frequently. Transportation issues were most often mentioned as having negatively influenced attendance. Given the positive response of study participants to the programme, and its ability to sustain intervention with limited resources, it was concluded that the BLRC stroke group has a valid place within stroke rehabilitation in the community of Bishop Lavis.

Recommendations were made in terms of the group programme, which included; investigating methods of improving, or providing transportation; provision of childcare facilities; greater variety in the content of health education talks; and reviewing the focus of input of the stroke group to address areas of greatest remaining deficit, identified by the SIS v3. Further recommendations were to maintain the positive staff attitude, as well as the current activities of the programme. More group outings should be planned, and strategies for inclement weather explored.

The study had several limitations, including: a small population size; limited, or no time post-group involvement of the participants; the examiner's close involvement with the population; and the limited ability of the study design to yield data, on an objective level, around stroke recovery. Recommendations were made with regards to overcoming these limitations in future studies. Group programmes at other institution should also be researched, and comparisons drawn, in order to move towards a model of stroke group rehabilitation.

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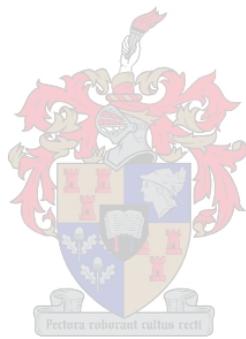
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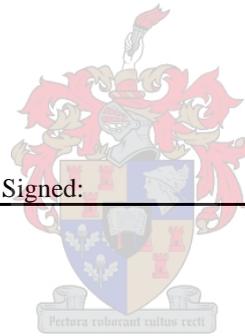
Bishop Lavis Rehabilitation Centre

Group Planning and Progress

Group: _____

Year: _____

Date	Occupational Therapy		Physiotherapy	Other	Att
	Plan	Report	Plan & Report		
	Signed:		Signed:	Signed:	
	Signed:		Signed:	Signed:	



Bishop Lavis Rehabilitasie Sentrum
GROEP TERUGVOER

Datum: _____ Groep: _____

Ja, baie! **'n bietjie/
soms** **Nee**

Geniet jy die groep?			
Is die personeel behulpsaam en vriendelik?			
Is die personeel altyd voorbereid vir die groep en begin dit stiptelik?			
Dink jy dat die groep goed is vir jou gesondheid, en die kwaliteit van lewe wat jy het?			
Is die rehab sentrum se gebou, apparaat, ens. voldoende vir die groep se gebruik?			

Waarvan hou jy die meeste in die groep?

Waarvan hou jy nie in die groep?

Watter voorstelle het jy om die groep te verbeter?

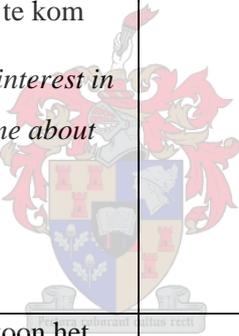
Baie Dankie!

QUESTIONNAIRE

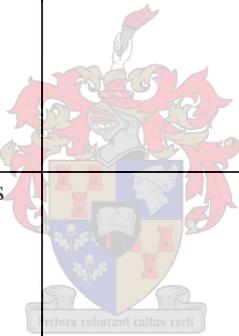
Afdeling A - almal

Voorletters:	ID no:	Groep:
1) Hoe kom jy by die rehabilitasie sentrum uit? <i>How do you get to the rehabilitation centre?</i>	1 = Loop onafhanklik (Met / sonder hulpmiddels) 2 = Stoot jousef in `n rolstoel 3 = Word deur iemand gestoot in rolstoel 4 = Privaat vervoer (iemand anders bestuur) 5 = Privaat vervoer (bestuur self) 5 = Gebruik openbare vervoer onafhanklik 6 = Gebruik openbare vervoer met hulp 7 = Vervoer vir gestremdes 8 = Ander (Noem).....	
2) Hoeveel kos dit jou om na die rehabilitasie sentrum te kom ? <i>What does it cost you to attend the group?</i>	1 = Niks 2 = R5,00 of minder 3 = Tussen R5,01 en R10,00 4 = Meer as R10,00	
3) Kom jy alleen na die rehabilitasie sentrum toe? Indien nie, wie kom saam met jou? <i>Do you travel alone to the rehabilitation centre? If not, who accompanies you?</i>	1 = Ja 2 = Nee Wie:	
4) Hoe lank neem dit vir jou om by die rehabilitasie sentrum uit te kom? <i>How long does it take you to get to the rehabilitation centre?</i>	1 = Minder as 10 minute 2 = Tussen 10 en 29 minute 3 = Tussen 30 minute en 1 uur 4 = Langer as 1 uur	
5) Woon jy enige ander organisasies/groepe by? Indien ja, watter? <i>Do you attend any other clubs/groups? If so, what?</i>	1 = Ja 2 = Nee Verskaf besonderhede:	
6) Wie is bedags saam met jou by die huis? <i>Who is with you at home during the day?</i>	1 = Een naby familielid (ouer, kind, broer, ens) 2 = Een ver familielid 3 = Een onbetaalde versorger 4 = Betaalde versorger 5 = Meer as een persoon 6 = Ander: Besonderhede.....	
7) Hoe lank neem dit vir jou om reg te maak om die groep by te woon? <i>How long does it take you to get ready for the group?</i>	1 = 10 minute 2 = Tussen 10 en 29 minute 3 = Tussen 30 minute en 1 uur 4 = langer as 1 uur	
8) Hoeveel volwassenes bly saam met jou in die huis? <i>How many adults live with you in the house?</i>	1 2 3 4 5 6 7 8 9 10 Meer:.....	
9) Hoeveel van hulle het 'n inkomste? <i>How many of those have an income?</i>	0 1 2 3 4 5 6 Meer:	
10) Ontvang jy 'n ouderdomspensioen of 'n "disability" (ongeskiktheidstoelaag)? <i>Do you receive a social pension?</i>	1 = Ja 2 = Nee	

Afdeling B – Groep A

<p>1) Hoekom woon jy nie die “stroke” groep by nie? <i>Why do you not attend the stroke group at the rehab centre?</i></p>	
<p>2) Dink jy enige van die dinge waaroor ek al gevra het jou bywoning beïnvloed het? - bv. Geldsake, vervoer, hoe lank dit neem om reg te maak, ens. Indien ja, watter? <i>Do you think that any of the things I have already asked about might have influenced your attendance? E.g. Financial matters, transport, how long it takes to get ready, etc. If yes, which?</i></p>	
<p>3) Was daar iets wat jou laat belangstelling verloor het in die groep of laat besluit het om nie te kom nie? Vertel vir my daarvan. <i>Was there something that made you lose interest in the group or not want to attend it? Tell me about this.</i></p>	
<p>4) Indien jy ‘n paar keer die groep bygewoon het, waarvan het jy gehou in die groep? <i>If you did attend a few group sessions, what did you enjoy about the group?</i></p>	
<p>5) Indien jy ‘n paar keer die groep bygewoon het, wat omtrent die groep het jy nie geniet nie?/wat was nie vir jou lekker nie? <i>If you attended a few group sessions, what did you not enjoy/ what was not nice?</i></p>	
<p>6) Watter voorstelle het jy om die groep te verbeter?/Hoe kan ons die groep verander om dit beter te maak? <i>What suggestions do you have to improve the group?/ How can we change the group to make it better?</i></p>	

Afdeling C – Groepe B & C

<p>1) Dink jy dat enige van die dinge waaroor ek nou gevra het beïnvloed hoe gereeld jy groep toe kom? In dien ja, watter? <i>Do you think that any of the things I have already asked you might have influenced how regularly you attend the group? If yes, which?</i></p>	
<p>2) Hoekom woon jy die “stroke” groep by? <i>Why do you attend the stroke group?</i></p>	
<p>3) Waarvan in die groep het jy gehou, of hou jy van? <i>What do you/did you enjoy about the group?</i></p>	
<p>4) Wat omtrent die groep geniet jy nie?/Is nie vir jou lekker nie? <i>What do you not enjoy about the group?</i></p>	
<p>5) Het jy enige verskil in jou vermoëns of gesondheid gesien as gevolg van jou groep bywoning? Vertel vir my daarvan. <i>Have you noticed any improvement in your abilities or lifestyle as a result of attending the group? Tell me about this.</i></p>	
<p>6) Watter voorstelle het jy om die groep te verbeter?/Hoe kan ons die groep verander om dit beter te maak? <i>What suggestions do you have to improve the group? How can we change the group to make it better?</i></p>	

Afdeling D - Stroke Impact Scale (VERSION 3.0)

Die volgende vrae vra ek om van jou self te hoor hoe die “stroke” (beroerte) jou gesondheid en jou lewe verander het. Ek wil jou ooggpunt hieromtrent weet. Die vrae gaan oor die gestremdhede wat die “stroke” veroorsaak het, sowel as oor hoe die “stroke” jou kwaliteit van lewe verander het. Laastens gaan ek vir jou vra wat jy dink hoeveel jy herstel het na die “stroke”.

*The purpose of this questionnaire is to evaluate how stroke has impacted your health and life. We want to know from **YOUR POINT OF VIEW** how stroke has affected you. We will ask you questions about impairments and disabilities caused by your stroke, as well as how stroke has affected your quality of life. Finally, we will ask you to rate how much you think you have recovered from your stroke.*

Die volgende vrae gaan oor die fisiese probleme wat jy ervaar as gevolg van jou “stroke” (beroerte).

1. In die afgelope week, wat sal jy sê was die krag van die....	Baie krag	Matige krag	‘n Bietjie krag	‘n Klein bietjie krag	Geen krag
a. Arm wat die meeste deur jou “stroke” geafekteer was?	5	4	3	2	1
b. Greep van die hand wat die meeste deur jou “stroke” geafekteer was?	5	4	3	2	1
c. Been wat die meeste deur jou “stroke” geafekteer was?	5	4	3	2	1
d. Voet/enkel wat die meeste deur jou “stroke” geafekteer was?	5	4	3	2	1

E1.1 Het jou fisiese vermoë verbeter as gevolg van jou groep bywoning? _____

E1.2 Hoe het dit verbeter? _____

E1.3 Het jou fisiese vermoë jou bywoning beïnvloed? _____

E1.4 Hoe? _____

Die volgende vrae gaan oor jou geheue en gedagtes.

2 In die afgelope week, hoe moeilik was dit vir jou om...	Glad nie moeilik nie	‘n klein bietjie moeilik	‘n bietjie moeilik	Baie moeilik	Onmoontlik
a. Dinge wat mense nou net vir jou gesê het te onthou?	5	4	3	2	1
b. Dinge wat die vorige dag gebeur het te onthou?	5	4	3	2	1
c. te onthou om dinge te doen - soos jou pille drink, of afsprake bywoon?	5	4	3	2	1
d. Die dag van die week te onthou?	5	4	3	2	1
e. Te Konsentreer?	5	4	3	2	1
f. vinning te dink?	5	4	3	2	1
g. alledagse probleme op te los?	5	4	3	2	1

E2.1 Het jou gedagtes en geheue verbeter as gevolg van jou groep bywoning? _____

E2.2 Hoe? _____

E2.3 Het jou gedagtes en geheue jou bywoning beïnvloed? _____

E2.4 Hoe? _____

Die volgende vrae gaan oor hoe jy voel, oor veranderinge in jou gemoed en jou vermoë om jou emosies te beheer na jy jou “stroke” gekry het.

3. In die afgelope week, hoe dikwels het jy...	Nooit	‘n Klein bietjie van die tyd	‘n bietjie van die tyd	Die meeste van die tyd	Die hele tyd
a. Hartseer gevoel?	5	4	3	2	1
b. gevoel dat daar niemand is tot wie jy aangetrokke is?	5	4	3	2	1
c. Gevoel dat jy ‘n las vir ander mense is?	5	4	3	2	1
d. Gevoel dat daar niks is om na uit te sien nie?	5	4	3	2	1
e. Jouself geblameer vir die foute wat jy gemaak het?	5	4	3	2	1
f. Dinge geniet soos altyd?	5	4	3	2	1
g. Angstig gevoel?	5	4	3	2	1
h. gevoel dat die lewe die moeite werd is?	5	4	3	2	1
i. elke dag gelag en geglimlag?	5	4	3	2	1

E3.1 Het jou gevoelens en gemoed verbeter as gevolg van jou groep bywoning? _____

E3.2 Hoe het dit verbeter? _____

E3.3 Het jou gevoelens en gemoed jou bywoning beïnvloed? _____

E3.4 Hoe? _____

Die volgende vrae gaan oor jou kommunikasie vermoëns, so wel as hoe maklik jy goed wat jy lees of hoor verstaan.

4. In die afgelope week, hoe moeilik was dit vir jou om...	Glad nie moeilik nie	‘n klein bietjie moeilik	‘n bietjie moeilik	Baie moeilik	Onmoontlik
a. Die naam van iemand wat voor jou staan te sê?	5	4	3	2	1
b. Te verstaan wat iemand vir jou sê?	5	4	3	2	1
c. Op vrae te antwoord?	5	4	3	2	1
d. dinge op hulle regte name te noem?	5	4	3	2	1
e. In ‘n gesprek te wees saammet ‘n groepie mense?	5	4	3	2	1
f. ‘n gesprek op die telefoon te voer?	5	4	3	2	1
g. Om iemand op die telfoon te bel – insluitend die regte nommer te soek en in te druk?	5	4	3	2	1

E4.1 Het jou kommunikasie vermoëns verbeter as gevolg van jou groep bywoning? _____

E4.2 Hoe het dit verbeter? _____

E4.3 Het jou kommunikasie vermoëns jou bywoning beïnvloed? _____

E4.4 Hoe? _____

Die volgende vrae gaan oor die aktiviteite/dinge wat jy moontlik in 'n tipiese dag sal doen.

5. In die afgelope 2 weke, hoe moeilik was dit vir jou om...	Glad nie moeilik nie	'n klein bietjie moeilik	'n bietjie moeilik	Baie moeilik	Onmoontlik
a. Jou kos met 'n mes en vurk te sny?	5	4	3	2	1
b. die boonste deel van jou liggaam aan te trek?	5	4	3	2	1
c. Jouself te was?	5	4	3	2	1
d. jou toonnaels te knip?	5	4	3	2	1
e. Betyds by die toilet uit te kom?	5	4	3	2	1
f. Om jou blaas te beheer? (nie 'n ongeluk kry nie)	5	4	3	2	1
g. Om jou opelyf te beheer? (nie 'n ongeluk kry nie)	5	4	3	2	1
h. Om ligte huiswerkies te doen (soos afstof, kooi opmaak, vuilus uitgooi, skottelgoed was)?	5	4	3	2	1
i. Inkopies te doen?	5	4	3	2	1
j. Swaar huis werk te doen? (soos stofsuig, wasgoed was, tuin skoonmaak)	5	4	3	2	1

E5.1 Het jou vermoë om dinge wat jy in 'n tipiese dag sal doen verbeter as gevolg van jou groep bywoning? _____

E5.2 Hoe het dit verbeter? _____

E5.3 Het jou vermoë om dinge wat jy in 'n tipiese dag sal doen jou bywoning beïnvloed? _____

E5.4 Hoe? _____

Die volgende vrae gaan oor jou vermoë om in jou huis en gemeenskap te beweeg.

6. In die afgelope 2 weke, hoe moeilik was dit vir jou om...	Glad nie moeilik nie	'n klein bietjie moeilik	'n bietjie moeilik	Baie moeilik	Onmoontlik
a. te sit sonder jou balans te verloor?	5	4	3	2	1
b. te staan sonder jou balans te verloor?	5	4	3	2	1
c. te stap sonder om jou balans te verloor?	5	4	3	2	1
d. van jou kooi tot jou stoel te beweeg?	5	4	3	2	1
e. Een blok te stap?	5	4	3	2	1
f. Vinnig te stap?	5	4	3	2	1
g. Een 'lot' trappe te klim?	5	4	3	2	1
h. Meer as een "lot" trappe te klim?	5	4	3	2	1
i. in en uit die kar te klim?	5	4	3	2	1

E6.1 Het jou vermoë om te beweeg verbeter as gevolg van jou groep bywoning? _____

E6.2 Hoe het dit verbeter? _____

E6.3 Het jou vermoë om te beweeg jou bywoning beïnvloed? _____

E6.4 Hoe? _____

Die volgende vrae gaan oor hoe jy die hand wat die meeste aangetas is gebruik.

7. In die afgelope 2 weke, hoe moeilik was dit vir jou om die hand wat die meeste aangetas is te gebruik om...	Glad nie moeilik nie	'n klein bietjie moeilik	'n bietjie moeilik	Baie moeilik	Onmoontlik
a. Swaar goed te dra? (Soos inkopies sakke)	5	4	3	2	1
b. 'n deurknop oop te draai?	5	4	3	2	1
c. 'n blik of flessie oop te maak?	5	4	3	2	1
d. Skoene vas te maak?	5	4	3	2	1
e. 'n muntstuk op te tel?	5	4	3	2	1

E7.1 Het die gebruik van jou hand verbeter as gevolg van jou groep bywoning? _____

E7.2 Hoe het dit verbeter? _____

E7.3 Het die gebruik van jou hand jou bywoning beïnvloed? _____

E7.4 Hoe? _____

Die volgende vrae gaan oor hoe die "stroke" jou vermoë om alledaagse dinge te doen beïnvloed het – die dinge wat jy gewoonlik doen, wat vir jou belangrik is, en wat die lewe sin gee.

8. In die afgelope 4 weke, hoe veel van die tyd het die "stroke" jou...	Nooit	'n klein bietjie van die tyd	'n bietjie van die tyd	Meeste van die tyd	Die hele tyd
a. in jou werk beperk? (betaald, vrywillig, ander)	5	4	3	2	1
b. in jou sosiale geleenthede beperk?	5	4	3	2	1
c. in jou stil vryetyd aktiwiteite beperk? (soos lees, TV kyk, handwerk)?	5	4	3	2	1
d. in jou aktiewe vryetyd aktiwiteite beperk? (soos sport, uitstappies, reis)	5	4	3	2	1
e. in jou rol as familie lid of vriend beperk?	5	4	3	2	1
f. deelname in geloofs aktiwiteite beïnvloed?	5	4	3	2	1
g. vermoë om jou eie lewe te beheer soos jy wil beperk?	5	4	3	2	1
h. vermoë om ander te help beperk?	5	4	3	2	1

E8.1 Het jou vermoë om alledaagse dinge te doen verbeter as gevolg van jou groep bywoning? _____

E8.2 Hoe het dit verbeter? _____

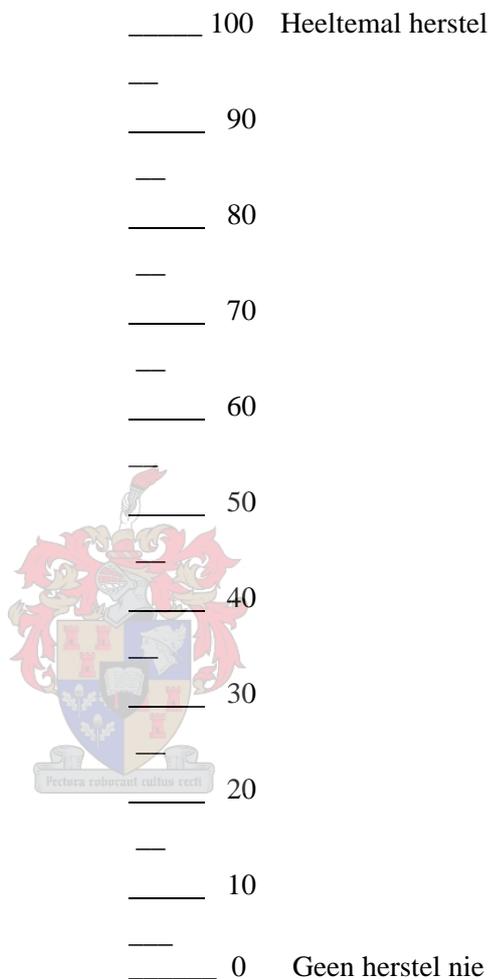
E8.3 Het jou vermoë om alledaagse dinge te doen jou bywoning beïnvloed? _____

E8.4 Hoe? _____

9. Herstel na “stroke” (beroerte)

Hoe ver dink jy het jy herstel tot nou toe? 100 beteken heeltemal herstel, en 0 beteken geen herstel nie.

On a scale of 0 to 100, with 100 representing full recovery and 0 representing no recovery, how much have you recovered from your stroke?



E9 Watter verskil het jou ‘stroke’ groep bywoning in jou lewe gemaak?

Focus group – Interview schedule**Topic 1: Meaning**

Tell me about what the group has meant or means to you.

Vertel vir my wat die groep vir jou beteken het, of betken.

Prompts – Psychosocial level

Physical level

Topic 2: Stroke recovery

In which areas did you notice improvement because you came to the group? Where did you see the most improvement? Tell me about the things you can now do that you couldn't do before?

In watter areas het jy verbetering gesien omdat jy groep toe te kom het? Waar het jy die meeste verbetering gesien? Vertel vir my van die dinge wat jy nou kan doen wat jy nie van tevore kon gedoen het nie.

Prompts – SIS v3 categories

Topic 3: Activities of the group

Tell me about the things you do in the group – which things do you like about the group, and which things not?

Vertel vir my van die dinge wat jy in die groep doen – watter van dit het jy van gehou, en watter nie?

Topic 4: Issues of interaction

Is there anything that you can tell me about how the other people in the group help you? Do the other members of the group mean something to you?

Is daar iets wat jy kan vir my sê van hoe die mense in die groep vir jou help? Het die ander lede van die groep iets vir jou beteken?

Topic 5: Issues of organisation

Is there anything you would like to say about how the group is run and the facilities or staff?

Is daar iets wat jy wil sê oor hoe die groep gestruktureer is, of oor die fasiliteite of personeel?

Prompts – Staff

Timing issues

Punctuality, predictability

Topic 6: Factors influencing attendance

What are the reasons you think people don't come to the group? What are the reasons that you sometimes couldn't come to the group?

Hoekom dink julle km die mense nie na die groep toe nie? Wat is die redes dat julle party keer nie kan gekom het nie?

Topic 7: Recommendations

If you were in charge of the group, and you could change it in any way you wanted to to make it better – how would you change it? What other suggestions do you have for improving the group?

As jy in beheer was van die groep, en jy kon enige iets verander om dit te verbeter, wat sal jy verander het? Watter ander voorstelle het jy om die groep te verbeter?

INFORMATION AND INFORMED CONSENT DOCUMENT**TITLE OF THE RESEARCH PROJECT:**

Participants' experience of the Bishop Lavis Rehabilitation stroke group.

REFERENCE NUMBER:

.....

PRINCIPAL RESEARCHER:

W. DE LA CORNILLÈRE

ADDRESS:BISHOP LAVIS REHABILITATION CENTRE
LAVIS DRIVE, BISHOP LAVIS**DECLARATION BY OR ON BEHALF OF PARTICIPANT:****I, THE UNDERSIGNED,** (name)

[ID No:] the participant/*in my capacity as

..... of the participant [ID No:] of

.....

.....

(address).

A. HEREBY CONFIRM AS FOLLOWS:

1. I was invited to participate in the abovementioned research project, which is being undertaken by the Centre for Care and Rehabilitation, Faculty of Health Sciences, Stellenbosch University.
2. The following aspects have been explained to me/ the participant:
 - 2.1 **Aim of the study:** To describe how participants experience the stroke group programme, and how they feel their attendance has influenced their recovery after a stroke. To investigate why people come or don't come to the group. To make suggestions about how the group can be improved.
 - 2.2 **Procedures:** Approximately 30 people will take part in the study. Each participant will attend one individual interview, where he/she will need to answer questions about his/her strength, mobility, memory and thinking, activities of daily life, mood and emotions and communication. The researcher will also ask information regarding how the participant experiences the stroke group programme and how well the participant feels he/she has recovered from the stroke. The interview will take approximately 45 minutes.
 - 2.3 **Confidentiality:** All information collected will be treated as confidential. The findings will be included in a thesis, possible publications and articles, but no names of participants will be used.
 - 2.4 **Access to findings:** Should the participant wish, he/*she may request to see the findings of the study upon its completion in August 2006. No access to individual results will be possible.
 - 2.8 **Voluntary participation/refusal/discontinuation:** The participant has consented to take part in this study of his/her own free will. He/*She may change his/*her mind and refuse to participate at any time. If the participant chooses not to participate, this will not be held against him/her for future treatment at the Bishop Lavis Rehabilitation Centre.
3. The information above was explained to me/*the participant by W. de la Cornillère in Afrikaans/*English/*other..... and I am/*the participant is in command of this language. I/*The participant was given the opportunity to ask questions and all these questions were answered satisfactorily.

4. No pressure was exerted on me/*the participant to consent to participation and I/*the participant understand(s) that I/*the participant may withdraw at any stage without any penalization.
5. Participation in this study will not result in any additional costs to myself/*the participant

B. HEREBY CONSENT VOLUNTARILY TO PARTICIPATE IN THE ABOVE-MENTIONED PROJECT/*THAT THE PATIENT/*POTENTIAL PARTICIPANT MAY PARTICIPATE IN THE ABOVEMENTIONED STUDY.

Signed/confirmed at on20

(place) (date)

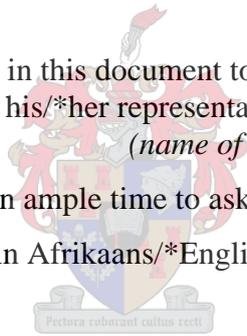
.....
*Signature or right thumb print of
 representative of the participnt/*participant*

.....
Signature of witness

STATEMENT BY OR ON BEHALF OF RESEARCHER(S):

I, W. de la Cornillère, declare that

- I explained the information given in this document to
 (*name of the participant*) and/*or his/*her representative
 (*name of the representative*);
- he/*she was encouraged and given ample time to ask me any questions;
- this conversation was conducted in Afrikaans/*English/*Xhosa/*Other and no translator was used.



Signed at Bishop Lavis on200...

(date)

.....
*Signature of researcher/*researcher's representative*

.....
Signature of witness